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Abstract

Organ transplantation is currently considered the gold standard therapy for extending the lives of individuals with end-stage organ failure. At present, demand for donor organs significantly exceeds supply. To ensure best use of resources, transplant teams rigorously assess individuals before adding them to the waiting list. Individuals must demonstrate that they have a good social support network, often comprising close family members, to meet their informal care needs. Traditionally, social science research in the field of transplantation has focused overwhelmingly on organ recipients, clinicians, and donor families; comparatively little is known about the experience of family members providing such support. This thesis addresses this dearth of knowledge by exploring the experience of, and impact on, family members supporting relatives through the transplantation process. Potential participants were recruited to qualitative interviews through UK-based transplant charities. Twenty family members of individuals living with a transplant were interviewed retrospectively. Four family members of individuals on the transplant waiting list were interviewed longitudinally, on two occasions between six and nine months apart. All interviews were audio-recorded, transcribed verbatim, and analysed using a thematic approach. Data demonstrate that family members experienced significant disruption throughout the transplantation process, and that this had a notably detrimental effect on participants' relationships, their wellbeing, and their sense of self. Accounts reveal that family members perform emotion work to manage this disruption, with varying degrees of success. Existing literature exploring disruption and emotion work among informal carers predominantly focuses on those supporting relatives with specific conditions, such as dementia and cancer. This thesis is among the first to explore disruption and emotion work in the context of transplantation and thus clarifies similarities between this and other care contexts, as well as issues that appear specific to, or particularly problematic for, family members supporting relatives through transplantation.

Dedication

I dedicate this thesis to my Granny and Granda Marshall, whose love and devotion to one another towards the end of his life sparked my interest in family care.

Your love planted the seedling; I hope you are proud of the tree.

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Firstly, I wish to express my gratitude to my participants and their families. Their openness and willingness to share their experiences in such detail was truly admirable. I feel very blessed to have been entrusted with their stories. Their accounts have proved to be the greatest source of motivation throughout this PhD and will, I'm sure, continue to echo in my thoughts and inspire me for the rest of my life.

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Chapter 1.

Introduction

1.1 Chapter introduction

This thesis presents qualitative research undertaken in order to understand the family experience of the transplantation process in the UK. In this chapter I introduce this work by providing justification for this study. Following this, I state the aims and objectives upon which this research is based. I conclude this chapter with an overview of the nine individual chapters within this thesis.

1.2 Study justification

In this thesis, I explore the experience of family members¹ of individuals waiting for and/or living with a heart, liver, and/or lung transplant in the UK.² Organ transplantation is currently considered the gold standard therapy for extending the lives of individuals with end-stage organ failure (Bowker *et al.*, 2012; Wilhelm, 2015). In the financial year 2017-2018, 5,090 transplants were performed in the UK (NHS, 2018b). Though a significant number, it is exceeded by the number of individuals on the transplant waiting list during the same period: 6,044 (NHS, 2018b). As demand for donor organs significantly exceeds supply, to ensure best use of resources transplant teams are required to rigorously assess individuals before adding them to the waiting list. As part of this assessment, individuals must demonstrate that they have good social support - an individual, or group of individuals, willing and able to provide informal care pre- and post-transplantation (NHSBT, 2017a; NHSBT, 2017d; NHSBT, 2017c). Reflecting other illness contexts, this informal care role is often assumed by close family members (Barrett *et al.*, 2014). To date, few studies have explored the family experience,³ in comparison to that of other individuals involved in the transplantation process, such as: organ recipients, clinicians, and donor families. Given the acknowledged significance of family support on the success of a transplant (Fisher, 2007; Ladin and Hanto, 2010; Ladin *et al.*, 2018), and what is known about the detrimental impact of living with and/or providing care for ill relatives (Bellou and Gerogianni, 2007; Passos *et al.*, 2015; Aghahosseini *et al.*,

¹ The term 'family members' refers to individuals sharing physical and emotional resources over a significant period of time, typically with reproductive and/or nurturing functions (Benning and Smith, 1995).

² See Chapter 2 for definition of the 'transplantation process' and an overview of its constituent parts.

³ In terms of individual family members and the whole family unit.

2017),⁴ this omission warrants exploration. Existing research exploring the family experience of transplantation is largely dated and rarely focuses on the UK-context. As a result, little is known about how families in the UK are affected by their involvement in the transplantation process and the extent to which this changes over time⁵. This thesis was devised to address this dearth of knowledge and explore the availability of, and potential for improving, the support offered to family members in this position.

1.3 Aims, objectives, and research questions

The main aim of this study is to explore the extent to which, and in what ways, involvement in the transplantation process affects family members of individuals waiting for or living with a heart, liver, and/or lung transplant in the UK.

The key objectives of this study are as follows:

- To explore family member experiences in relation to their roles, relationships, identity, and wellbeing.
- To examine whether, how, and in what ways the impact of the transplantation process changes over time.
- To ascertain what support is available for families and how it might be improved.

Within this, I aim to address three core research questions:

1. What impact does the transplant procedure have on the everyday lives of individual family members and the wider family unit?
2. How does the experience of organ transplantation affect them individually and collectively?
3. What are the hopes and expectations (regarding process, outcome, and support) of individual family members involved in the organ transplantation process?

1.4 Thesis structure

In this thesis, I discuss the experience of living with and/or providing informal care for individuals waiting for or living with a heart, liver and/or lung transplant in the UK. Within

⁴ The impact of illness reverberates through the family, affecting every member in some way – disrupting/threatening individual’s way of life, wellbeing, and/or sense of self. Indeed, Aghahosseini et al. (2017) liken the onset of illness to “the explosion of a hand grenade in the house” as it’s “fragments affect every family member” (p. 5).

⁵ Or by ‘transplant stage’ (see Chapter 2).

this, I pay particular attention to the extent to which, and in what ways, family member wellbeing and sense of self were reportedly affected as a result of involvement in this process.

I begin this thesis with a background chapter, to set the scene for this research. Within this, I explore what is meant by the term ‘transplantation process’ and discuss its constituent parts. As well as highlighting the uncertain and complex nature of this process, I provide definitions and explanations of terms related to the process (that feature within this thesis), which may not be widely understood.

In chapter three I provide a critical review of the available qualitative and quantitative literature concerning transplantation and the family, and outline the key gaps in the knowledge base. Further, I explore literature relevant to the core concepts within this thesis, including more general literature on family experience of chronic illness; particularly concerning practical, social, and personal implications of providing informal care for an ill relative.

In chapter four I introduce the methods used to collect and analyse the empirical data discussed within this thesis. I outline my methodological position before describing the research process. I provide a detailed exploration of the recruitment strategy, data collection techniques, and analytic approach. I also include a table outlining key participant characteristics to aid comprehension of the data presented in the subsequent empirical chapters. To conclude, I present a discussion of key practical and ethical challenges that I experienced during the fieldwork and subsequent data analysis.

In chapters five, six, and seven, I present the empirical findings of this study. In chapter five I focus on family member experience within the transplant centre, with regard to the clinical environment and interactions with the transplant team. Moving on from this, in chapter six I discuss the impact of the transplantation process on family life, specifically family roles and lifestyle. In the final empirical chapter, chapter seven, I explore family members’ social interactions and accounts of support, in relation to their ‘established’ (family, friends, neighbours, and colleagues) and ‘emerging’ (other transplant families) social network.

In chapter eight I provide a discussion of the findings of this thesis, focusing particularly on the themes of disruption and impression management in relation to family member wellbeing and sense of self. I discuss key findings of my research in relation to wider transplantation and care literature, drawing comparisons and distinctions where appropriate. In addition to this, I consider the key strengths and limitations of my study.

Finally, in chapter nine, I present a number of recommendations regarding clinical practice and conclude by discussing potential avenues for future research highlighted by my research.

Chapter 2. Situating the study

2.1 Introduction

In this chapter I provide contextual information on organ transplantation to aid the reader's understanding of this intervention. This includes a brief history of organ transplantation, details on the provision of transplantation within the UK, and an overview of what involvement in the transplantation process means for the transplant patient and, by extension, their family. Acknowledging the interrelated nature of patient and family experience, I have outlined the patient pathway through the transplantation process to illuminate the challenges that family members face during this time. Particular attention has been given to heart, lung, and liver transplantation, as these procedures are the focus of this thesis.

2.2 Organ transplantation

Organ transplantation is a procedure involving the replacement of a damaged or failing organ with a functioning donor organ. It is recognised to be an effective form of therapy for many individuals living with end-stage conditions (Manara *et al.*, 2012). The origins of the transplantation of internal organs date back to the early twentieth century, particularly the work of French doctors Alexis Carrel and Mathieu Jaboulay. By successfully developing a surgical technique for joining blood vessels, Carrel and Jaboulay opened the door to internal organ transplantation (Dunning and Calne, 2011). Carrel made further contributions to the field, developing techniques for patching arteries and the successful storage of tissue for transplantation (Dunning and Calne, 2011). Early attempts to transplant internal organs in humans, recorded by Jaboulay and others, were unsuccessful. Reflecting upon this, surgeons realised while they had overcome the practical surgical issues associated with transplantation, there were a number of serious biological barriers that they had not considered (Dunning and Calne, 2011). It was some time before the biological response to transplantation was understood and associated techniques were developed to manage it (Dunning and Calne, 2011).

Dr Joseph Murray and his colleagues are credited with the first successful solid organ transplant for a living-related kidney transplant conducted in Boston, Massachusetts in 1954. Six years later in 1960 a similar procedure was performed in the UK for the first time, by Sir Michael Woodruff at the Royal Infirmary of Edinburgh (NHS Choices, 2015). Mirroring the

work of Murray and colleagues, this transplant was conducted using a kidney donated by the patient's twin to reduce the chance of rejection. Following the success of these operations, the field of transplantation progressed rapidly as numerous medical teams across the world worked to develop procedures to permit the successful transplantation of organs from non-related donors. This was first achieved with the liver and lung in 1963, then the heart in 1967. Figure 1 illustrates the progression of liver, heart, and lung transplant procedures from the early 1960s to the present day, in addition to detailing key milestones in NHS provision.

Early attempts to transplant solid organs between non-relatives proved challenging and success was limited, with patients dying soon after the procedure. Patient death was linked to poor post-transplant management of the donor organ. As anti-rejection and immunosuppressant drugs were not fully developed, organ rejection was common.

Recognising this, many medical professionals worked to improve the drugs used to control the side effects of the transplant procedure. Advancements in this field, particularly the introduction of cyclosporine in 1978, the first single drug able to prevent organ rejection (Colombo and Ammirati, 2011), led to an improvement in the survival rates for recipients. Advancements in operative techniques, anaesthetic care, and the process of tissue typing also contributed to improved survival rates, leading transplantation to become widely established as a successful life-enhancing or life-saving intervention for individuals with end-stage conditions (Devlin and O'Grady, 1999; Burra and De Bona, 2007; US Departments of Health & Human Services, 2017; World Health Organization, 2017b).

Today, kidney, pancreas, heart, lung, liver, and intestinal transplants are considered routine medical treatments across the world (World Health Organization, 2017a). The most recent figures from the Global Observatory on Donation and Transplantation suggest around 120,000 transplants are conducted world-wide each year (2015). In the last financial year (2017-18), 5,090 transplants were performed in the UK (NHS, 2018b). Though this is a significant number, the transplant waiting list remains substantial. At present in the UK, around 6,044 individuals are waiting for a transplant (NHS, 2018b).⁶ As the demand for donor organs far outstrips the supply of suitable organs,⁷ every year a significant number of individuals waiting for a transplant die before a donor organ is found (411 died in need of a transplant in the last financial year (NHS, 2018b)). In the last decade, steps have been taken to

⁶ With a further 3,404 temporarily suspended (see Section 2.3.3.1).

⁷ Though more than 500,000 people die every year in the UK, less than 6,000 die in circumstances whereby they can become donors (NHSBT, 2017d).

address this shortfall of donor organs. Techniques, such as ex-vivo lung perfusion (EVLP),⁸ have been developed to enhance the functionality of ‘marginal’ organs⁹ (otherwise known as ‘borderline’, ‘high risk’, ‘extended criteria’, or ‘liminal’ organs (Botha *et al.*, 2006)). In addition, greater emphasis is being placed on maximising the use of live donors. Partial liver transplants from live donors are becoming increasingly commonplace, a process whereby the patient receives a section of an individual’s liver, typically a blood relative, in the hope that it will regenerate and function as a healthy liver (Florman and Miller, 2006). At present, a similar process is being developed to enable the transplantation of lung tissue from live donors. This process is in its infancy, however, and is extremely rare in the UK (NHS, 2017f).

⁸ EVLP is a technique used to maintain donor lung condition after procurement through use of a perfusion circuit, also known as a ‘rig’. This circuit works to preserve cell metabolism and thus aid regeneration of the organ (Machuca and Cypel, 2014; Krueger *et al.* 2015).

⁹ Donor organs that would otherwise be considered unsuitable for transplantation (Fisher *et al.*, 2016). Donors can be considered marginal in relation to a number of factors including, but not exclusive to: age, engagement in ‘risky behaviour’ (including smoking and drug use), and period of ventilation (Botha *et al.*, 2006b).

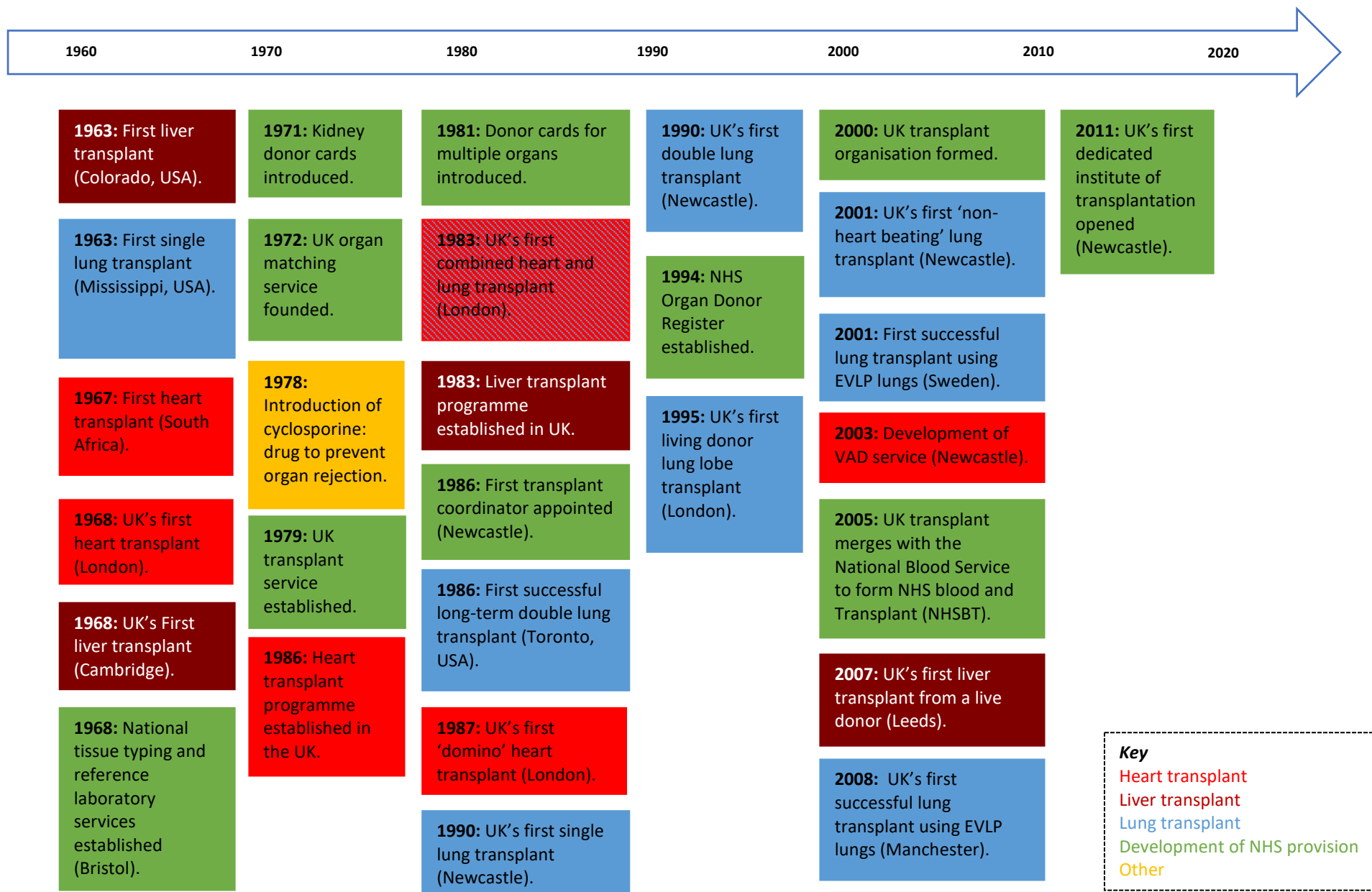


Figure 1: Key milestones in heart, lung, and liver transplantation and NHS provision

2.2.1 Heart, lung, and liver transplantation

Though various forms of organ, tissue, and cell transplantation are conducted in the UK, this thesis focuses specifically on the processes of heart, liver, and/or lung transplantation. The decision to focus solely on these three forms of transplantation was rooted in their ‘life saving’ nature (Sharp, 1995, p. 363; Grinyó, 2013). While other transplants, for example kidney and pancreas, hold the potential to drastically improve the patient’s quality of life, these procedures are not deemed ‘life saving’, rather ‘life enhancing’, as other effective therapies exist to manage the impact of these conditions, such as dialysis and insulin (Sharp, 1995; Cook, 2006; Farah and Gill, 2014). Conversely, limited treatment options are available for those living with end-stage heart, liver, or lung disease. For these individuals transplantation is a matter of life or death; if a donor is not found in time they will die (Sharp, 1995; Cook, 2006).

The following tables present contextual information on heart, liver, and lung transplantation in the UK. Table 1 details general information relating to the provision of these procedures, including: common conditions leading to transplant, types of transplant surgery available, the prevalence of the procedure, and hospitals offering the procedure (otherwise known as transplant centres). Table 2 provides figures for the number of transplants conducted, individuals on the waiting list, and those who died waiting for a transplant in the UK during the course of this study (2014-2018).

UK specifications	Transplant type		
	Heart	Lung	Liver
Common conditions leading to transplant	<ul style="list-style-type: none"> • Cardiomyopathy • Congenital heart disease • Coronary heart disease <p>(NHS, 2017b).</p>	<ul style="list-style-type: none"> • Chronic obstructive pulmonary disease (COPD) • Cystic fibrosis • Pulmonary hypertension • Idiopathic pulmonary fibrosis <p>(NHS, 2017h).</p>	<ul style="list-style-type: none"> • Alcohol-related liver disease (ARLD) • Hepatitis (B & C) • Primary biliary cholangitis (PBC) • Primary sclerosing cholangitis (PSC) <p>(NHS, 2016b).</p>
Types of transplant surgery	Two forms of heart transplant are offered in the UK: deceased donor ¹⁰ and ‘domino’ transplantation. ¹¹ A domino heart transplant occurs when a patient in need of a lung transplant undergoes a heart-lung transplant and their heart is given to a listed heart patient (Khaghani <i>et al.</i> , 2004). A shortage of suitable donors means heart-lung transplants are uncommon (around 6 performed in the UK each year), thus domino transplants are rare (NHS, 2017a).	Three types of lung transplant are conducted in the UK: single lung, bilateral lung, and heart-lung (NHS, 2017h). Lung transplants are usually performed using organs from deceased donors; however, in rare cases a transplant can be performed using a section of a lung from a living donor. This process is known as living donor lobar lung transplantation (Date, 2011; NHS, 2017f).	Three forms of liver transplant are offered in the UK: deceased donor transplant, living donor transplant, and split donation (a process whereby a donor liver is split between two recipients in the hope it will regenerate) (NHS, 2016b).
Prevalence	Almost 200 heart transplants are conducted each year in the UK (see table 2). While this figure has been relatively stable over the last few years, it is a significant decrease from the number conducted during the early 1990s, averaging nearly 300 a year (Banner <i>et al.</i> , 2011). This decrease has	Nearly 200 lung transplants are performed each year in the UK (see table 2). As with heart transplant, the demand for donor lungs far outweighs the supply and thus this operation is rare and only undertaken in circumstances where professionals believe there will be a	With over 800 performed each year (see table 2), liver transplants are significantly more common than heart or lung transplants in the UK (British Liver Trust, 2017a).

¹⁰ Transplantation using organs retrieved following the donor death (circulatory/brain).

¹¹ Domino transplantation permits a more controlled process regarding donor retrieval, matching, and evaluation (Khaghani *et al.*, 2004).

	been attributed to a fall in the number of suitable donor organs, which has led to greater disparity between the number awaiting a heart transplant and the number of transplants performed each year in the UK.	good chance of survival (NHS, 2017f).	
Centres	<ul style="list-style-type: none"> • Great Ormond Street (London) • Harefield (London) • Papworth (Cambridge) • University Hospitals Birmingham • University Hospital of South Manchester • Freeman (Newcastle) • Golden Jubilee Hospital (Glasgow) (NHSBT, 2017e). 	<ul style="list-style-type: none"> • Papworth (Cambridge) • Harefield (London) • Queen Elizabeth (Birmingham) • Wythenshawe (Manchester) • Freeman (Newcastle) (NHSBT, 2017e). 	<ul style="list-style-type: none"> • Queen Elizabeth (Birmingham) • Birmingham Children's hospital • Addenbrook's (Cambridge) • Royal Infirmary (Edinburgh) • St James's (Leeds) • Freeman (Newcastle) • King's College (London) • The Royal Free (London) (NHSBT, 2017e).

Table 1: Heart, lung, and liver transplantation provision in the UK

Transplant type	Transplants conducted (Deceased donor)				Patients actively listed				Deaths of listed patients			
	2014-15	2015-16	2016-17	2017-18	2014-15	2015-16	2016-17	2017-18	2014-15	2015-16	2016-17	2017-18
Heart	181	195	197	197	267	248	246	281	34	42	32	23
Lung (incl. heart/lung)	187	188	176	201	338	330	360	344	45	59	72	69
Liver	842	878	934*	990*	611	584	489	333	80	82	74	59

Table 2: Number of transplants conducted, patients listed as waiting, and patients who died while waiting for a heart, liver, and/or lung transplant in the UK 2014-2018 (NHSBT, 2015b; NHSBT, 2016b; NHSBT, 2016a; NHS, 2017g; NHS, 2018b; NHSBT, 2018).¹²

*Includes liver lobe transplants (from deceased and living donors)

¹² Data collected over the financial year April to April.

2.3 The transplantation process

While the term ‘transplantation process’ is widely used in transplantation literature, exactly what this means or involves appears to vary to some degree depending on the type of transplant. Within this thesis, this term will be used to refer to the main period during which the patient and their family members interact with and depend upon the transplant team (transplant coordinators, consultants, surgeons, social workers, psychologists, physiotherapists, transplant unit nurses) for advice and support. Typically, this is the time between patient referral to the transplant team and patient recovery or death. It can prove challenging to pinpoint a definitive end to involvement in the process as continued clinic attendances mean that patients, and thus their families, can remain involved with the transplant team, to some degree, for the rest of their lives. It is important to highlight the uncertain nature of transplantation means no two experiences of this process are the same.

The vast majority of social science literature addressing the transplantation experience focuses on one of two phases of the transplantation process: pre- or post-transplant. It is rare for studies to discuss these phases simultaneously. Figure 2 presents a diagram of the primary stages comprising the pre- and post-transplant phases. This diagram illuminates four pre-transplant stages: referral, assessment, the wait, and the call; and two post-transplant stages: recovery and readmission. The operation constitutes a seventh stage, bridging the pre- and post-transplant phases. In addition, this diagram highlights three common occurrences which can disrupt or delay one's progression through the process, namely: clinical refusal to list the patient, suspension from the waiting list, and ‘false alarms’. The following sections of this chapter provide detail on the seven stages and three main disruptive events featured in this diagram.

Note, in addition to information within NHSBT guidelines,¹³ journal publications, clinical textbooks, and other grey literature (e.g. NHS website and charity publications), this section has been informed by personal conversations with transplant professionals. Though great effort was expended to find text references to support the information gleaned from these exchanges, it has not always been possible to locate appropriate sources. This suggests that the information on transplantation currently available to the public, via the internet or through library sources, is sporadic and provides only a partial picture of what this process involves

¹³As this section is informed by national policy documentation, it does not reflect local variation that may exist in the implementation of these procedures across the UK.

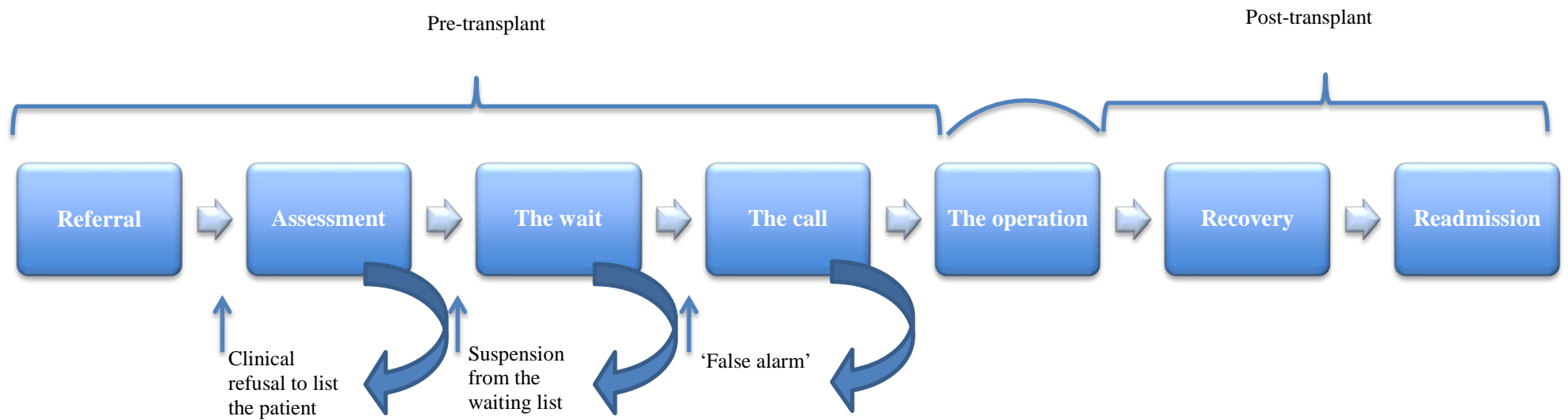


Figure 2: The transplantation process (informed by academic, clinical, and national policy documentation referenced throughout this chapter)

N.B. The aim of this figure is to provide a sense of the transplantation process as a whole and its constituent parts, thus it does not reflect the potential for variation in individual experiences, nor does it depict the time invested in each stage.

2.3.1 Referral

The time between receiving a diagnosis of organ failure and referral to the transplant team can vary depending on the onset of the patient's condition (NHSBT, 2012a). The vast majority of those referred to the transplant team are individuals living with end-stage organ failure as a result of a chronic or congenital condition. In most cases, these individuals have been aware of their diagnosis for a significant period of time and are cognisant of the fact that they may require a transplant. However, this is not the case for all. A proportion of those referred have been diagnosed with end-stage organ failure following the sudden onset of an illness. Depending on the severity of this illness, there may be very little time between diagnosis and referral to the transplant team.

Referral to a transplant centre can be challenging. This is, in part, a result of the 'fragmented' organisation of transplantation in the UK, described as such because of the dispersed commissioning and delivery of transplantation between hospitals, healthcare professionals, commissioners, departments of health, regulators, and NHS Blood and Transplant (NHSBT, 2017e). Clinicians providing care to a prospective transplant candidate are expected to discuss the case with a suitable centre and arrange a formal referral when appropriate (NHSBT, 2017d). The timing of this exchange is recognised to be vitally important. Patients must be referred before complications associated with their condition threaten the chance of a successful transplant (Banner *et al.*, 2011). Effort is made to refer the patient to the nearest transplant centre; however, this is not always possible. In some cases, patients can be referred to specialists in a transplant centre a significant distance from where they live. Though patients can opt to be treated at an alternative transplant centre, this is rare (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015).¹⁴

2.3.2 Assessment

All transplant patients are assessed by a multidisciplinary team (MDT) within the transplant centre prior to being admitted to the waiting list. This team typically

¹⁴ Occurred during a two-week placement within the Institute of Transplantation (Freeman Hospital), during which I shadowed various members of the transplant team. Knowledge of the transplantation process acquired during this time (re. the stages, expectations, frequency, outcome etc.) imbues the foundations of this chapter.

comprises physicians, surgeons, anaesthetists, intensive care specialists, organ specialists, infection specialists, transplant nurses, physiotherapists, psychologists, social workers, and the transplant coordinator (NHS, 2017h). Patients are assessed on a number of criteria, including: physical health, to establish their fitness level and organ condition; psychological state, to determine if they can cope with the post-transplant treatment regime; and social situation, to assess if they have adequate support (NHSBT, 2017a; NHSBT, 2017d; NHSBT, 2017c). The presence of a robust social-support network, in the form of close family or friends, is recognised to be crucial for a facilitating a good outcome (Fisher, 2007). Close family or friends providing informal care for a patient are expected to attend the assessment, where they are encouraged consider the implications of involvement in the transplantation process upon their lives and seek answers to any questions they may have (NHSBT, 2015a). The assessment process is as much about educating the patient and their family about the risks and implications of having a transplant as it is about evaluating patient suitability (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015).

In emergency cases, the assessment process is less formal. In light of time pressures, it is often not possible to conduct a complete assessment or consult the full MDT. In these circumstances the decision to offer a transplant is typically made by two or more senior clinicians (NHSBT, 2017b).

2.3.2.1 *Assessment outcomes*

The MDT can reach one of three decisions based on information acquired during the assessment:

1. The patient is suitable for admission to the waiting list
2. The patient is suitable for transplant but not sick enough to be listed
3. The patient is unsuitable for a transplant

Deeming a patient ‘suitable for a transplant’ is not a straightforward decision. The MDT must use their clinical expertise and experience to weigh up the benefits, risks, and alternatives, whilst also considering the scarcity of donor organs (Banner *et al.*, 2011). To ensure the best use of a scarce resource, transplant professionals seek individuals in the “window of opportunity” – those who are ‘sick enough’ to need a

transplant and yet 'fit enough' to survive the procedure (Fisher, 2007, p. 300). A significant number of patients assessed are considered not yet sick enough to be listed. These individuals are closely monitored by the transplant team and referred for reassessment if and when their test results indicate a significant decline in health. Conversely, some assessed are deemed too sick to be listed. In this situation, the risk of death during or immediately after surgery is believed too high to recommend the patient for transplant surgery. In addition to poor health, transplant professionals can deem a patient 'unsuitable' for a number of other reasons, including:

- Non-compliance or unreliability (continued involvement in 'risky behaviour' e.g. smoking or alcohol consumption. Patients must demonstrate an ability to abstain from such substances prior to being listed).
- Very low or high body-mass index
- Recent history of cancer (<5 years)
- Infection
- Psychological issues
- Social problems
- Age (65 is the current national cut off point, although in some cases a particularly fit individual may be considered)

(Parmar, 2011; Venkateswaran and Parameshwar, 2011; NHS, 2017h; NHSBT, 2017d; NHSBT, 2017c; NHSBT, 2017a).

'Unsuitable' patients are able to request a second opinion from another transplant centre (NHSBT, 2017b). Some transplant centres in the UK are more willing to take what may be deemed 'risky' patients, such as those with a high BMI, and thus being turned down by a transplant team does not necessarily mean one may never be admitted to the waiting list (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015).

Those who meet all criteria are deemed suitable for a transplant and are recommended for admission to the transplant waiting list. Ultimately the decision to be placed on the waiting list for a transplant lies with the patient (Fisher, 2007). Some decide against being listed in light of the associated risks.

2.3.3 *The wait*

The wait begins once the patient is officially added to the transplant waiting list. The timing of this depends on how long it takes the patient to address outstanding health issues flagged as potentially problematic by the assessment team, typically dental and weight issues (very low/very high BMI). Though a proportion of patients are hospitalised following their assessment, most are able to wait at home for some or all of their time on the waiting list, with support from their family and friends (British Liver Trust, 2017b).

The term ‘transplant waiting list’ refers to the database, or pool, of individuals waiting for a transplant. It is a common misconception that patients are transplanted in the order they are admitted to the list; in reality there is no rank. Patients are transplanted based on need and/or donor organ compatibility. Individuals deemed eligible for a transplant are admitted to the ‘active’ waiting list, meaning they can be called regarding a potential transplant at any time (NHS, 2017h). This list is comprised of numerous categories, or bands, denoting patient need,¹⁵ including: ‘non-urgent’, ‘urgent’, and ‘super-urgent’ (NHSBT, 2017d; NHSBT, 2017a). Transplant teams closely monitor the health of those listed to ensure they are transplanted at the most appropriate time. Should their health decline rapidly, individuals may be ‘upgraded’ to a higher category to reflect their need (NHS, 2017h). Conversely, if their condition improves, they can be ‘downgraded’ to a lower category (NHSBT, 2017d).

The length of time an individual remains on the waiting list depends on a number of factors, including: the condition of other listed patients, their blood group, their antibody profile, and donor availability (Stanford *et al.*, 2014; NHS, 2017h). Liver patients typically wait less than five months for a suitable donor organ; however, heart and lung patients often wait substantially longer than this (NHS, 2016b). The average wait for a lung patient is approximately 18 months and it is not uncommon for heart patients to wait over two years¹⁶ (NHS, 2016a; NHS, 2017f). During this time, suitable heart patients can be fitted with a ventricular assist device (VAD), a pump which acts as a ‘bridge’ to transplant, sustaining the patient’s condition until a

¹⁵ These categories vary slightly between transplant-type. For example, liver patients can also be categorised as ‘priority’ (Queen Elizabeth Hospital Birmingham, 2017)

¹⁶ Limited information exists regarding the average waiting time for a heart transplant in the UK.

donor can be found (MacGowan *et al.*, 2015). This form of therapy can also be offered to some individuals deemed unsuitable for a transplant, in the hope that a period of support on a VAD could improve their condition and thus act as a “bridge to candidacy” (MacGowan *et al.*, 2015, p. 528). However, while beneficial for some, implantation of a VAD can have significant implications for one’s subsequent transplant and has been linked to increased post-transplant mortality (Potlolla *et al.*, 2009; Bull *et al.*, 2010).

There are a number of policies that prospective patients must adhere to in order to remain on the transplant waiting list. Failure to adhere to these policies can result in the patient being temporarily or permanently suspended from the transplant waiting list. Some of the most prominent policies include the requirement to:

- Remain contactable at all times (NHSBT, 2015a; Leeds Teaching Hospitals, 2016)
- Attend regular reviews at the transplant centre (NHSBT, 2017b)
- Consult with the transplant team before going away on holiday (contact information, dates, and location of the holiday must be shared with the transplant coordinator) (Queen Elizabeth Hospital Birmingham, 2017)
- Cut down, or abstain, from ‘risky’ behaviours such as consuming alcohol or smoking (NHS, 2018a)

2.3.3.1 Suspension from the waiting list

All individuals on the waiting list are subject to regular clinical reviews, akin to a mini-assessment, on a regular basis to monitor their condition (NHSBT, 2017b). Individuals who remain on the waiting list for a significant period of time may be subject to another full assessment to ensure they are still suitable (NHS, 2017h). A significant decline in health can result in patients being permanently suspended from the transplant list, as they become ‘too sick’ to undergo transplant surgery (Watson and Dark, 2012; NHSBT, 2017d). Patients can also be temporarily suspended as a result of transitory shifts in their health state, most commonly the presence of infection (NHSBT, 2017f). Once resolved, the patient is readmitted to the list. The number of individuals temporarily suspended from the transplant list is significant. Since 2013 the figure has increased by nearly 400, from 3,030 to 3,404 individuals

(NHS, 2018b). The reason for this increase is unclear. Patients are also able to self-suspend from the waiting list for personal reasons, such as family or work issues, or to travel abroad (British Liver Trust, 2017b; Queen Elizabeth Hospital Birmingham, 2017). Those suspended long-term are reviewed at intervals, a minimum of six months apart, and readmitted when/if it is deemed appropriate (NHSBT, 2017b).

2.3.4 *The call*

The ‘call’ refers to at the point at which the transplant centre contacts the patient to inform them that a suitable donor organ has become available. Patients and their family members are advised travel to the transplant centre, either independently or by ambulance (road/air). Once at the centre, the transplant team perform a series of tests to check the patient’s compatibility with the donor organ and to ensure they are fit for surgery (NHS, 2017h). Significant changes in their health state or the presence of infection can prevent patients from undergoing surgery at this point. To prevent the donor organ from being wasted, it is not uncommon for a second (‘back-up’) patient to be called at the same time (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015). Upon the completion of these tests, the most suitable patient begins preparations for surgery.

While the patients are tested, a separate surgical team is sent to the donor site to assess the organ. This can be any hospital site in the UK and Western Europe (NHSBT, 2017g). The donor organ can be deemed unsuitable at this point for many reasons, most notably: the presence of disease, poor function, infection, or irreparable damage (NHSBT, 2012b). Suitable donor organs are transported to the transplant centre. As organs only survive for a limited period of time outside of the human body, great effort is expended to limit transportation time (Cooper *et al.*, 1997; Quick *et al.*, 2014).

2.3.4.1 *False alarms*

As the success of the call is dependent on numerous unpredictable factors, it is common for patients and their families to experience at least one unsuccessful call while waiting for a transplant. Unsuccessful calls are widely referred to as ‘false alarms’ (MacDonald, 2006; Scottish Health Council, 2015; Cormier *et al.*, 2017). Patients and families are widely acknowledged to struggle following a false alarm as a

result of lost hope (Festle, 2012; Scottish Health Council, 2015; healthtalk.org, 2017). To manage this, transplant teams are careful to iterate the uncertainty of the process when communicating with the patient and their family during their initial assessment, while they wait, and in the hours following the call (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015).

2.3.5 The operation

The duration of the operation is primarily determined by the condition of the patient and the type of transplant being conducted. On average a heart transplant procedure takes between four and six hours to complete, a liver transplant between six and eight hours, and a lung transplant around 12 hours (NHS, 2017j; NHS, 2017d; NHS, 2017h). During the operation family members are free to leave the hospital or stay and wait for news. Efforts are made to keep the family informed on the progress of the surgery where possible. Should the family leave the hospital it is common practice for the transplant team to contact them upon the completion of the procedure, to provide an update on the patient's condition and visitation details (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015).

2.3.6 Recovery

Patient recovery following transplantation is often a lengthy process, initiated with admission to the intensive care unit after surgery. Heart and liver recipients usually remain in the intensive care unit for one to two days. This period is typically longer for lung recipients but rarely exceeds one week (NHS, 2016c). During this time, visitation is highly regulated to minimise the chance of infection (personal communication with the transplant team, Freeman Hospital Newcastle, May 2015). Once deemed fit enough, patients are transferred to a high dependency or general care ward, where they remain until they are discharged. Heart, liver, and/or lung recipients are typically discharged two to three weeks after their transplant surgery (NHS, 2017e; NHS, 2017j; NHS, 2017h). Following discharge, they require a great deal of support from family and friends as they continue to recover. They also require continued support from the transplant team and must attend regular outpatient clinic appointments. Beyond six months post-transplant, patients are generally seen at three monthly intervals (Corris, 2011).

Though most heart, liver, and/or lung recipients are able to resume some normal activities within a couple of months, full recovery can take a substantial length of time (NHS, 2017f; NHS, 2017c; NHS, 2017j; NHS, 2017e). Successful long-term recovery depends on a number of factors related to the patient, donor organ, and the transplantation procedure (see table 3):

Patient	Donor organ	Transplantation procedure
Age	Organ condition	Type of transplant (partial/whole organ)
Gender	Time between retrieval and transplantation	Number of organs transplanted (single or double lung, heart/lung)
Frailty		Number of previous transplant operations
Diagnosis		
Lifestyle choices		
Response to anti-rejection medication		
Adherence to medication and physiotherapy regime		
Availability and quality of social support		

Table 3: Factors influencing transplant patient recovery (Manara et al., 2012; Lung Institute, 2016)

Organ rejection and infection are two of the greatest threats to patient recovery. Organ rejection is common in the first three months post-transplant, as the body responds to the presence of a foreign object (NHS, 2017i). Use of immunosuppressants to control organ rejection can increase the patient's susceptibility to infection, as their immune response is compromised (NHS, 2017i). Though vital to sustaining the donor organ, immunosuppressants have long-term implications for the transplant patient, increasing their risk of kidney disease, diabetes, high blood pressure, osteoporosis, and cancers (NHS, 2017i).

Comparatively, outcomes after transplantation are as good or better in the UK than in other European and North American countries (NHSBT, 2013b). The five-year survival rate for heart and for liver recipients is relatively similar, at between 80 and 90 per cent; however, it is much poorer for lung recipients at only 50 per cent

(Hirschfield *et al.*, 2009; NHS, 2017b; NHS, 2017f). Though survival after transplantation is less than that expected in an otherwise healthy individual, if managed correctly it is possible for heart, liver, and/or lung recipients to survive for more than 20 years (Hirschfield *et al.*, 2009; NHSBT, 2013b; NHS, 2017f).

In addition to extending the patient's life span, one of the main aims of transplantation is to improve the patient's quality of life (Burra and De Bona, 2007). Studies assessing quality of life scores among transplant patients generally report improved quality of life post-transplant; however, this is variable and can decrease over time (Burra and De Bona, 2007). This trend is particularly apparent among liver recipients a year after transplantation (Gelson and Alexander, 2011). Quality of life can be impacted by the demands of a complex medical regime, altered body image, the stress and uncertainty of potential complications, unfulfilled expectations, and psychosocial difficulties (Rainer *et al.*, 2010; Parthasarathy and Lewis, 2011). Patients are acknowledged to be at risk of anxiety and depression post-transplant and thus psychological support is deemed important (Kalra and Desousa, 2011; Parthasarathy and Lewis, 2011; Bag *et al.*, 2014).

2.3.7 Readmission

For many, life is acknowledged to improve post-transplant; however, this is not the case for all (Dew *et al.*, 1997; Heinrich and Marcangelo, 2009; Bag *et al.*, 2014). Contrary to popular belief, transplantation is not a cure and while patients may recover physically from the operation, this does not mean their life returns to 'normal' (Ohler, 1998; Crowley-Matoka, 2005; Heinrich and Marcangelo, 2009). In reality, transplantation allows individuals to trade one chronic condition for another (Johnson, 1990; Bag *et al.*, 2014). Though their health may improve and may potentially be more manageable, transplant patients continue to require care for the remainder of their lives (LoBiondo-Wood *et al.*, 2004; Heinrich and Marcangelo, 2009; NHSBT, 2017e). At times, the outpatient care provided by the transplant centre is not sufficient to manage the patient's condition and hospital readmission is necessary. The risk of readmission is particularly high in the first year post-transplant (Chen *et al.*, 2015; Patel *et al.*, 2016). Acute episodes of rejection and infection are often the root cause of early readmission (Alba *et al.*, 2016). In the long-term, risks associated with living

with a transplant can also result in readmission. One of the most common causes of long-term readmission is the development of malignant cancer, particularly skin malignancies and lymphomas (Alba *et al.*, 2016).

As transplanted donor organs have a limited life span, eventual readmission to hospital for rejection is inevitable. Research suggests awareness of this can mean patients and their families live in fear of rejection for some time post-transplant (Martin *et al.*, 2010). While in some cases organ rejection necessitates another transplant, re-transplantation is not an option for all patients. For a number of organs, outcomes from re-transplant are notably worse than for first transplants (Venkateswaran and Parameshwar, 2011; Mehra *et al.*, 2016; NHSBT, 2017b; NHSBT, 2017c). In light of the limited benefit and scarcity of donor organs, the selection criteria for re-transplant are strict and few patients are deemed suitable (NHSBT, 2017d). Re-transplant is much more prevalent among liver recipients than those living with a heart and/or lung transplant (Gelso and Alexander, 2011).

2.4 Chapter summary

In this chapter I have provided key contextual information regarding the provision of organ transplantation in the UK. This has included a brief overview of the history of organ transplantation, with particular focus on the development of heart, lung, and liver transplantation. Subsequent to this, I have presented an overview of the transplantation process, detailing the various routes to and potential outcomes of transplant surgery. Through presenting the patient pathway, I have illuminated the complex and uncertain nature of the transplantation process, knowledge of which is essential to understanding the content of this thesis. In the chapter that follows I review qualitative and quantitative literature on the family experience of chronic illness, informal caregiving, and transplantation, to outline key gaps in the knowledge base.

Chapter 3. Literature Review

3.1 Introduction

The purpose of this chapter is to introduce and critically assess key literature on the experience of living with, and/or providing care for, a family member waiting for or living with a heart, liver, and/or lung transplant. I begin this chapter by detailing the scoping review approach adopted to obtain relevant literature. Following this, I present the key themes within this literature, focusing particularly on disruption to family lifestyle, roles, relationships, and wellbeing. I conclude this chapter by considering the limitations of this research and outline the key gaps that my research aims to address.

3.2 Scoping review

This literature review was conducted using scoping review approach, as outlined by Arksey and O'Malley (2005). Scoping reviews are deemed suitable in a number of circumstances, such as when: it is difficult to identify a narrow review question(s); studies in the reviewed sources are likely to have used a range of data collection and/or analysis techniques; or no prior synthesis has been undertaken on this topic (Crooks *et al.*, 2010). As all of the above reasons are applicable in this case, a scoping review was deemed to be the most appropriate approach for this research project. A scoping review is characterised by five stages: 1) identifying the initial research question(s), 2) identifying relevant studies, 3) study selection, 4) charting the data, and 5) collating, summarising, and reporting the results (Arksey and O'Malley, 2005). The following subsections explore each of these stages in greater detail.

3.2.1 Identifying the initial research question(s)

Arksey and O'Malley (2005) acknowledge that defining the parameters of interest and considering the implications of adopting particular positions is of paramount importance when conducting a scoping review. As the scoping review framework recommends that researchers maintain a wide approach, to generate a breadth of coverage, I centred my review on the broad question: 'What is known about the

experience of supporting a family member through heart, liver, and/or lung transplantation?’

3.2.2 Identifying relevant studies

Upon determining my research question, I examined online databases to identify appropriate options and conducted an initial scope of the literature to determine the most suitable keywords to use in searches. From this process I identified the key words displayed in Table 4.

Key words			
Main concepts			Population group
Transplant	Action	Impact type	Family carers
Transplant	Impact	Social	Family
Heart	Affect	Mental	Relative
Liver	Effect	Psychological	Care (carer/caregiver)
Lung	Experience	Physical	Informal care(r) ¹⁷
		Health	Support person
		Psychosocial	Parent
		Financial	Partner
		Emotion	Spouse
		Identity	Sibling
			Child

Table 4: Key words used in database searches

These key words were used to search the title, abstract, and key words of references held in several databases, full-text journals, and search engines, namely: Scopus, Pubmed, Web of Science, CINAHL, Science Direct, Google Scholar advanced search, ETHoS, and WorldCat. Key words were used in various configurations, depending on database functionality. Search tools were used to narrow and broaden the search where appropriate, such as the Asterisk tool and Boolean searching. Table 5 outlines the linked descriptive key search terms used as a basis for these searches. Search limits were set to publications in English and post-1967, as this was the year of the first successful heart and liver transplantation.

¹⁷ The term ‘informal carer’ refers to family members, neighbours, and/or friends who “provide physical and/or emotional support for people, enabling them to function independently in the community and without whom statutory provision would be required” (Procter, *et al.* 2001).

Linked search terms
(‘transplant*’) AND (‘heart’ OR ‘liver’ OR ‘lung*’) AND (‘impact*’ OR ‘affect*’ OR ‘effect*’ OR ‘experience*’) AND (‘social*’ OR ‘mental*’ OR ‘psychological*’ OR ‘physical*’ OR ‘health’ OR ‘psychosocial*’ OR ‘financ*’ OR ‘emotion*’ OR ‘identit*’) AND (‘care*’ OR ‘support*’) AND (‘famil*’ OR ‘relative*’ OR ‘informal care*’ or ‘support person*’) AND (‘parent*’ OR ‘sibling*’ OR ‘child*’ OR ‘partner*’ or ‘spouse*’)

Table 5: Linked descriptive key search terms used in database searches

3.2.3 Study selection

Using this search strategy, 1028 articles were located and downloaded to Endnote V8 for storage and management purposes. A further 35 articles were located through hand searching reference lists, bringing the total number of articles to 1063. As is recommended by Arksey and O’Malley’s (2005) scoping study framework, ‘post-hoc’ inclusion criteria, rooted in my knowledge of the literature, were developed and used to review the title and abstract of each reference (see Table 6). This process revealed a large number of duplicates (n=145) and irrelevant references (n=791), which were subsequently excluded from the review. The remaining 127 references were subject to full-text review, during which the inclusion and exclusion criteria were applied to the whole document.

Criterion	Inclusion criteria	Exclusion criteria
Time period	Post-1967	Pre-1968
Language	English	Non-English
Type of article	Original research, peer-reviewed, and published	Not original research, peer-reviewed, or published Systematic review protocol Conference proceeding or poster abstract
Population/sample	Family, caregivers, and/or support persons (of heart, liver, or lung transplant candidates or recipients)	Patient (sole or main focus) Clinical team Donor family Donor
Study focus	Family experience of supporting a relative waiting for or living with a heart, liver, or lung transplantation (incl. LVAD as a bridge to transplant)	Limited-to-no focus on transplantation Not specific to heart/liver/lung LVAD as a destination therapy Organ donation Organ procurement Intervention review

Table 6: Inclusion and exclusion criteria

This process identified 70 full-text articles for inclusion in the review. Figure 3 provides an overview of the full study selection process.

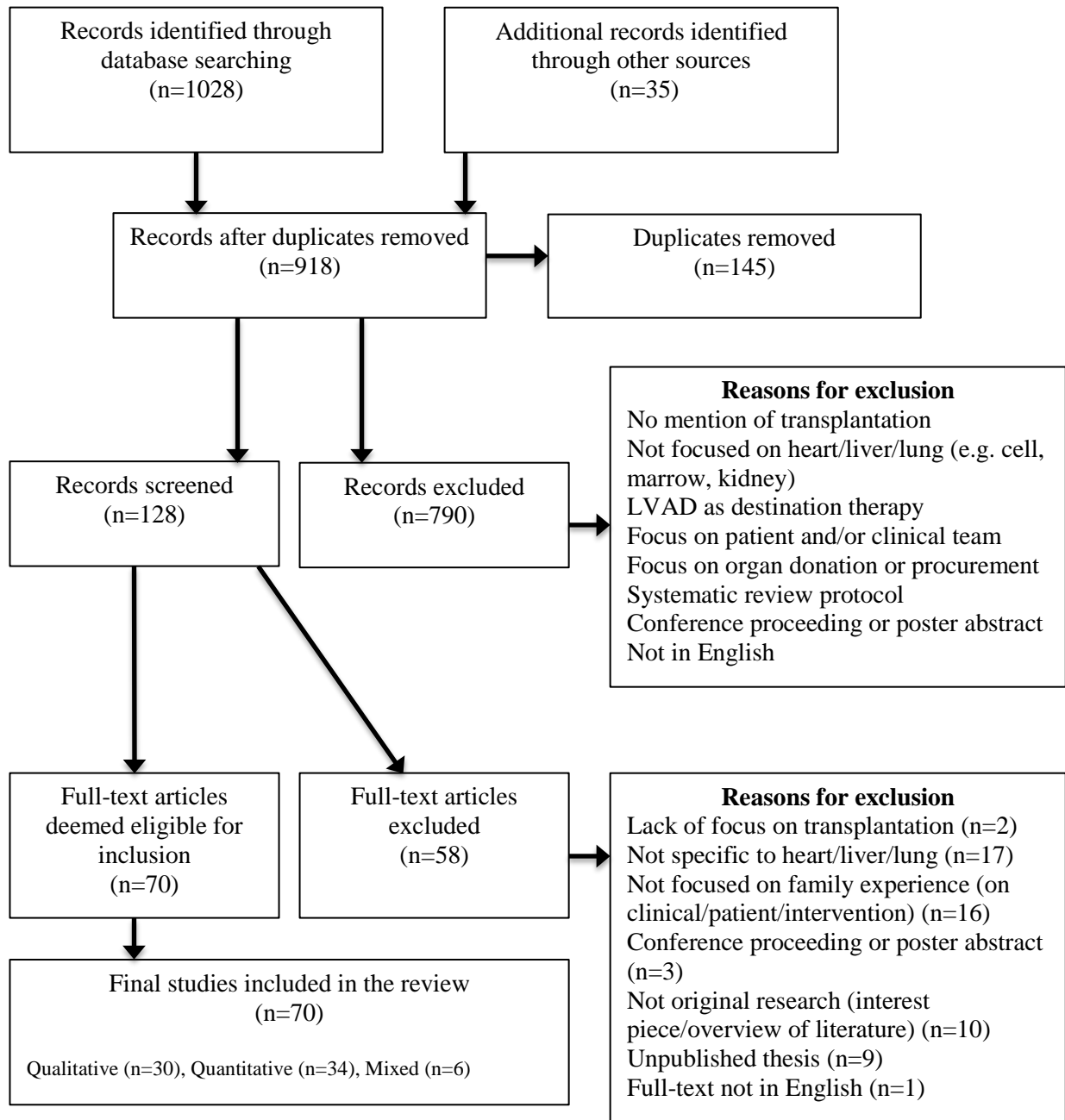


Figure 3: Diagram of the study selection process

3.2.4 Charting the data

The next stage of the scoping review involved charting the data, a process of synthesising the data, similar to data extraction in a systematic review (Arksey and O'Malley, 2005). This involved recording information about the studies deemed eligible for inclusion, to aid comparison. For the purposes of this review, six categories of data were recorded: 1) author(s), 2) type and stage of transplant, 3) country of origin, 4) participant (number and population), 4) methods and methodology, and 6) key findings. An overview of key characteristics of these studies, derived through this charting process, is presented in Table 7. The complete chart is presented in Table 8. Upon completion of this process, I reviewed the full chart (Table 8) to compare study type and identify key themes to inform the final stage of the review.

Characteristic	Subgroups	No. studies
Year of publication	≤1990	4
	1991-1995	3
	1996-2000	9
	2001-2005	20
	2006-2010	11
	2011-2015	16
	2016-2019	7
Method	Qualitative	30
	Quantitative	34
	Mixed methods	6
Transplant type	Heart (paediatric)	23 (5)
	Liver (paediatric)	9 (11)
	Lung (paediatric)	12 (3)
	Mix of heart/liver/lung (paediatric)	6 (1)
Transplant stage	Pre-transplant	23
	Post-transplant	26
	Pre- and post-transplant	21
Country of origin	Austria	4
	Australia	2
	Brazil	7
	Canada	4
	China	1
	Germany	2
	Israel	1
	Japan	1
	Spain	1
	Sweden	3
	Turkey	2
	UK	2
	US	40

No. participants (family members)	≤10	18
	11-20	12
	21-30	16
	31-40	4
	41-50	1
	51-60	5
	61-70	1
	71-80	2
	81-90	3
	91-100	1
	>100	6
	N/A	1
Type of family member	Parent	19
	Partner	15
	Child	2
	General*	34

Table 7: Overview of key characteristics of included studies (*reference to general terms include: ‘family’, ‘relative’, ‘caregiver’, ‘support person’ – identifying a sample of various relatives e.g. parent/partner/sibling/child/other)

Table 7 illustrates that most literature exploring the impact of heart, liver, and/or lung transplantation on family members originates from the United States of America (US). Though studies have been conducted elsewhere, most notably in Brazil, Canada, and Northern and Central Europe, they are much fewer in number. This literature review reveals the paucity of UK-based research on this topic. There appears to be a relatively equal balance between qualitative and quantitative research, however, studies adopting a mixed methods approach are rare. The bulk of research on this topic was conducted between 2001 and 2015, though there has been a recent surge in publications exploring parent experiences of paediatric liver transplantation (see Table 8). In the main, studies focus on either the pre- or post-transplantation experience, rather than the whole process. Samples are generally small (<20 individuals) and comprised of predominantly partners and/or parents.

Study no.	Author(s)	Type and stage of Transplant	Country of origin	Participants (no. and population)	Methods and Methodology	Key findings
1	Gold <i>et al.</i> (1986)	Paediatric heart and liver Pre- and Post-transplant	US	Parents (number not specified)	Qualitative approach. Collection of accounts from a transplant-centre parent support group over 4 years.	<p>Framework developed highlighting the psychological issues encountered by parents at the main stages of the transplant process: 1) preoperative, 2) perioperative, 3) long-term post-operative.</p> <p><i>Preoperative:</i> Initial hospital experience (Loss of control, Denial of medical reality, Building trust in staff), Waiting at home (Concrete tasks: financial burdens, public involvement; Guilt: death of donor, competition for limited organs, burden of informed consent; Anger: loss of control, feeling forgotten/abandoned; Depression: endless wait, child's deteriorating condition).</p> <p><i>Perioperative:</i> First 24 hours (Anxiety, Numbness/shock), First 2 weeks (Exhilaration/new beginning, Cease fire period: realignment in parent/child interaction, emotional integration of organ), Remainder of Hospitalisation (Roller coaster period: fear of rejection/infection, lack of control/powerlessness, continued guilt/fear of death, isolation/marital stress; Preparation for discharge: realisation of hospital dependency, building confidence).</p> <p><i>Long-term post-operative:</i> Return home (adaptation of new parenting role, fear of rejection/death, readjustment in family structure), Long-term (continued public involvement in transplantation issues, uncertainties about the future).</p>
2	Mishel and Murdaugh (1987)	Heart Post-transplant	US	20 family members	Grounded theory. Three family support groups, 12 weeks in duration, provided data for constant comparative analysis.	Family readjustment to heart transplant as a process of 'redesigning the dream'. Acknowledge family members gradually become aware that life cannot return to normal. Process of redesigning the dream

						comprises three concepts: 1) immersion, 2) passage, and 3) negotiation.
3	Uzark and Crowley (1989)	Paediatric heart Post-transplant	US	10 parents	Quantitative study using: Hymovich Chronicity Impact and Coping Instrument and/or the Feetham Family Function Survey, 3 to 24 months post-transplant	Parents face significant psychological and social stresses after their child's heart transplant related to: 1) the uncertainty of the child's future health and wellbeing, 2) role strain, 3) social isolation, and 4) financial burdens.
4	Buse and Pieper (1990)	Heart Pre- and post-transplant	US	30 partners	Cross-sectional study using quantitative measures: The Perception of Heart Transplant Stress Questionnaire, and The Subjective Stress Scale.	Spouses perceived the pre-transplant phase to have a greater influence on their lives and relationships than the post-transplant phase. They were significantly more positive about the post-transplant phase, than the pre-transplant phase. No significant difference was found in stress scores, pre- to post-transplant.
5	LoBiondo-Wood <i>et al.</i> (1992)	Paediatric liver Post-transplantation	US	58 mothers	Quantitative study using several measures: The Family Inventory of Life Events, The Coping Health Inventory for Parents, The Norbeck Social Support Questionnaire, and The McMaster Family Assessment Device. Asked two open-ended questions: 1) 'What has been the most stressful for you and your family since your child's transplant?' and "What has been most helpful to you and your family since your child's transplant?"	Family stress and parental coping were not significantly related to family adaptation. A significant negative correlation was found between social support and family adaptation. Major themes from the open-ended question regarding stress included: uncertainty, fear, finances, and separation issues. Major themes from the open-ended question regarding helpful factors since transplantation included: support, return to daily routine, and seeing the child healthy, happy, and growing.
6	Saxe-Braithwaite and Chapman (1992)	Lung Pre- and Post-transplant	Canada	5 support persons	Grounded theory. Longitudinal unstructured interviews (min. of six, max. of nine times). Participant observation of daily on-site interactions and a weekly support group.	Key theme: life on hold. Three sub-themes: 1) uncertainty (health status, obligations, waiting), 2) commitment (fight, determination, hope) and 3) realignment (time management and relationships).

7	McSweeney <i>et al.</i> (1995)	Heart Post-transplant	US	10 partners (9 women, 1 man)	Mixed methods: quality-of-life instrument and in-depth interviews.	Quality of life was lower for spouses than for transplant recipients. Spouses concerns included: finances, future plans, and personal desires, stress and secrets. Numerous relationship concerns were reported including: recipient's sexual function, sexuality issues, other marital concerns, burdens of others needing assistance, and reaction of others to the transplant couple. Feelings of resentment and guilt were also noted.
8	Canning <i>et al.</i> (1996)	Heart Post-transplant	US	83 caregivers	Mixed methods. Longitudinal interviews (3 times in first year post-transplant), using quantitative scales to measure distress). Multiple regression analysis.	Findings: a) employment status and caregivers' physical health were strong predictors of post-transplant distress while psychiatric history was not; b) the burden of caregiving was associated with increased distress early post-transplant but not in later months; and c) intrapersonal and social support resources early post-transplant were associated with distress both short- and long-term.
9	Collins <i>et al.</i> (1996)	Heart Pre-transplant	US	85 partners	Comparative cross-sectional survey, using Spouse Transplant Stressor Scale - SSTS (developed by Collins). Five instruments used: the STSS, the Family Inventory of Resources for Management, the Jalowiec Coping Scale, Ferrans and Powers' Quality of Life Index, and a 6-item rating form (consisting of 6 subject rates: overall stress, overall coping, spouse's health, patient's health, quality of life, and the impact of the HT experience).	Partners reported high levels of stress during the wait for a donor heart. Factors related to transplant experience were rated as the most stressful, the worst being fear that the partner would die before a donor was found. Working individuals perceived more stressors related to responsibility, socioeconomics, and self. Transplant-specific stressors were equally stressful for those in and out of work.
10	Suddaby <i>et al.</i> (1997)	Paediatric heart Pre-transplant	US	26 parents (18 mothers, 8 fathers)	Descriptive exploratory study using quantitative measures: The Family Inventory of Life Events and Changes (FILE), The Family Crisis	Over 70% of scores showed moderate stress levels among parents. Common coping mechanisms included: having faith in God, accepting that difficulties occur, and facing problems head on. Use

					Orientated Personal Scales, The Parents Perception of the Transplant Experience.	of coping mechanisms decreased over the 3-month study period. Parents of girls viewed transplant more negatively than parents of boys.
11	Dew <i>et al.</i> (1998)	Heart Post-transplant	US	133 family caregivers	Longitudinal quantitative assessment of family member physical health and wellbeing at 2, 7, and 12 months post-transplant. Cluster and multivariate analysis.	Change in caregivers' physical health identified, showing either: 1) worsening of general medical condition with weight gain, 2) worsening of medical condition with weight loss, 3) weight gain with stable medical condition, 4) weight loss with slightly improving medical condition, or 5) worsening health perceptions with relative little evidence of change in condition. Caregivers who experienced medical decline with weight gain had the greatest level of caregiver burden.
12	Bunzel <i>et al.</i> (1999)	Heart Pre- and post-transplant	Austria	26 couples (partners and patients)	Data collected using quantitative measures (The Family Assessment Measure) at three points: waiting list, 1 year post-transplant, and 5 years post-transplant.	During transplant process, both patient and spouses report a significant deterioration in the partner relationship. Spouses reported a significant worsening in role performance, communication, emotional involvement, and values and norms. These changes persisted five years post-transplant. Heart transplant has a significant negative impact on the partner relationship 1-5 years after transplantation.
13	Stubblefield and Murray (1999)	Paediatric lung Pre- and post-transplant	US	15 parents	Phenomenological study. Unstructured in-depth interviews, on two occasions.	Two main themes: 1) Concerned care (being treated as an individual, seeing familiar faces, feeling that their children really mattered, experiencing a feeling of abandonment), and 2) Collaborative Care (being part of the team, feeling caught in the middle). The theme of concerned care reflected the value placed on continuity of care.
14	Stukas <i>et al.</i> (1999)	Heart Post-transplant	US	142 caregivers 158 patients	Structured standardised interview and DSM-III-R criteria. Transplant related PTSD (PTSD-T) assessed at 12 months post-transplant with Michigan version of the WHO/ADAMHA composite international diagnostic instrument.	During the first year post-transplant 7.7% of caregivers met the full criteria for PTSD-T and an additional 11.0% were probable cases. Severity and duration of PTSD-T were similar across caregivers and patients. Females, with a history of psychiatric illness and lower friend support, were at increased risk of PTSD-T.

15	Collins <i>et al.</i> (2000)	Heart Pre- and post-transplant	US	72 partners	Quantitative measures: Quality of Life Index, Spouse Transplant Stressor Scale, Jalowiec Coping Scale, and Rating Form. Questionnaires completed during the pre-transplant phase and at 1 year post-transplant.	Overall, the perceived quality of life among spouses of heart transplant patients did not change significantly from pre- to post-transplant. Conversely, specific factors influencing quality of life (incl. health, socioeconomic satisfaction, family satisfaction, coping styles, and impact of transplant experience of spouses' life) did change post-transplant. One year post-transplant spouses were less satisfied with their health and socioeconomic status, but more satisfied with their family than before transplant. Spouses used less fatalistic, emotive, optimistic, and self-reliant coping styles post-transplant, and viewed the transplant experience more positively.
16	LoBiondo-Wood <i>et al.</i> (2000)	Liver Pre-transplant	US	29 mothers	Exploratory study using the Double ABC-X Model of Family Adaptation.	Higher family strains, fewer coping skills, and higher perception of stress were related to more unhealthy family adaption pre-transplant. There is a need for close evaluation of child and family needs as the family begin the transplantation process.
17	Bohachick <i>et al.</i> (2001)	Heart Pre- and post-transplant	US	51 couples (partner and patient)	Panel design, measurements taken on acceptance to waiting list and 12 months after transplantation. Completion of self-report questionnaires.	Prior to transplant, spouses experience profound psychosocial functional distress related to their partners' illnesses. Spouses of patients awaiting transplantation are a vulnerable to disruption in their social lives and to psychological distress as the patient themselves. High levels of anxiety, depression, and worry were reported. Spousal psychosocial adjustment improves significantly over the 12 months following the transplant. However, substantial difficulties persist.
18	Higgins (2001)	Paediatric heart Pre-transplant	US	24 parents	Prospective qualitative ethnographic study. In-depth interviews (<2 weeks of decision) and observations.	Style of parental decision-making ranged from a desire to make an independent, autonomous choice of treatment to a wish that the physician make an authoritarian, paternalistic choice for the child. It is imperative for clinicians to assess and support each parent's individual style of decision-making.

19	Kurz (2001a)	Heart and Lung Pre- and post-transplant	US	25 couples (9 pre-transplant, 16 post-transplant)	Surveys: the Desire for Control Scale, the Family Crisis Oriented Personal Evaluation Scale, and the Quality of Life Index.	A statistically significant difference was noted with quality of life when comparing transplant candidates and their spouses with the main contributing domain, the health and functioning area. It is clinically significant that there were no differences detected when comparing desire for control, coping, or quality of life of transplants recipients with their respective spouses, except in the pre-transplant group. Transplant teams should direct interventions at both patients and their spouses.
20	Kurz (2001b)	Lung Post-transplant	US	12 partners	Interviews. Family Inventory of Life Events survey completed prior to interview.	Key elements of the transplant experience discussed included: coping, giving medications, knowing the donor, making comparisons, togetherness or couple relationship, and caring for me – the well spouse. The core theme within these elements was transplant as a ‘roller coaster ride’. Five identified transplant stages were: 1) transplant event, 2) cocooning, 3) normalising, 4) branching-out, and 5) settling-down.
21	Kurz and Cavanaugh (2001)	Lung Pre-transplant	US	13 partners	Telephone interviews. Constant comparative method. Self-report surveys: The Family Inventory of Life Events (to measure stress) and The Centre for Epidemiological Studies Depression Scale (to measure depression).	Reports numerous sources of stress: changes, normal routines, waiting, work, family and friends, partner’s declining health. Positive factors noted included family support and discovering source of strength. Coping was discussed in terms of: action, acceptance, disengagement, and planning. Support was discussed in terms of: emotional support, esteem support, information sharing, and tangible support.
22	Meltzer and Rodrigue (2001)	Liver and Lung Pre-transplant	US	52 ‘caregivers’ (28 liver, 24 lung)	Questionnaires (Psychosocial Adjustment to Illness Scale, SF-36 Health Survey, Caregiver Strain Index, and qualitative questions about benefits and stressors).	The most commonly reported benefit of being a caregiver could be categorised as ‘helping the patient’. The most common stressors were associated with uncertainty, waiting, and fears. Compared to normative samples of caregivers of people with Alzheimer’s disease, caregivers of liver transplant candidates reported more caregiver strain; there were no differences for lung transplant caregivers. Caregiver social functioning was found to be the only

						significant predictor of caregiver distress, with those caregivers who report greater distress also reporting extreme and frequent interference with normal social activities.
23	Stubblefield and Murray (2001)	Paediatric lung Pre- and post-transplant	US	15 parents of 12 children	Semi-structured interviews.	Five key sources of support identified: family members and friends, parents of other children, members of the community, professional counsellors, and religious affiliations. Reported experiencing diminished support, as they felt 'misunderstood' and 'labelled' as 'not normal'.
24	Young <i>et al.</i> (2001)	Heart Post-transplant	Canada	7 families	Unstructured interviews, guided by three questions: 1) Who do you consider as part of your family? 2) How has the experience of heart transplant been for your family? 3) What are your perceptions of your information and support needs? Families were also given a disposable camera and asked to capture day-to-day family life during the wait for a heart.	Key themes: 1) Support needs and 2) Information needs. Participants recommended many potential support strategies, including: provision of temporary housing, establishment of a family mentoring programme, establishment of family support groups for the specific phases of the transplant process, creation of a communications and support network, revision of the heart transplant information manual to include everyday challenges and issues, and the development of a support team of professionals.
25	Kurz (2002)	Lung Pre- and post-transplant	US	24 partners (12 pre- and 12 post-transplant)	Telephone interviews. Secondary analysis.	Focus on caregiver role strain. In the context of transplantation, this comprises six elements: 1) insufficient time or energy, 2) difficulty performing required caregiving activities, 3) caregiving responsibilities interfering with other important roles, 4) apprehension about the patient's future health and ability to provide care, 5) apprehension about patient's care when caregiver is ill or deceased, and 6) feelings of depression or anger.
26	McCurry and Thomas (2002)	Heart Post-transplant	US	7 female partners	Phenomenology. In-depth interviews.	Four major interrelated themes: 1) death-life, 2) vigilance (watching and letting go), 3) change (in

					Analysed according to steps of Pollio <i>et al.</i>	recipient, self, faith, roles, and relationships), and 4) gift (giving and receiving).
27	Stubblefield and Murray (2002)	Paediatric lung Pre-transplant	US	6 parents	Phenomenology. Interviews.	Six themes: 1) putting life on hold, 2) experiencing diminished social support, 3) establishing new sources of support, 4) undergoing role change, 5) worrying about money, and 6) making the best of the situation.
28	Dew <i>et al.</i> (2004)	Heart Post-transplant	US	190 caregivers	Psychiatric and psychosocial evaluations at 2, 7, 12, and 36 months post-transplant. Survival analysis.	Rates of depressive and anxiety-related disorders met or exceeded other caregiver populations' rates. PTSD associated to transplantation occurred primarily during the first year post-transplant. Rates of other disorders increased over the study period. Risk of disorder was elevated by lifetime history of psychiatric disorder, greater post-transplant caregiving responsibilities, and poorer relationship with the patient. Risk of Major Depressive Disorder was increased by caregiver unemployment. Risk for anxiety disorders was increased by younger age, low sense of personal mastery, and high use of avoidance coping strategies.
29	LoBiondo-Wood <i>et al.</i> (2004)	Paediatric liver Pre and post-transplantation	US	15 mothers	Descriptive longitudinal study using several measures, including: The Family Inventory of Life Events and Changes, The Profile of Mood States, The Coping Health Inventory for Parents, The Parent Perception of Uncertainty Scale, and The McMaster Family Assessment Device.	Maternal stress, coping, and uncertainty demonstrated significant changes over time, whereas family stress did not. Pre-transplantation family stress, anger, and confusion were related to poorer family adaptation.
30	Ullrich <i>et al.</i> (2004)	Lung Pre- and post-transplant	Germany	39 relatives	Cross-sectional study using questionnaires with numerical scales and fill-in-the-gap-items concerning subject burden, stress symptoms, unmet needs,	Most participants rated the acute illness stage as extremely stressful, this continued for one third of respondents post-transplant. Symptoms mostly referred to depressive and anxiety states. Most reported experiencing financial burden and conflict

					suggestions to improve the support person's situation.	with organisations to enable them to stay with their ill relative. Participants suggested improvements to information provision, aspects of communication, and better access to psychosocial professionals.
31	Bunzel <i>et al.</i> (2005)	Heart Pre- and post-transplant	Austria	27 partners (of VAD patients who had a heart transplant) 41 patients	Retrospective assessment using standardised instruments: Impact of Event Scale, Hospital Anxiety and Depression Scale.	Despite patients being much closer to a life threat, their partners experience significantly more psychological distress over time. Six partners met the criteria for PTSD, compared with no transplant patients. Partner scores indicated greater levels of depression and anxiety compared with patients.
32	Burker <i>et al.</i> (2005)	Heart Pre-transplant	US	28 partners	Cross sectional study using the COPE Inventory and Depression Scale.	Partners reported using adaptive coping strategies more than less adaptive strategies. High levels of depression were associated with 'behavioural disengagement', and mitigated by 'planning' coping strategies.
33	Casida (2005)	Heart Pre-transplant	US	3 partners (of LVAD patients waiting for transplant)	Phenomenological study. Semi-structured interviews. Van Manen approach to analysis (highlighting method).	Three main themes: 1) emotional distress, 2) determination, and 3) optimism: a new lease on life. Eight subthemes: 1) guilt and realisation of severity of illness, 2) fear and anxiety, 3) recognition that being a caregiver is an overwhelming experience and a burden, 4) coping, 5) living with hope, 6) realisation of loving relationship, 7) adaptation to a new life, and 8) joyful feeling.
34	Claar <i>et al.</i> (2005)	Lung Pre-transplant	US	82 caregivers	Psychosocial measures, including: the Beck Depression Inventory-II, State-Trait Anxiety Inventory, Medical Coping Modes Questionnaire, Scale for Caregiver Burden, and Medical Outcomes Survey.	Reports of depression and anxiety were relatively low among caregivers. Passive coping strategies were associated with higher levels of emotional distress: resignation was associated with increased depression, avoidance with increased anxiety. Caregivers who reported greater perceived caregiver burden experienced higher levels of depression. Caregivers experienced significant disruption to their social functioning.
35	Myaskovsky <i>et al.</i> (2005)	Lung Pre-transplant	US	134 pairs of patients and caregivers	Mixed methods. Semi-structured interviews, including measures of	Better patient QOL equated to better caregiver QOL. Caregivers who used more emotionally orientated

					QOL and coping. Multivariate, canonical correlation analysis.	coping had poorer QOL. Patient's coping and QOL may be critical for understanding caregiver wellbeing.
36	Ullrich <i>et al.</i> (2005)	Lung Pre- and post-transplant	Germany	39 relatives 50 patients	Mixed methods: semi-structured interviews and questionnaires.	Relatives were predominantly dissatisfied with the information provided and reported feeling somewhat excluded by staff across the transplantation trajectory. Relatives felt less supported than transplant patients. Regarding enhancing support, two themes were apparent: information giving (especially pre-transplant) and having someone to talk to (physician or psychosocial staff).
37	Bunzel <i>et al.</i> (2007)	Heart Pre-transplant	Austria	27 partners 38 patients	Cross-sectional study using the Impact of Event Scale-Revised Version to investigate symptoms of PTSD and VAD-related fears and concerns.	Patients who were operated on at the early stages of the VAD program were significantly more likely to have a partner with PTSD symptoms than those operated on later. Partners worried more about device-related problems (malfunctioning, pain, infection, and stroke) than the patient themselves.
38	Cohen <i>et al.</i> (2007)	Liver Post-transplant	Israel	24 caregivers	Questionnaires administered: Pearlin's caregiving stress questionnaire, a depression questionnaire, and a perceived caregiver's health questionnaire.	Caregivers experienced considerable caregiving overload. Women reported performing more caregiving activities, higher perceived overload, and higher levels of depression than men. High levels of depression and poor perceived health were associated with time since transplant, higher perceived overload, higher sense of relational deprivation, and lower sense of personal gain. Perceived support and level of depression were not significantly associated with perceived health. Caregiving stress endures post-transplantation.
39	Farley <i>et al.</i> (2007)	Paediatric heart Post-transplant	US	52 parents	Questionnaires assessing illness-related parenting stress and post-traumatic stress symptoms.	Almost 40% of parents indicated moderately severe to severe post-traumatic stress symptoms. Ten met the criteria for PTSD. Significant levels of illness-related parenting stress were identified.
40	Haugh and Salyer (2007)	Heart Pre-transplant	US	3 family members 8 patients	Two focus groups. Content analysis.	Six core themes identified: 1) tolerating uncertainty, 2) sharing information, 3) sensitivity to family, 4) maintaining respect and dignity, 5) doing the 'extra little things', and 6) facilitating coping. This study

						stresses family member's desire to be recognised as partners in the transplant experience.
41	Rodrigue and Baz (2007)	Lung Pre-transplant	US	73 caregivers	Survey study, using: QOL inventory, SF-35 Health Survey, Profile of Mood States, Caregiver Strain Index, Caregiver Benefit Index, and Miller Social Intimacy Scale.	Compared to a normal sample, partners reported significantly lower physical and emotional QOL. Some participants reported clinically low QOL. More than half had clinically elevated caregiving strain. Factors contributing to caregiving strain, included: physical strain, inconvenience, feeling confined, and feeling upset about patient change. Reported caregiving benefits included: discovering inner strength, support from others, and realising what is important in life. Higher caregiving strain was associated with mood disturbance, lower emotional QOL, lower social intimacy, and longer disease duration.
42	Green <i>et al.</i> (2009)	Paediatric heart Post-transplant	US	11 parents	Ethnographic design. In-depth interviews. Content analysis.	Parents described their experiences positively, while acknowledging hardships. Key themes: 1) constantly responsible, 2) constantly worried, 3) constantly blessed, and 4) coping with life.
43	Lefaiver <i>et al.</i> (2009)	Lung Pre-transplant	US	29 pairs of caregivers and patients	Descriptive study using self-report surveys, including: Quality of Life Index, SF-12 health survey, Profile of Mood States-Short Form, and the Caregiver Reaction Assessment.	Caregivers reported reasonable quality of life levels, physical health, and mood pre-transplant. Problem areas included: fatigue, depression, and the financial impact of the transplant. Greatest effect on caregivers' quality of life came from depression, caregiver general health, impact on finances, and lack of family support.
44	Mendes and Bousso (2009)	Pediatric liver Pre- and post-transplant	Brazil	8 families	Descriptive study. Semi-structured interviews. Grounded theory.	Two phenomena identified related to the overall finding of 'not being able to live like before' First, life becomes controlled by the transplantation. Second, families struggle to acquire autonomy as they continually adapt to the situation.
45	Baker <i>et al.</i> (2010)	Heart Pre-transplant	US	6 caregivers (4 partner, 1 parent, 1 friend)	Semi-structured interviews. Phenomenological analysis.	Two main themes identified: 1) sacrifice (in terms of relationships with friends and family, jobs and livelihood, health, and peace of mind) and 2) moving beyond (coping and adaptation to the sacrifices of

						being a caregiver). Experiences described suggest that participants successfully incorporated the role of caregiver for patients with a complex therapeutic regimen into their daily lives.
46	Miyazaki <i>et al.</i> (2010)	Liver Pre-transplant	Brazil	61 caregivers	Mixed methods. Semi-structured interviews. Quantitative questionnaires: The Caregiving Burden Scale, and The Beck Depression Inventory	The main stressors identified by the participants were: doubts about ways to react in a crisis or an emergency, patient mood swings, and care involving food and medication. Approximately 25% reported that they felt unprepared for the caregiving role. Caregivers of patients with alcoholic liver disease showed higher depression and overall burden.
47	Young <i>et al.</i> (2010)	Heart Pre- and post-transplant	Canada	15 families 12 health professionals	Constructivist grounded theory. Semi-structured interviews. (Children were invited to draw pictures of their experience).	Three primary stages explored: 1) preparing for the transplant, 2) recovering, and 3) rejoicing (or grieving). Few resources supported family members in their caregiving work. Both families and health professionals reportedly benefitted from each other's contribution to care. Worry and uncertainty about recipient health reportedly changed the family's usual way of being. Family members experienced multiple tensions, were stretched economically and taxed physically prior-to and in the six months following transplant surgery.
48	Holtzman <i>et al.</i> (2011)	Heart or lung Pre-transplant	Canada	93 patient-caregiver dyads (partner, parents, children, siblings, other)	Quantitative approach using a questionnaire comprising multiple scales: The Centre for Epidemiological Studies-Depression Scale, The Ways of Providing Support Scale, The Caregiver Reaction Assessment Scale, and The Physical Component Score.	Females caring for male patients reported significantly higher depressive symptoms than other caregivers. This difference was explained to an extent by less support from family members and a greater negative health impact of caregiving. Women caring for men were also perceived as more overprotective.
49	Denny <i>et al.</i> (2012)	Paediatric liver Post-transplant	Australia	30 families of transplant recipients	Cross-sectional study comparing the family functioning and QOL of children living with a liver transplant with non-transplant	Parents of paediatric liver transplant recipients made significantly more adjustments to family routines to accommodate their children, particularly in relation to

				33 families of non-transplant children	children. Quantitative measures used: Family Accommodations Questionnaire, and PedsQL 3.0 Transplant Module Parent Report.	childcare. Impaired family functioning was also found to be associated with decreased QOL.
50	Mendes-Castillo <i>et al.</i> (2012)	Paediatric liver Post-transplant	Brazil	8 families	Secondary analysis of interview data.	Five styles of management identified: 1) thriving family, 2) accommodating family, 3) enduring family, 4) struggling family, and 5) waiting family.
51	Myaskovsky <i>et al.</i> (2012)	Heart and Lung Post-transplant	US	242 caregivers (lung n=134, heart n=108)	Quantitative surveys assessing demographics, psychological characteristics and caregiver burden at 2, 7, 12 months post-transplant.	Caregiver health-related quality of life (HRQOL) was generally high across the first-year post-transplant in emotional and social functioning; caregiver physical functioning significantly worsened. There were no differences by type of transplant recipient. Greater caregiver burden predicted poorer caregiver HRQOL in several domains post-transplant.
52	Williams <i>et al.</i> (2012)	Liver Pre- and post-transplant	US	5 parents or guardians	Semi-structured telephone interviews.	Three focal points: 1) the parents' and guardians' perceptions of their interactions with the transplant team, 2) their interactions with the local health care systems, and 3) caring for themselves and the child at home.
53	Xu <i>et al.</i> (2012)	Lung Post-transplant	US	21 dyads of lung transplant recipients and their family caregiver	The Day Reconstruction Method. Content analysis.	Participants reported 286 daily activities and 138 associated positive and negative emotions. No activities or emotions were unique to recipients or caregivers, revealed the shared responsibility for caregiving and health maintenance. Most activities reported were health-related. Caregivers reported positive emotions more often, but lower overall daily mood than recipients.
54	Fulbrook <i>et al.</i> (2013)	Lung Pre- and post-transplant	Australia	10 children, (between 8-16 years old)	Phenomenology. Children produced artwork to depict their experience, before being interviewed using a semi-structured approach.	Six themes emerged from the data: 1) uncertainty and anxiety, 2) disruption, 3) separation, 4) desire for normality, 5) importance of social support, 6) adjustment and avoidance.
55	Sadala <i>et al.</i> (2013)	Heart Post-transplant	Brazil	11 caregivers (Parent, child, partner, sibling)	Phenomenology. In-depth interviews.	Post-transplant, caregivers lives change dramatically as their priorities shift toward caring for their relative. Uncertainty about the future remains, generating

						permanent distress. Anxiety is exacerbated by familial or economic problems. Caregivers sought support from their local communities. Some participants reported learning from their experience and planning to return to normal activities. Others stated feeling helpless, as they struggled to overcome personal losses and difficulties.
56	Ågren <i>et al.</i> (2014)	Heart Pre- and post-transplant	Sweden	13 children	Retrospective interviews with adults exploring their childhood experience of a parents' heart transplant. Content analysis.	Three main themes re. support provision: 1) Health care professionals' approaches, 2) family and friends' approaches, and 3) society approaches. Findings reveal there was a lack of support for children of heart transplant patients.
57	Gutermann <i>et al.</i> (2014)	Liver Post-transplant	UK	37 parents	Cross-sectional survey using a 9-part questionnaire, focusing on medicines, training, and proposed improvements.	Many medication-related issues were reported, including: supply issues, administration problems, and blood test issues. Not all reported experiencing problems, with 30 parents rating the medication training as 'excellent' or 'very good' and 36 stating that the written information provided was comprehensible and accurate. Parents outlined that they would like access to an online learning tool, explanatory comic book for children, and pharmaceutical consultations.
58	Ivarsson <i>et al.</i> (2014a)	Heart or lung Pre- and post-transplant	Sweden	15 relatives with a 'close' relationship with the patient	Semi-structured interviews, conversational approach. Content analysis.	Three main categories: 1) navigating through specific circumstances (involvement in decision making, reaction to the call, influenced by patients' condition, and circumstances about dependent children), 2) facilitating the transplantation journey (meeting expectations, active information seeking, being preoccupied with practical and mental support, and handling the consequences of life-threatening situations), and 3) experiencing information and support (receiving support and information from health professionals, feeling of being uninformed or unsupported, and impression of the in-hospital time).

59	Ivarsson <i>et al.</i> (2014b)	Heart or lung Pre-transplant	Sweden	18 relatives	Descriptive design with a qualitative approach, incorporating a critical incident technique (CIT).	Two main areas emerged: 1) experiencing information and support (dissatisfaction with the health care system, being relatively satisfied, supporting patients hands-on, and the social network role), and 2) reflecting upon information and support (finding strength, and uncomfortable with their own emotions).
60	Malik <i>et al.</i> (2014)	Liver Pre-transplant	Austria	24 caregivers 47 patients	Surveys conducted at baseline and intervals of 4-6 weeks using The Hospital Anxiety and Depression Scale, and The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire.	Results show significantly higher anxiety scores in caregivers than in patients. Caregiver's anxiety levels increased significantly. Relatives showed more depression than patients only at month 1-2 and a significant increase in depression from baseline to month 1-2.
61	Mendes-Castillo <i>et al.</i> (2014)	Paediatric liver Post-transplant	Brazil	1 family	Case study, using the Family Management Style Framework (FMSF) as theoretical framework. Semi-structured interviews.	Family defines the transplantation as threatening and there are divergence between mother and daughter (recipient) related to the patient's capability to take care of herself alone. The family adopts a protective posture in response to this uncertainty. Uncertainty permeates the family environment.
62	Zhang <i>et al.</i> (2014)	Liver Pre- and post-transplant	China	25 parents (6 fathers and 19 mothers)	Narrative interview-based study, using a semi-structured approach. Content analysis.	Five primary themes: 1) guilt and self-blame for not giving a happy life to the sick child; 2) seeking social support for helping to treat the sick child; 3) standing firm by not giving up on treating the sick child; 4) cautious caretaking; 5) compromise: a helpless acceptance of truth.
63	Mary and Ward (2015)	Heart Post-transplant	US	59 caregivers	Secondary analysis of data collected for a cross-sectional study which used multiple valid instruments: The SF-36 health	Depressive symptoms were negatively correlated with perceived social support, and positively correlated with the number and severity of psychological

					survey, checklist of chronic health problems, weekly stress inventory, perceived social support, and dyadic adjustment scale.	stressors and the likelihood of caregiver hospitalisation during the past year.
64	Sá <i>et al.</i> (2016)	Liver Pre-transplant	Brazil	42 families	Cross-sectional study. Participants asked to rank 10 subjects in order, according to their importance and amount of interest they had in learning about each.	All reported receiving some information, from physicians and the transplant team, via the transplant candidate. Most reported that they felt prepared to undertake patient care. The number of participants who had not read the information leaflet (providing by clinical staff) was an important finding.
65	Sahin <i>et al.</i> (2016)	Paediatric liver Pre-transplant	Turkey	38 parents 35 transplant candidates	Quantitative study using the Hamilton Depression Rating Scale, Hamilton Anxiety Rating Scale, and Clinical Global Impression Scale.	Twenty-five parents were diagnosed with clinical psychiatric disease: 7 with depression, 18 with anxiety disorders.
66	Hiratsuka <i>et al.</i> (2017)	Paediatric liver Pre-transplant	Japan	6 mothers 6 children	Semi-structured interviews. Content analysis.	Uncertainty was identified as a key theme. Mothers were conscious of the potential need for transplantation, contributing to emotional and practical uncertainties. Mothers preferred to use buffering as a coping strategy. It is suggested that living with the uncertainty about the health and survival of their children is advantageous for mothers. Problem-solving coping strategies should be promoted.
67	Mendes-Castillo <i>et al.</i> (2017)	Paediatric liver Post-transplant	Brazil	1 family	Qualitative case study, using a hybrid model of thematic analysis and the theoretical framework: the Family Management Style Framework. In-depth semi-structured interviews and analysis of medical records.	The family defines the condition as threatening and has dichotomous feelings about the child's identity ("special" VS "like any other child"). Uncertainty about the future was seen as an important issue that deserves nursing attention.
68	Ordin <i>et al.</i> (2017)	Paediatric liver Post-transplant	Turkey	5 parents 10 liver recipients	In-depth semi-structured interviews. Content analysis.	Seven main themes: 1) coping (undesirable habits), 2) self-management (financial problems), 3) body

						image, 4) social relationships, 5) academic life, 6) work life, 7) live donors. Recipients and parents often report being ill informed about what to expect after transplantation. Parents have conflicting ideas about their children's increasing autonomy regarding medication and hospital check-ups.
69	Wright <i>et al.</i> (2017)	Paediatric liver Post-transplant	UK	9 parents	Semi-structured interviews. IPA analysis.	Three themes: 1) emotional impact of transplantation, 2) protection VS. independence, and 3) ending relationships and changing roles. Parents stressed the dichotomous nature of desire to promote independence in their child, while maintaining control and protection, and discussed how changing roles and relationships were difficult to navigate. Parents should be supported to move from a "managerial" to a "supervisory" role during transition to help young people engage independently with the healthcare team.
70	Pérez-San-Gregorio <i>et al.</i> (2018)	Liver Post-transplant	Spain	218 caregivers	Quantitative survey, using: the Post-traumatic Growth Inventory and the Brief COPE.	Results showed that, regardless of time elapsed since the stressful life event, the caregivers with the highest levels of post-traumatic growth used positive reframing and religion to a greater extent. Caregivers with a medium level of post-traumatic growth also employed self-distraction more (e.g. activities that make them think less about the problem).

Table 8: Complete chart of all included studies

3.2.5 *Collating, summarising, and reporting the results*

In this section I summarise the findings of the studies identified in this scoping review (see Table 8) by focusing on recurrent themes, namely: 1) family lifestyle and routine, 2) family roles, 3) family relationships, and 4) family wellbeing. Within each theme, I emphasise the similarities and differences between the included studies. Broader caregiving literature is referenced, where appropriate, to contextualise key findings.

3.2.5.1 *Family lifestyle and routine*

Throughout the transplantation procedure families are subject to various elements of change (Gold *et al.*, 1986; Mendes-Castillo *et al.*, 2012; Mary and Ward, 2015). To ensure the maintenance of a sense of ‘normal’ family functioning during this time each family member is required to adjust their behaviour, thus over the course of the transplantation process the family unit can undergo substantial transformation (Gold *et al.*, 1986; Mendes and Bousso, 2009; Baker *et al.*, 2010; Denny *et al.*, 2012; Mendes-Castillo *et al.*, 2012; Sá *et al.*, 2016). Existing literature primarily focuses on the detrimental aspects of this transformation, accentuating that the transplantation process can take a significant toll on families, regardless of their commitment and resourcefulness. Family members are recognised to alter, and somewhat restrict, their routines in the lead up to the transplant in order to support the individual awaiting a transplant, an occurrence that some have likened to putting normal life ‘on hold’ (Mishel and Murdaugh, 1987; Buse and Pieper, 1990; Saxe-Braithwaite and Chapman, 1992). Several studies highlight that family members neglect everyday activities pre-transplantation, postponing future plans and/or long-held dreams, to prioritise the needs of the ill individual (Mishel and Murdaugh, 1987; Benning and Smith, 1994; McSweeney *et al.*, 1995). This element of the transplant experience echoes the findings of research conducted with family members caring for a chronically ill relative, which demonstrates the disruptive impact that illness can have on the family system and individuals’ ability to continue on with ‘normal’ life (Rolland, 1994; Gregory, 2005; Eriksson and Svedlund, 2006; Golics *et al.*, 2013; Wittenberg *et al.*, 2013; Årestedt *et al.*, 2014; Aasbø *et al.*, 2016). A qualitative study by Mendes and Bousso (2009) of the pre-transplant experience of eight Brazilian families indicates that family members can feel as though their life is controlled by

the transplantation process, a finding supported by similar research conducted in Canada:

Once a patient is considered for heart transplant, patients' and family members' everyday lives become organised and coordinated around the health care system leaving them vulnerable not only physiologically, but also psychologically, financially, socially, and existentially (Young, 2010, p. 7).

Further research from the US identifies that family members continue to feel controlled by the transplant process post-transplantation. In a qualitative study exploring the experience of 12 partners of individuals living with a transplant, Kurz (2001b) found that participants felt that their lives were dictated by hospital appointments, strict medication regimens, and the need to constantly monitor their relative's condition. As these studies have small sample sizes, the wider applicability of their findings is uncertain, however, it is important to note that these ideas can be argued to be theoretically generalisable, as they have "some relevance beyond the actual participants in the study" (Green, 1999, p. 46). There is little evidence to counter the claim that the families of those awaiting, or who have undergone, a transplant become controlled by the process.

Perhaps the most extreme example of the extent to which family life can become 'controlled' by the transplantation process and needs of the ill relative is the decision made by some families to relocate to be closer to the transplant centre (Gold *et al.*, 1986; LoBiondo-Wood *et al.*, 1992; Stubblefield and Murray, 2002). Though the ill family member benefits from being nearer optimal healthcare, evidence presented within several studies reveals that the same cannot be said for the relatives that accompany them. Family members reportedly struggle during this period of relocation for several reasons, including: financial strain, marital tension, and isolation due to loss of trusted social support networks (Gold *et al.*, 1986; Mishel and Murdaugh, 1987; LoBiondo-Wood *et al.*, 1992; Kurz, 2001b; Young *et al.*, 2001; Stubblefield and Murray, 2002; Mendes and Bousso, 2009; Williams *et al.*, 2012). It is worth noting that most research discussing family relocation originate from the US and Brazil. At present there exists little evidence to suggest this would be the case in the UK, however, considering that specialist NHS transplant centres are scattered across the country it is possible some British families may relocate whilst their family

member waits for a transplant. Research is needed to determine the extent to which families in the UK are affected by this decision.

3.2.5.2 *Family roles*

As individuals awaiting a transplant become increasingly restricted in their ability to contribute to household functioning (chores, financial duties, childcare responsibilities), they often relinquish previously held roles (Mishel and Murdaugh, 1987; Bunzel *et al.*, 1999; Kurz, 2002; Mendes and Bouso, 2009; Denny *et al.*, 2012). Thus, to maintain 'normal' family functioning, other family members are required to integrate these relinquished activities into their routine (Buse and Pieper, 1990; Mendes and Bouso, 2009; Ågren *et al.*, 2014). Whilst this process is not uncommon among families living with chronically ill individuals (Barrett *et al.*, 2014), it can be viewed as particularly difficult for families of transplant patients because of the uncertain nature of the transplantation process. Unaware of the duration of this role change, family members are forced to live in a liminal state of responsibility; balancing care provision for the ill relative with increased accountability for the household upkeep, greater childcare responsibilities, and increased financial obligations (Gold *et al.*, 1986; Mendes-Castillo *et al.*, 2012).

Literature reveals that the stress of balancing roles does not necessarily dissipate when the ill relative becomes well enough to resume their relinquished roles. Rather, the shift in roles is noted to be a potential source of family conflict post-transplant (Mishel and Murdaugh, 1987; Kurz, 2002). An Austrian study by Bunzel *et al.* (1999), using a mixed methods approach to explore the impact of heart transplantation on 26 couples, details that family members can struggle to re-establish roles post-transplant as partners often experience role ambiguity and disagree about which roles they should fulfil. Mothers of transplant recipients are also acknowledged to experience role ambiguity post-transplant and struggle to relinquish control of their child's routine as they recover (Gold *et al.*, 1986; Ullrich *et al.*, 2004; Green *et al.*, 2009; Mendes-Castillo *et al.*, 2014, 2017; Ordin *et al.*, 2017; Wright *et al.*, 2017). For example, a recent UK-based study by Wright *et al.* (2017) reports that mothers of teenage liver recipients can feel conflicted by simultaneous urges to protect their child

and encourage independence. This conflict, Wright *et al.* argue, is primarily rooted in doubts about their child's ability to manage their condition, specifically concerns that they would not: understand/listen to the transplant team, ask the right questions, and/or share important information with their family. While such studies suggest that families find it challenging to re-establish roles post-transplant, it must be stressed that the sample sizes are relatively small considering the research techniques implemented, thus these findings must be interpreted with caution.

As is apparent from the literature discussed (and figures in Table 7), most studies exploring the process of role reorganisation in transplant families focuses on partners or parents. There is scant literature detailing the potential impact on children (both young and old) and/or siblings of those awaiting or living with a transplant, or indeed what roles these individuals typically adopt in this situation. Further research is required to better understand the impact of role reorganisation and re-establishment within families throughout the transplantation process.

3.2.5.3 *Family relationships*

Mirroring wider caregiving research (e.g. Rolland, 1994; Cheung and Hocking, 2004; Årestedt *et al.*, 2014; Aasbø *et al.*, 2016), a key finding of studies exploring the family experience of heart, liver, and/or lung transplantation relates to the effect of the process on personal relationships. Most studies exploring the impact of transplantation on family relationships focus on spousal relationships.¹⁸ Spousal relationships are reportedly placed under great strain throughout the transplantation process. One of the largest contributing factors to this is noted to be the extent to which the ill partner can change throughout the transplant process: physically, psychologically, and emotionally. Literature highlights deteriorating health, medication, and even the incorporation of 'traits' from the donor organ can result in physical, psychological, and/or emotional changes (Mishel and Murdaugh, 1987; McCurry and Thomas, 2002). While some changes, such as lower energy levels or inconsistent food urges (Mishel and Murdaugh, 1987), are thought to have a minor impact upon the relationship, others are believed to be more detrimental. Changes

¹⁸ The term 'spousal relationship' refers to married individuals and co-habiting partners.

such as severe anger, poor social interaction, decreased libido, and depression (Mishel and Murdaugh, 1987; Tabler and Frierson, 1990; McSweeney *et al.*, 1995; Bunzel *et al.*, 1999; Kurz, 2001b; Ivarsson *et al.*, 2014b) are recognised to significantly disrupt physical and emotional intimacy levels, potentially leaving the well partner feeling detached from their spouse (Canning *et al.*, 1996).

Research providing detailed insight into the impact of transplantation on spousal relationships is limited. One novel example is US-based qualitative research conducted by McSweeney *et al.* (1995). The findings of this study, conducted with ten partners of individuals living with a heart transplant, reveal that even though 'sexuality' is a key concern for partners post-transplant, they rarely discuss their sexual problems with others. Still, this is not unusual. Reflecting accounts of information sharing documented in wider caregiving literature (e.g. Kuyper and Wester, 1998), partners of transplant patients are recognised to remain silent about a multitude of problems, preferring instead to engage in a practice they liken to keeping 'secrets', to prevent disturbing the dynamic of the relationship (McSweeney *et al.*, 1995, p. 62). The negative impact of heart transplantation on spousal relationships has since been elaborated by Bunzel *et al.* (1999) through quantitative surveys with 26 couples, which demonstrate an adverse effect on spousal relationship up to five years post-transplant, in relation to changed: role performance, communication, emotional involvement, and values and norms. Other research has countered these findings, however, by highlighting that involvement in the transplantation process can act to strengthen the spousal relationship (Kurz, 2001b; Casida, 2005). Qualitative work conducted by Kurz (2001b) with 12 well spouses of lung recipients, for example, emphasises a propensity for couples to develop a sense of togetherness - or 'unity of spirit' (p. 487) - as they progress through the transplant experience.

Studies providing insight into the impact of the transplantation process on spousal relationships are limited in that they are relatively small-scale studies and offer little evidence from the male partner perspective. The reason for this skew is unclear, however, it is possible to reason that this may be associated with the fact that middle-aged men comprise a significant proportion of transplant patients and thus partners are more likely to be women. Further, the generalisability of these findings from such

studies is questionable given the fact that they are US-based and are significantly dated. No literature focusing specifically on relationship change between individuals waiting for or living with a heart, liver, and/or lung transplant and their adult children, siblings, and/or extended family members was identified during searches; nor were any longitudinal assessments of relationship change across the transplantation trajectory.

3.2.5.4 *Family wellbeing*

Like individuals with other chronic conditions, those waiting for, or living with, a transplant do not face the physical and psychological challenges of their condition alone; rather their family members can be adversely affected as demands on time, energy, finances, and relationships place strain upon the family structure (Uzark and Crowley, 1989; LoBiondo-Wood *et al.*, 1992; Collins *et al.*, 2000; Kurz, 2002; Bunzel *et al.*, 2005; Lefaiver *et al.*, 2009; Ågren *et al.*, 2014). Evidence suggests that the outcome of transplantation and long-term patient health (emotional and physical) are highly dependent upon the health of family members, particularly those providing care, thus it is important to acknowledge the impact of transplantation upon family wellbeing (Claar *et al.*, 2005; Rodrigue and Baz, 2007; Sá *et al.*, 2016). Most literature exploring the health implications of looking after ill family members uses the term ‘caregiver burden’ to facilitate discussion (Bastawrous, 2013), transplantation literature is no exception.

Caregiver burden

To aid understanding of the full extent of caregiver burden, it is important to first summarise the activities encompassed within the role of ‘caregiver’. The minutiae of the care role vary case by case, however, the act of caring is acknowledged to have two key elements: physical and emotional work (Bowlby, 2012; Barrett *et al.*, 2014). Physical tasks typically include responsibilities such as addressing the care recipients’ personal hygiene and helping them to remain mobile (Plank *et al.*, 2011; Hughes *et al.*, 2013). While the physical component of care is often readily identifiable, many of the emotional elements of care work remain hidden from view; ‘invisible’ to those outside (and sometimes inside) of the care relationship (James, 1992). Emotional elements of care often centre on monitoring the ill individual’s emotional wellbeing, providing emotional support, and managing one’s personal emotions (Hochschild,

1979; Hochschild, 1983; Erickson, 1993; Mac Rae, 1998; Plank *et al.*, 2011; Simpson and Acton, 2013). Work by Arlie Hochschild (1979, 1983) provides in-depth exploration of the intricacies of the emotion work that individuals perform, both within and beyond caregiving, by inducing or inhibiting feelings to “render them ‘appropriate’ to the situation” (Hochschild, 1979, p. 551).¹⁹ Numerous studies have explored the emotion work performed by formal and informal carers (James, 1992; Mac Rae, 1998; Bolton, 2000; Bolton, 2001; Bone, 2002; Thomas *et al.*, 2002; Karner and Bobbitt - Zeher, 2005; Mann and Cowburn, 2005; Lopez, 2006; Olson, 2011; Simpson and Acton, 2013; Olson, 2015; Kinman and Leggetter, 2016), determining several potential motivations for this behaviour, including a desire to: preserve the emotional wellbeing of the ill individual, foster a sense of normality, and adhere to social understandings of what it means to be a “good carer” (Thomas *et al.*, 2002; Olson, 2011; Simpson and Acton, 2013; Olson, 2015). While research recognises that emotion work can have a positive effect on the caregiver and care recipient, enhancing wellbeing and improving relationships, negative implications have also been acknowledged, most notably emotional exhaustion; a key factor contributing to caregiver burden (Erickson, 2005; Karner and Bobbitt - Zeher, 2005; Simpson and Acton, 2013).

‘Caregiver burden’ refers to the culmination of physical, psychological, emotional, and financial problems experienced by those providing care (George and Gwyther, 1986). Two forms of caregiver burden are recognised: objective and subjective. Whilst ‘objective burden’ refers to that developed as a result of the physical provision of care, ‘subjective burden’ depicts the emotional or psychological toll of objective burden upon caregivers, e.g. anxiety and stress (Bastawrous, 2013). Most of the research exploring caregiver burden among informal carers of individuals waiting for or living with a transplant employs quantitative methods to measure carers’ experience, including the Quality of Life Inventory, Caregiver Strain Index, and the

¹⁹ Hochschild proposed that this management is directed by social conventions concerning the “accepted extent, direction, and duration of feelings given a particular situation”, conventions she refers to as “feeling rules” (Simpson and Acton, 2013, p. 52). As such, these feeling rules encourage individuals to “shape and control their feelings so that they are appropriate to the particular situation” (Mac Rae, 1998, p. 142). Another key component of the theory of emotion work is the concept of “emotional deviance” or “emotional dissonance”, which describes the “the tension between socially expected emotions and actually experienced emotions” (Hochschild, 1979). To ease this tension individuals must engage in further emotion work and thus over time they run the risk of becoming alienated from how they truly feel (Hochschild, 1983).

Caregiver Burden Scale. Though some mixed methods research exploring caregiver burden exists, implementing quantitative measures alongside semi-structured interviews, it is rare (Miyazaki *et al.*, 2010; Xu *et al.*, 2012). No studies of caregiver burden using qualitative methods alone were identified during searches.

The physical impact of providing informal care in the context of transplantation has received little research attention. The limited data available suggest that providing care for individuals waiting for or living with a transplant can be detrimental to one's health, with those who fulfil this role reporting poorer physical functioning (Dew *et al.*, 1998; Collins *et al.*, 2000) and increased bodily pain (Myaskovsky *et al.*, 2012). In comparison, the psychological burden of transplantation is widely reported. Most studies assessing the psychological impact of caregiving in the context of transplantation highlight that family members often experience increased levels of stress, anxiety, and depression, both pre- and post- transplant (Gold *et al.*, 1986; Canning *et al.*, 1996; Collins *et al.*, 1996; Suddaby *et al.*, 1997; LoBiondo-Wood *et al.*, 2000; Bohachick *et al.*, 2001; Kurz, 2002; Dew *et al.*, 2004; LoBiondo-Wood *et al.*, 2004; Ullrich *et al.*, 2004; Bunzel *et al.*, 2005; Bunzel *et al.*, 2007; Cohen *et al.*, 2007; Rodrigue and Baz, 2007; Green *et al.*, 2009; Lefaiver *et al.*, 2009; Miyazaki *et al.*, 2010; Xu *et al.*, 2012; Malik *et al.*, 2014; Mary and Ward, 2015; Sahin *et al.*, 2016).²⁰ Though prevalent in male and female carers, rates of stress and depression are recognised to be higher among female carers than male carers, prior-to and following transplantation (Cohen *et al.*, 2007; Holtzman *et al.*, 2011). Reasons for this disparity include a perceived volume of caregiving activities and social isolation (Canning *et al.*, 1996; Cohen *et al.*, 2007; Holtzman *et al.*, 2011). A widely cited longitudinal study by Dew *et al.* (2004) of 190 informal carers of individuals waiting for a heart transplant reported high rates of depressive- and anxiety-related disorders, which they suggest puts carers at risk of developing a psychiatric illness post-transplant, most notably post-traumatic stress disorder (PTSD). Numerous studies from Europe and the US support this, by documenting the prevalence of PTSD among informal carers of transplant patients (Stukas *et al.*, 1999; Bunzel *et al.*, 2005; Bunzel *et al.*, 2007; Farley *et al.*, 2007). Yet, this notion has been contested. Opposing studies argue that informal carers appear to adjust well during the pre-transplant phase,

²⁰ For information on the source of stress see the section on 'stressors'.

exhibiting low levels of stress, depression, and anxiety (Meltzer and Rodrigue, 2001; Claar *et al.*, 2005). Further, some longitudinal studies exploring burden throughout the transplantation process dispute findings of long-term stress, indicating family members are comparatively less stressed post-transplant than pre-transplant (LoBiondo-Wood *et al.*, 2004). Proposed reasons for the alleviation of stress post-transplant include: lower levels of confusion, increased vigour, improved understanding of medical communication, patient improvement, and increased family satisfaction (Canning *et al.*, 1996; Collins *et al.*, 2000; LoBiondo-Wood *et al.*, 2004; Myaskovsky *et al.*, 2005).

It remains the case that the caregiver burden experienced by family members of individuals waiting for or living with a transplant is “poorly understood” (Myaskovsky *et al.*, 2012, p. 3387). The quantitative nature of most existing work could be viewed as contributing to this issue, as quantitative measures are believed to overlook the context of individual situations and consequently fail to acknowledge the true complexities of caregiving (Bastawrous, 2013; Hennings *et al.*, 2013). Existing research on this topic is overwhelmingly cross-sectional, assessing burden at a single point pre- or post-transplant, rather than longitudinally. Consequently, little is known about the extent to which caregiver burden fluctuates over time or at different stages of the transplantation process. The sample sizes of most studies assessing caregiver burden in this context are small considering the analytic techniques used, e.g. LoBiondo-Wood *et al.* (2004), Cohen *et al.* (2007), and Malik *et al.* (2014) used quantitative measures with, and produced statistical data on, samples totaling n=15, n=24, and n=24 respectively. Most studies focus on the burden experienced by partners, either specifically (Bunzel *et al.*, 2005, 2007) or as a result of the sample recruited (e.g. Malik *et al.* (2014) 20 of 24 ‘caregivers’ recruited were spouses; Dew *et al.* (2004) 137 of 190 ‘caregivers’ were spouses), thus little is known about the extent to which these findings are applicable to other family members. No studies appear to examine caregiver burden in the context of transplantation in the UK, meaning it is difficult to comment on the transferability of the findings within existing research, whether quantitative or qualitative in nature.

Stressors

Numerous sources of stress or ‘stressors’ are outlined within literature exploring the impact of transplantation upon family members, many of which are similar to those detailed within wider caregiving literature e.g. diagnosis, role ambiguity, and external resources (Knafl and Gilliss, 2002). One of the most widely discussed stressors within transplantation literature is financial concern (Gold *et al.*, 1986; Uzark and Crowley, 1989; LoBiondo-Wood *et al.*, 1992; Collins *et al.*, 1996; Bohachick *et al.*, 2001; Lefaiver *et al.*, 2009; Sadala *et al.*, 2013; Ordin *et al.*, 2017). Families are noted to be at great risk of experiencing financial issues as the patient and informal carer become restricted in their ability to maintain employment (Baker *et al.*, 2010). In cases where the ill family member is unable to work, the responsibility of financially supporting the family unit often falls to the carer (Miyazaki *et al.*, 2010). This responsibility is recognised to potentially conflict with caregiving demands, triggering emotional strain and subsequent stress (Uzark and Crowley, 1989; Kurz, 2002). Loss of income is not the only way families can be impacted financially. Families caring for an ill relative, in context of transplantation and beyond, are recognised as being at risk of experiencing extensive ‘hidden costs’ associated with caregiving, such as travel to clinic appointments and paying for medication (Mair and May, 2014).

While there are evidently commonalities between the stressors experienced among families experiencing transplantation and those caring for other chronic conditions, most notably: conflicting roles and responsibilities, social isolation, and a sense of limited autonomy (Pearlin and Aneshensel, 1994; Skaff *et al.*, 1996; Cheung and Hocking, 2004; Orzeck and Silverman, 2008; Barrett *et al.*, 2014); there are also important differences. The unpredictability of the transplantation process means that informal carers typically experience more stressors regarding ‘the unknown’ than those caring for other conditions (Gold *et al.*, 1986; Uzark and Crowley, 1989; LoBiondo-Wood *et al.*, 1992; Saxe-Braithwaite and Chapman, 1992; Collins *et al.*, 1996; Kurz, 2002; Green *et al.*, 2009; Mendes-Castillo *et al.*, 2014; Hiratsuka *et al.*, 2017; Mendes-Castillo *et al.*, 2017). Pre-transplantation, concerns about patient death, when/if the transplant will occur, and whether the transplant will be successful weigh heavily on the family (Gold *et al.*, 1986; Buse and Pieper, 1990; Collins *et al.*, 1996; Mendes and Bouso, 2009; Fulbrook *et al.*, 2013). As a result, families often enter a ‘state of alert’ pre-transplant, becoming consumed by the compulsion to monitor the

patient's condition (Kurz, 2001b; McCurry and Thomas, 2002; Mendes and Bousso, 2009). Literature highlights family members can feel overwhelmed and underprepared for the responsibility of caring for a transplant patient, as they fear that they do not possess the capabilities to provide adequate care (Mishel and Murdaugh, 1987; Green *et al.*, 2009; Miyazaki *et al.*, 2010; Williams *et al.*, 2012). Though this reaction is not uncommon among carers in other conditions, the associated stress is arguably greater in the context of transplantation due to the great uncertainty surrounding, and numerous immediate and long-term risks associated with, this procedure, including: death during surgery, infection, graft rejection, and/or subsequent re-hospitalisation (Saxe-Braithwaite and Chapman, 1992; LoBiondo-Wood *et al.*, 2004; Wright *et al.*, 2017; Pérez-San-Gregorio *et al.*, 2018). Other significant stressors documented across the transplantation process include: waiting list stipulations, isolation from support networks, patient change, relocation, disrupted relationships, poor interaction with healthcare teams, guilt about donor death, and uncertainty surrounding their relative's future health (Gold *et al.*, 1986; Mishel and Murdaugh, 1987; Uzark and Crowley, 1989; Saxe-Braithwaite and Chapman, 1992; McSweeney *et al.*, 1995; Canning *et al.*, 1996; Meltzer and Rodrigue, 2001; Young *et al.*, 2001; Claar *et al.*, 2005; Rodrigue and Baz, 2007; Green *et al.*, 2009; Baker *et al.*, 2010; Williams *et al.*, 2012; Gutermann *et al.*, 2014; Ivarsson *et al.*, 2014a; Hiratsuka *et al.*, 2017; Wright *et al.*, 2017).

Coping strategies

Numerous coping strategies are reportedly used by family members to deal with the stress they experience across the transplant trajectory. Some of the most commonly discussed strategies include: seeking social support (from family, friends, and support groups), problem solving (planning, changing mental attitude), problem avoidance, information seeking (from health professionals, via the internet), thinking positively, use of humour, and spirituality (faith) (Rodrigue *et al.*, 1997; Suddaby *et al.*, 1997; Collins *et al.*, 2000; Kurz, 2001a; Kurz and Cavanaugh, 2001; Burker *et al.*, 2005; Casida, 2005; Myaskovsky *et al.*, 2005; Haugh and Salyer, 2007; Mendes-Castillo *et al.*, 2012; Hiratsuka *et al.*, 2017; Ordin *et al.*, 2017; Pérez-San-Gregorio *et al.*, 2018). Most studies discuss the coping strategies used by families pre-transplant. A key example is a mixed methods study conducted in the US by Kurz and Cavanaugh (2001). This research, exploring the experience of 13 partners of lung transplant

candidates, identifies four coping strategies: 1) action (seeking social support, information seeking), 2) acceptance (making peace with limited ability to control the situation), 3) disengagement (avoiding the ill relative, seeking space), and 4) planning (making preparations for the call e.g. childcare, packing a bag). Though all of these strategies were apparent in their dataset, some were more prevalent than others, particularly action and planning (Kurz and Cavanaugh, 2001). The dominance of this coping style has been documented by others. For example, another US-based quantitative study conducted with 28 spouses of individuals waiting for a heart transplant indicates that spouses are more likely to use ‘adaptive coping strategies’, such as planning, positive reinterpretation, and growth, than ‘maladaptive coping strategies’, such as disengagement and denial (Burker *et al.*, 2005). These findings are not specific to the US. Qualitative studies conducted in China and Japan, by Zhang *et al.* (2014) and Hiratsuka *et al.* (2017) respectively, report that active coping strategies, such as problem-solving and seeking support and/or information from health professionals, are key to reducing the distress experienced by parents of paediatric liver patients pre-transplant. Comparatively few studies explore the coping strategies used by family members post-transplant. Those that do exist appear to suggest that family members remain significantly distressed and thus continue to use coping strategies in the post-transplant period. Kurz (2001a) report similar findings, presenting survey data from 25 couples that reveals that spouses continue to rely on coping strategies to the same extent post-transplant as pre-transplant. As quantitative studies with relatively small sample sizes constitute the majority of research on this topic, the findings presented must be interpreted with caution.

Most of the research exploring coping strategies used by family members throughout the transplantation process is quantitative in nature and predominantly focuses on spouses and/or parents of paediatric transplant patients. Consequently, little is known about the coping strategies used (type and duration) by other family members, such as adult children, siblings, and parents of adults waiting for or living with a transplant.

Support (professional and social)

The support offered by an individual's social network and/or health professionals is recognised to be a vital factor that can influence family member experience of the transplantation process. Within this section I present key findings from research discussing the impact of support, professional and social, on family wellbeing. I begin by examining studies that assess the provision of support by professionals within the transplant centre.

Professional support

The body of existing research exploring family perspectives of the support provided by transplant teams communicates conflicting messages. Numerous studies report positive experiences of the professional support, highlighting the crucial role that the transplant team play in aiding them to make difficult decisions concerning their relative's care (Higgins, 2001; Kurz, 2001b; Young *et al.*, 2001; Casida, 2005; Gutermann *et al.*, 2014; Wright *et al.*, 2017). Key examples of this include qualitative research conducted in Canada by Young *et al.* (2001) and the US by Casida (2005), with families pre- and post-heart transplant respectively, which emphasise that healthcare professionals are key to pacifying anxieties and instilling confidence in the family throughout the transplantation process. Findings documented by Kurz (2001b), confirm this, highlighting positive anecdotes from family members about their experience of health professionals during their relatives lung transplant. Yet, other studies portray an opposing picture. European research conducted by Ullrich *et al.* (2004; 2005) highlights dissatisfaction among relatives regarding the professional support that they received throughout the transplantation process. Reporting on data collected from surveys with 50 transplant recipients and 39 relatives, Ullrich *et al.* (2005) found that whilst recipients appear generally satisfied with the professional support they receive during the transplantation process, relatives are not, with family members rating the helpfulness of staff markedly worse than recipients did, during all stages of the transplantation process (Ullrich *et al.*, 2005). These findings are supported by more recent qualitative research from Sweden by Ivarsson *et al.* (2014b) conducted with 18 relatives of individuals awaiting a heart and/or lung, which indicates that "healthcare professionals may take for granted that patients give their relatives the information they need" (p. 193). Likewise, further Swedish research by Ågren *et al.* (2014), the only study located during searches to focus on the experience of children of transplant recipients, emphasises that transplant teams are felt to

routinely overlook the information needs of the family unit throughout the transplantation process. These findings are not specific to European research however, studies from the US, Canada, and Brazil also call for improvements to the information provided to families throughout the transplantation process, particularly post-transplantation (re. variability in recovery time, possible complications, and physical functioning) (Stubblefield and Murray, 1999; Young *et al.*, 2001; Sá *et al.*, 2016).

Research exploring familial experiences of professional support further reveals an eagerness to develop a positive relationship with the transplant team and establish a collaborative approach to their relatives' care. Studies often emphasise that family members want to feel like part of the team, as though they are partners in their relative's care, rather than observers or 'outsiders' (Haugh and Salyer, 2007). This finding is particularly prevalent in studies conducted with parents of young transplant patients (Stubblefield and Murray, 1999; Higgins, 2001; Young *et al.*, 2001; Wright *et al.*, 2017). Recent UK-based research by Wright *et al.* (2017), a qualitative assessment of the post-transplant experience of nine parents of liver recipients, reveals that they often feel anxious that they may be side-lined by healthcare professionals, and thus lose their carer role. These findings are reflective of broader care research which documents the potential for friction between formal carers and family members providing informal care, due to the lack of clarity surrounding their responsibilities and authority in the care relationship (Twigg, 1989; Allen, 2000; Ward-Griffin and McKeever, 2000). There is a general consensus in transplant literature that healthcare professionals must do more to establish positive relationships with family members and involve them in decision making processes and care responsibilities, where possible, as this is believed to be essential for long-term family and patient wellbeing (Buse and Pieper, 1990; Higgins, 2001; Young *et al.*, 2001; Ullrich *et al.*, 2005; Ågren *et al.*, 2014; Sá *et al.*, 2016).

Social support

It is acknowledged in the literature that families depend upon numerous avenues of social support to varying degrees throughout the transplant procedure, including: extended family members, friends, neighbours, community members, work colleagues, church members, other transplant families, support groups and

professional counsellors (Kurz, 2001b; Stubblefield and Murray, 2001; Stubblefield and Murray, 2002; Mendes and Bouso, 2009; Fulbrook *et al.*, 2013; Sadala *et al.*, 2013; Ivarsson *et al.*, 2014b). Families are documented to rely heavily on such support throughout their involvement in transplantation process, particularly during the wait for a donor organ, to aid the maintenance of a 'normal' family life (Young *et al.*, 2010). Despite this, research reveals that families routinely struggle to access such support, as association with, and involvement in, the transplantation process can lead them to become socially isolated. Pre-transplantation, relocation away from trusted social networks and the withdrawal of family and friends are key factors contributing to this sense of isolation (Young *et al.*, 2001; Ågren *et al.*, 2014). A qualitative study conducted in Sweden by Ågren *et al.* (2014) exploring the experience of thirteen adult children of heart transplant recipients acknowledged that close relatives and friends can disengage from the family as the parent's health deteriorates, leaving family members feeling isolated from individuals outside of the immediate family unit. This feeling is recognised to persist or even increase post-transplantation, as the resource-intensive nature of ongoing caregiving duties can limit the amount of time and energy that family members have to engage with others (Uzark and Crowley, 1989; Kurz, 2001b). Further, US research by Uzark and Crowley (1989) and McSweeney *et al.* (1995), with parents and partners of heart recipients respectively, indicate that families are at risk of losing friends post-transplant as others struggle to understand what the family have been through or how to behave around someone with a transplant. Widespread misunderstanding of the reality of post-transplant life (e.g. the complexities inherent in transplant recovery and the potential for mortality) has been reported to have a detrimental impact on how supported family members feel by their peers, as their social network is felt to be ignorant to their needs (McSweeney *et al.*, 1995; Stubblefield and Murray, 2001; Williams *et al.*, 2012; Ågren *et al.*, 2014). Experiences of social isolation, such as these, are not unique to transplant families, rather they are relatively common among family members living with and/or caring for relatives with a chronic illness (Bury, 1982; D'Ardenne, 2004; Gordon and Perrone, 2004; Eriksson and Svedlund, 2006; Årestedt *et al.*, 2014; Aasbø *et al.*, 2016). A number of qualitative studies, including the UK-based research by Wright *et al.* (2017), report that transplant families often attempt to address this issue by interacting with other transplant families; individuals with whom they can share fears, frustrations, and challenges (Stubblefield and Murray, 2001; Young *et al.*, 2001;

Green *et al.*, 2009; Wright *et al.*, 2017). Though successful for some, this approach is recognised to have a detrimental effect on others, leading to increased feelings of isolation, stress, and/or guilt (Young *et al.*, 2001; Wright *et al.*, 2017).

As is the case with most transplantation literature, the majority of studies discussing professional and/or social support during transplantation focus on the needs of the individual waiting for or living with a transplant, rather than those of their family. Most research exploring family support has been published in the US and Europe, further research is required to determine if the findings of studies conducted elsewhere reflect family experience of support within the UK context. While all the findings reported within this section are noteworthy, some are only apparent within one study and/or are rooted in research with a small sample size, meaning they require further exploration.

Positive aspects of caregiving

Caregiving literature often outlines that providing care can be a positive experience, with psychological benefits for the carer (e.g. enhancing self-confidence, outlook on life, and sense of purpose) and social benefits for the wider family (e.g. development of stronger relationships) (Gordon and Perrone, 2004; Eriksson and Svedlund, 2006). Literature documenting experiences of transplantation is largely reflective of this. Some of the most frequently discussed positives include: discovering inner strength, closer emotional connection with the ill relative, and strengthening family relationships (Kurz, 2001b; Meltzer and Rodrigue, 2001; Casida, 2005; Ordin *et al.*, 2017). This raises questions about the extent to which providing informal care in the context of transplantation can be widely conceptualised as a 'burden'. Mirroring a trend apparent in wider caregiving research (Hunt, 2003), much of what is known about the positives experienced by those caring for relatives waiting for or living with a transplant has been ascertained through qualitative studies. One of the only studies employing quantitative measures to explore the positives experienced by those providing informal care in the context of transplantation is a mixed methods study by Xu *et al.* (2012). Using the Day Reconstruction Method and semi-structured interviews, this study reported 77 different positive emotions experienced by 21 informal carers of transplant patients in the US, including: feeling blessed, motivated, useful, and loved. These self-reported positives must be interpreted with caution,

however, as it has been recognised that carers can over-report benefits in an attempt to justify the considerable stress they experience while providing care (Rodrigue *et al.*, 2011). Little is known about the positives experienced by those providing informal care for individuals awaiting or living with a transplant in the UK. Research is required to assess the extent to which socio-cultural factors impact the way that family members interpret their caregiving situation and the extent to which positives reported within literature are applicable to families experiencing transplantation outside of the US.

3.3 Limitations of, and gaps within, existing literature

The key limitations of the existing literature, detailed above, primarily concern the methods used to collect data. Most existing studies are cross-sectional and thus assess a single sample at one point in time, an approach that has been argued to lead the researcher to “ignore the longitudinal and dynamic nature of caregiving” (Montgomery and Kosloski, 2013, p. 133). This issue is may be considered particularly problematic within transplantation research, as the unpredictable nature of the procedure means families involved in the process often experience great changes in circumstances over a relatively short timeframe. While some studies discussed here have attempted to assess these changes by recruiting individuals post-transplant and interviewing them retrospectively about their experience, this is potentially problematic because of recall bias (Bunzel *et al.*, 1999). As understanding caregiving as a dynamic, rather than static, process is argued to be “essential for clarifying the links between caregiving and caregiver outcomes” (Montgomery and Kosloski, 2013, p. 133), further longitudinal research is required to explore in greater depth how family members are affected throughout the transplantation process.

Another key limitation of most studies exploring family experience of transplantation concerns sample size. Most qualitative studies presented findings based on less than 20 participants (24 out of 30 studies), with a significant number based on fewer than ten (see Table 7). Several quantitative studies also had a very small sample size (<40) considering the techniques used to analyse the data. Such small sample sizes call into question the validity and generalisability of the results presented. Further, with few

exceptions, the studies presented within this review recruited participants from a single transplant centre rather than multiple sites, a methodological decision that could be argued to introduce an element of bias to the results regarding individual experience.

While many studies explore the impact of transplantation upon female partners and/or mothers of transplant patients, there has been comparatively little focus on male relatives, siblings, and/or adult children. Few studies discuss the impact of the transplantation process upon the family as a whole, with most presenting the experience of one family member in isolation. Research is also lacking on the physical burden experienced among families of transplant patients and the impact of long-term health issues on the family (Kaller *et al.*, 2014).

When comparing transplantation literature with broader caregiving literature, another key gap becomes evident: the lack of focus on family member identity²¹ and how it can be affected by their involvement in the transplantation process, including provision of informal care. Wider caregiving literature acknowledges that family members can experience a significant shift in their sense of self, as their relatives health declines and they adopt the role of informal carer (Rolland, 1994; D'Ardenne, 2004; Eriksson and Svedlund, 2006; Golics *et al.*, 2013; Eifert *et al.*, 2015; Aasbø *et al.*, 2016). Barrett *et al.* (2014), for example, note once “a commitment to care is triggered”, a process occurs which challenges the carers normatively defined relational role and results in the development of new identities and roles (e.g. ‘spouse’ could change to ‘care-recipient’ or ‘caregiver’), with the potential to cause confusion or conflict between the couple (p. 42). This sudden or gradual change in roles is recognised to leave individuals in a “liminal position in terms of their identity” as they “evade classification, being ‘neither this nor that’” (Hennings *et al.*, 2013, p. 684). Further, the role of informal carer has been reported to hold the potential to ‘engulf’ the self, as care responsibilities leave little time for other activities (Skaff and Pearlin, 1992; Eifert *et al.*, 2015). In this sense, individuals who provide care for ill

²¹ The concept of identity refers to the way that individuals see themselves (Riches and Dawson, 2000), an image comprised of two central components: personal identity and social identity (Goffman, 1971). Personal identity refers to “the unique organic continuity imputed to each individual”, whereas social identity refers to the categories or groups “to which an individual can belong and be seen as belonging” (Goffman, 1971, p. 189). This social element means identity is not an individual project, but a contextual, relational, and interdependent entity rooted in the “weaving together of an individual’s assorted relationships” (Åberg *et al.*, 2004, p. 807).

family members not only “gain a new identity as caregiver but see previous identities fade away or become less relevant” (Eifert *et al.*, 2015, p. 360). Increasingly, researchers are using the theory of biographical disruption, originally developed by Bury (1982) to explain the experience of chronically ill individuals, to aid understanding of the broader family experience of illness (especially partners of individuals living with dementia) (Chamberlayne and King, 1997; Young *et al.*, 2002; Åberg *et al.*, 2004; Adamson and Donovan, 2005; Karner and Bobbitt - Zeher, 2005; Hasselkus and Murray, 2007; Roberts and Clarke, 2009; Bray *et al.*, 2014; Monaghan and Gabe, 2015; Aasbø *et al.*, 2016; Bell *et al.*, 2016; Hudson *et al.*, 2016). The concept of biographical disruption refers to a major disruptive event which alters the structure of individual’s everyday life, with severe implications for their expectations and plans for the future (Bury, 1982). Research considering Bury’s theory in relation to family members reports that while the illness is not their own, family members can experience disruption as a result of its presence in their lives and how it affects their daily routines and the way they view themselves. Despite this key finding, this review of transplant literature reveals that the concept of biographical disruption has not been considered in relation to the experience of families involved in transplantation. Indeed, there is practically no mention of the impact of transplantation on family identity at all, the only exception being research by Gold *et al.* (1986), which briefly documents anecdotal evidence that mothers can experience loss of self, upon returning home post-paediatric transplant.

The most obvious gap in the existing body of research, however, pertains to the lack of research on informal carers for those awaiting or living with a transplant in the UK. Only two UK-based studies were located through this review, the work of Gutermann *et al.* (2014) and Wright *et al.* (2017), exploring parents experiences of caring for a child post-liver transplant, using quantitative and qualitative methods respectively (see Table 8 for more details). No UK-based research on the family experience of heart, lung, and adult liver transplantation was found through searches. Research exploring transplantation in the UK predominantly focuses on the patient, with little mention of the wider family unit (Baines *et al.*, 2002). Due to the lack of UK-based research, this review largely discusses studies detailing family experiences of the transplantation process elsewhere, particularly the US, Brazil, and Europe. While it is

possible to contend the findings of such studies are not transferable to the UK care context (due to difference between the NHS and other healthcare systems etc.); the extent to which this is the case is unclear, thus it is important to consider their potential relevance. The severe lack of UK-based research can be viewed as problematic, as little contextual information has been documented upon which to ground this study. This scarcity highlights the need for this research in this area.

In this thesis I address some of the gaps and limitations outlined in this review by conducting a qualitative study, with longitudinal elements, of adult family members' experiences of transplantation in the UK. In doing so I provide much needed contextual information and sociological insight into the impact of the transplantation process on British families. Recognising the effect of family member illness and informal caregiving on identity, I pay particular attention to the impact of involvement in the transplantation process upon family member identity.

Chapter 4. Methodology and Methods

4.1 Introduction

The purpose of this study was to explore the impact of transplantation on family members of individuals awaiting or living with a liver, heart, and/or lung transplant in the UK. In this chapter, I present a full overview of the study structure, the methodological standpoint, and research methods employed, to enable to reader to gain a full understanding of the research context. The first section provides insight into the research methodology, highlighting how this shaped the choice of methods implemented. Secondly, I provide detail about the research methods used and a rationale for adopting the chosen interview approach to data collection. Following this, I describe the data analysis strategy. Finally, I reflect upon my approach and the ethical issues faced throughout the project, and I explore some of the limitations of this study.

4.2 Research methodology

The decision to use a qualitative method of data collection was informed by my ontological and epistemological beliefs: relativism and interpretivism respectively. Relativism is the philosophical position that asserts “all assessments are assessments relative to some standard or other, and standards derive from cultures” (Jarvie, 1983, p. 46). In this vein, relativists argue that attempting “to assess cognitive statements on some transcendental scale of truth, is futile” as “no assessment can escape the web of culture and hence all assessment is culturally relative” (Jarvie, 1983, p. 46). Within this philosophy, my ontological position is that of social constructivism, a stance which promotes the idea that “human beings do not find or discover knowledge so much as we construct or make it” (Schwandt, 2000, p. 197). Social constructivists argue that knowledge of the world is generated through daily interactions between people in the course of social life and thus is not constructed in isolation, but informed by “shared understandings, practices, languages, ...” (Burr, 2004, p. 3). In acknowledging historical and sociocultural influences on knowledge formation, social constructivism directly opposes epistemologies, such as empiricism and positivism that argue knowledge is the product of direct perception of reality (Burr, 2004).

My research methodology was further informed by symbolic interactionism, a theoretical framework developed by several scholars, most notably Charles Horton Cooley, George

Herbert Mead and Herbert Blumer (Cooley, 1902; Mead, 1934; Blumer, 1969; Denzin, 2004). Symbolic interactionism, embedded within the interpretivist approach, addresses the way in which society is created and maintained through repeated interactions between individuals (Carter and Fuller, 2016). In his book *Symbolic interactionism: Perspective and method*, Blumer (1969) outlined three main principles of this framework, based around meaning, language, and thought:

1. Humans act toward things on the basis of the meanings they hold for them
2. The meaning of such things is derived from the social interaction one has with others
3. These meanings are modified through an interpretive process (p. 2).

As these points illuminate, the attention of symbolic interactionists lies firmly in the subjective, rather than the objective. Symbolic interactionists work to interpret subjective viewpoints in order to understand how individuals make sense of their world from their “unique perspective” (Carter and Fuller, 2016, p. 2).

Combined, my social constructionist and symbolic interactionist beliefs provided a platform from which I was able to understand and develop an approach to my study. The cornerstone of my methodological approach is the belief that there exists no objective reality to be discovered, and thus research should not aim to find the truth *per se* but rather the truth “as the informant sees it to be” (Minichiello *et al.*, 1990, p. 128). By identifying and reflecting upon common themes within and across family member accounts of the transplantation process, it is possible to develop theoretical insight on such ‘truth’ and thus shed light on an often neglected experience.

As subjective interpretation is central to both social constructivism and symbolic interactionism, reflexivity was deemed essential throughout this research. Reflexivity is a process of continual critical self-evaluation undertaken by researchers to assess the impact of their position within “a particular social, political, cultural and linguistic context” on research progression and outcomes (Alvesson, 2002, p. 179). Blumer considers the process of reflexivity vital in work undertaken from a symbolic interactionist stance, if the researcher is to avoid creating a “fictitious world” (Blumer, 1969, p. 51). Acknowledging this, and the argument that “data are a product of the research process not simply observed objects of it” (Charmaz, 2008, p. 402), I endeavoured to be as reflexive as possible throughout this study. Some of the key reflexive points considered are presented at the end of this chapter.

4.2.1 *Qualitative methods*

This study was conducted using qualitative research methods. The decision to adopt a qualitative, rather than quantitative, approach was influenced by my research methodology and the nature of the research question. Qualitative research is “based on constructivist epistemology and explores what it assumes to be a socially constructed, dynamic reality through a framework which is value-laden, flexible, descriptive, holistic, and context sensitive” (Yilmaz, 2013, p. 312). In doing so, it is able to provide insight into:

...a wide array of dimensions of the social world, including the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants, the ways that social process, institutions, discourses or relationships work, and the significance of meanings (Mason, 2002, p. 1).

Qualitative research methods are highly appropriate in studies exploring “the ‘what’, ‘how’ or ‘why’ of a phenomenon, rather than questions about ‘how many’ or ‘how much’” (Green and Thorogood, 2004, p. 5). Indeed, qualitative approaches are acknowledged to have “unrivalled capacity” to answer such questions (Mason, 2002, p. 1). By focusing on the general picture and statistical averages, quantitative research methods are argued to be less adept at capturing phenomena in their “complexity” and facilitating understanding of “their contextual significance” (Bryman, 1984, p. 82).

Despite its strengths, qualitative research is often criticised as “merely anecdotal or at best illustrative” (Mason, 2002, p. 1). Critiques such as this are often rooted in misunderstandings about conducting research with ‘small’ sample sizes and the use of quantitative measures to evaluate findings. In social science, research findings are typically judged using quantitative measures, such as: reliability, “the replicability of research findings” (Lewis *et al.*, 2014, p. 270); validity, “the ‘correctness’ or ‘precision’ of a research reading” (Lewis *et al.*, 2014, p. 273); and generalisability, the extent to which study findings can be “extended to other settings, populations or topics” (Green and Thorogood, 2009, p. 285). While literature often suggests the findings of qualitative studies have limited wider applicability, it is important to stress that ideas developed through qualitative research have relevance beyond the participants and thus are, to some extent, “theoretically generalisable” (Green, 1999, p. 46). In other words, though it may not be possible to ascertain data representative of the full range of experiences, it is possible to find commonalities in individual experiences that reveal theoretical insights about a phenomenon.

4.2.2 *Interviewing*

This study employed one of the most common data collection techniques in qualitative research: interviews (Strauss and Corbin, 1990; Mason, 2002). There are three main types of interview: unstructured (otherwise known as narrative, open-ended, or in-depth interviews), semi-structured, and structured (Bowling, 2002; Corbin and Morse, 2003; Green and Thorogood, 2009). The appropriateness of each interview style varies depending on the research context (Green and Thorogood, 2009). While more structured interviews are informed, to varying degrees, by a number of pre-determined questions, the narrative interview approach is more open and often involves asking only one set question to start the interview (Chase, 2005). Though significant variations exist in style and tradition, qualitative interviewing is believed to possess a number of core features, namely:

1. The interactional exchange of dialogue
2. A relatively informal style
3. A thematic, topic-centred, biographical or narrative approach
4. Most operate from the perspective that knowledge is situated and contextual

(Mason, 2002, p. 62).

4.2.3 *Narrative interviews*

A narrative interview style was determined to be the most appropriate form of data collection for this study, due to the sensitive and unpredictable nature of this research context. An open, narrative style, approach to interviewing is often used to explore complex and sensitive research questions, as pre-determined questions are acknowledged to restrict participant response and potentially lead to erroneous and insensitive conclusions (Larossa *et al.*, 1981; Bowling, 2002; Byrne, 2004; Hopf, 2004; Squire, 2008; Yeo *et al.*, 2014). Narrative interviews are believed to be beneficial in challenging research contexts, as they open up the “possibility of seeing anew, of representing complexity, uncertainty, contradictions and silence”, and thus permit access to in-depth data unachievable through more structured approaches (Chataika, 2005, p. 5). Further, the relaxed, conversation-like quality of narrative interviews are argued to put the participant at ease and aid the generation of rapport, a vital requirement when attempting to access high quality data on a sensitive topic (Dickson-Swift *et al.*, 2007).

4.2.4 *Face to face and telephone interviews*

This study was conducted using a mix of face-to-face and telephone interviews. The decision to offer participants a choice of interview style was grounded in practical and methodological considerations, including: convenience, privacy, and participant limitations (e.g. care responsibilities). The vast majority of qualitative research is conducted using face-to-face interviews. Many researchers consider this the best way to conduct interviews, as it permits the collection of verbal and non-verbal data, in the form of dress, body language, and mannerisms (Oltmann, 2016). Face-to-face interviews have been criticised, however, for the “problem of reactivity”, referring to the propensity for participants to react to the observable characteristics of the interviewer, such as age, gender, and dress, and respond in “socially acceptable, rather than authentic” ways (Wilson *et al.*, 1998, p. 315). In spite of this, telephone interviews are often presented as the “less attractive alternative”, as the lack of visual cues is argued to result in the “loss of contextual and nonverbal data”, which can compromise “rapport, probing, and interpretation of responses” (Novick, 2008, p. 391). Comparative studies exploring the difference between these approaches dispute this view, however, arguing that little evidence exists to indicate that the use of telephone interviews results in data of a poorer quality (Sturges and Hanrahan, 2004; Musselwhite *et al.*, 2007; Novick, 2008; Holt, 2010). Telephone interviews are recognised to be beneficial in certain research contexts, as they facilitate the recruitment of ‘hard-to-reach’ participants and provide an additional degree of anonymity, which can suit those discussing sensitive topics (Sturges and Hanrahan, 2004; Musselwhite *et al.*, 2007; Oltmann, 2016). Further, telephone interviews have been argued to be beneficial in terms of privacy, as they allow participants to change the interview setting depending on the topic of discussion (Holt, 2010).

4.2.5 *Thematic analysis*

Qualitative data analysis is recognised to be an interpretive process involving “reflective thought throughout a structured and comprehensive process” of data reduction and organisation, completed in a cyclical manner “until the representation of the phenomenon is complete and theoretically sound” (Tong *et al.*, 2013, p. 1395). A thematic approach to analysis was adopted in this study. This method of analysis is typically used to identify, analyse and report patterns, or themes, within the data (Braun and Clarke, 2006). In thematic analysis, themes are believed to “capture something important about the data in relation to the

research question, and represents some level of patterned response or meaning within the data set” (Braun and Clarke, 2006, p. 82). This approach was chosen primarily because of its flexibility and on the basis that it is not “theoretically bound” (Braun and Clarke, 2006, p. 78).

An iterative approach to analysis was assumed; meaning it was performed alongside, and thus informed subsequent data collection (Lingard *et al.*, 2008). This iterative process continued until sufficient depth of understanding was reached, a point known as “data sufficiency” or “theoretical sufficiency” (Nelson, 2017). I am aware that qualitative research typically reports ceasing recruitment only at the point of “data saturation”, when no more patterns or themes are emerging from the data (O'Reilly and Parker, 2012). However, recognising the criticisms levelled against this concept, such as the belief that it is “tokenistic” (O'Reilly and Parker, 2012) and “misleading” (Nelson, 2017), it was never my intention to make such claims. Having outlined the theoretical underpinnings and methodological components of this study, I now provide an account of how I conducted the study.

4.3 Research method

In this section I report on the research method that I used in this study. Firstly, I provide detail on how I recruited my participants. Following this, I present my approach to data collection. Finally, I recount on data analysis and interpretation.

4.3.1 Recruitment

Recruitment began in May 2015, soon after obtaining ethical approval from Newcastle University ethics committee²² (Appendix 1), and continued for eight months to December 2015. The process of recruitment was facilitated by a number of transplant charities who agreed to act as gatekeepers for this study. The term ‘gatekeeper’ refers to a person or group from whom the researcher “must obtain approval to gain access to a group or cultural site” (Leech and Onwuegbuzie, 2008, p. 201). The main gatekeepers in this study, two transplant charities based in the North East of England, aided the recruitment process by facilitating the development and distribution of recruitment materials. Initial recruitment documents were assessed by these groups, and altered in light of their feedback. One key change made in light of their comments was expansion of the inclusion criteria to include non-relatives, as they

²² Originally obtained January 2015. Minor amendments subsequently submitted to broaden the proposed recruitment strategy, permitting recruitment through charities based outside of the North East, were approved by July 2015.

stressed that it was important to acknowledge that non-relatives can play a key role in supporting those awaiting and living with a transplant. Once approved, recruitment materials were disseminated by these charities via their newsletters, information boards at various healthcare sites, and at regional events. As well as local charities, a number of national transplant and disease-specific charities were contacted and asked to distribute recruitment materials, if and where appropriate. Online mailing lists maintained by these charities proved vital to recruitment on a local and national level. The most fruitful avenue of recruitment, however, was the use of group pages on Facebook, corroborating recent claims that Facebook should be considered a useful recruitment tool when implementing health research (Whitaker *et al.*, 2017). Almost half of the study participants learned of the research from a single post on a transplant charity's private Facebook page, which group members commented on and shared amongst themselves.

During the recruitment process, individuals who expressed an interest in the study, by email, phone call, or text, were subsequently sent an information sheet (Appendix 2). This document provided an overview of the study, outlining the: aim, participant requirements, risks/benefits of participating, data collection methods, and proposed dissemination practices. Within this document, I emphasised that participants were able to decline to answer questions or withdraw from the study at any point. The document further stated that participants could be interviewed alongside other family members if they preferred. Interested individuals were encouraged to contact the researcher to arrange an interview, to ensure the decision to involve oneself was made freely. Those that did not respond within two weeks of being sent the information sheet were contacted again at this point to check whether they were still interested. At this point some arranged interviews whilst a small proportion decided against participating, no further contact was made with these individuals.

4.3.2 Data collection

Data collection took place over twelve months (May 2015-May 2016). Twenty-four participants were recruited in total. Twenty participants were family members of individuals living with a transplant, and were interviewed retrospectively about their experience. The remaining four participants were recruited pre-transplant and interviewed longitudinally on two occasions, between six and nine months apart. Longitudinal participants were first interviewed as soon as possible after expressing interest, to capture their accounts while their relative was on the transplant waiting list. Though all agreed to participate in a second

(follow-up) interview, this was not a pre-requisite of their participation. When re-interviewed some months later, three of the four individuals were able to reflect on their experience retrospectively, as their relatives had since received a donor organ. A detailed overview of participant characteristics is presented in table 10 featured later this chapter (see Section 4.3.4.1). In addition to this, a summary is provided at the beginning of the empirical chapters to aid the reader in contextualising the data presented.

Twenty-five interviews were conducted in total. These interviews were a mix of one-to-one, dyadic (two participants interacting (Morgan *et al.*, 2013)), and group format. The vast majority of interviews were conducted one-to-one (n=21). Dyadic interviews (n=3) were conducted with the participant and their ill relative, at the participant's request. Ill relatives are not included in the participant total, as their data has not been featured within this thesis. The decision to exclude this data was rooted in the desire to retain a clear focus on the family member experience. One group interview was performed with four participants from the same family. Of the twenty-five interviews conducted, fifteen were face-to-face and ten were conducted via telephone. Most participants living some distance from Tyne and Wear were interviewed by telephone; however, some arranged face-to-face interviews to coincide with scheduled trips to the region. The average duration of interviews was 89 minutes, ranging from 51 to 130 minutes.

4.3.2.1 *Scheduling the interview*

Participants taking part in face-to-face interviews were encouraged to select a location for their interview to ensure they felt comfortable (Byrne, 2004; Yeo *et al.*, 2014). Locations included: restaurants, cafes, a private room within the university, and participant's home or place of work. Most participants opted to be interviewed at home, however, a number specifically stated they wanted to be interviewed elsewhere, to prevent the transplant patient or other family members from hearing, or being disturbed by, the interview process. Requests to be interviewed outside of the home environment were less common than I had anticipated. Most participants appeared comfortable discussing their experience in the presence of other family members. All participants were encouraged to choose the time of their interview, to ensure it would be convenient and fit around existing commitments. Interview start times ranged from 9am to 8pm. A confirmation email or text was sent around 24 hours before the interview. This procedure served as a reminder and afforded participants a convenient and non-threatening way to reschedule or terminate their involvement in the study if they wished to do so.

Researcher safety

For participant convenience a number of the interviews took place in settings unfamiliar to myself, some over an hour drive from the university. Researcher safety was taken very seriously during these times and I made sure to adhere by the lone worker policy, organising interviews in daylight hours and parking in public areas where possible. Ahead of every interview I sent details of the meeting (location, date, time, participant name and contact details) to my supervisors in line with our independently developed safety protocol (Appendix 3). I attempted to familiarise myself with the area as far as I was able, using Google Maps to pinpoint the most appropriate route of travel and a safe place to park. In agreement with the risk assessment and safety protocol I made sure to ‘check-in’ with a supervisor immediately before and after the interview, or my partner outside of office hours, ensuring someone was always aware of where I was. Both parties were fully aware that should they fail to hear from me within a specified time frame they were to alert the police.

4.3.2.2 Conducting the interview

Prior to commencing the interviews, written consent was obtained and participants were reminded that they could decline to answer questions or withdraw from the study at any point. Individuals interviewed via the telephone were sent a consent form via email or through the post and asked to return the completed version ahead of the scheduled interview. In cases where the consent form had not been received prior to the interview, verbal consent was recorded and the participant was encouraged to send the formal consent form as soon as possible, which they all did. At the start of the interview participants were encouraged to ask any questions they had, to ensure they fully understood the research and the implications of their participation. In addition to this, participants were given an overview of the narrative interview format. It was stressed that while they may find it helpful, it was not imperative for them to structure their narrative chronologically. Participants were informed that the aim of this research was not to catalogue a series of events, but rather to explore how they and their family responded throughout the process: emotionally, physically, and psychologically. Realising that the narrative interview style may not suit everyone, I offered to use a more semi-structured approach if they preferred. Two individuals requested this approach, noting personal comfort as the prime reason for this. Realising the limitations of this narrative style in interviews with more than one individual, in dyadic and group interviews I began the

interview by encouraging participants to tell their story but often adopted a more semi-structured approach to the remainder of the interview to encourage discussion.

Mirroring the narrative approach adopted in other qualitative research on transplantation I began the interview by asking one over-arching question to help me orient my interview to the particular transplant experience of the participant (Stone *et al.*, 2013). The primary question asked to every participant was: Can you tell me about your experience of the transplant process to date? This question provided context and constituted a good foundation for all subsequent questions. Without such information the questions asked could easily have been irrelevant, unfounded, or insensitive; given the wide array of situations it is possible for family members to experience throughout the transplantation process. This was the only consistent question asked to every participant. All subsequent questions varied based on the participant's experience and were rooted in what the participant had shared. An interview prompt, or topic guide, was used to inform, but not direct, this process (Appendix 4). This document was developed with the narrative (unstructured) interview style in mind and thus was brief and concise in nature. The interview prompt was informed by existing literature on family member experience of transplantation. In designing the prompt, great consideration was given to the potentially sensitive nature of the data and how best to broach sensitive topics with participants. This working document evolved throughout the project, as new themes from preceding interviews were incorporated and explored in subsequent interviews. Most participants were able to tell their story with relatively little encouragement, however, a small number required quite heavy probing. In such situations the interview prompt proved valuable. Given the open nature of the interviews, each interview was unique and thus not all sections of the prompt were covered with every participant.

Audio-recording

Interviews were digitally recorded, with participants' consent. All audio files were downloaded to a password protected university server and subsequently deleted from the recording device. Recording the interviews in this way worked well on the whole, however, I did experience a few technical problems. For reasons unknown, a small number of recordings had sound quality issues. Though the impact of this was very minor on most occasions, static interference left one recording completely inaudible: that of Rosalynn. Paraphrased notes, made during and immediately after speaking with Rosalynn, have been used in place of direct quotes to permit the inclusion of the data collected. This issue was avoided for future interviews by changing all recording equipment and testing it thoroughly prior to each use.

4.3.2.3 *After the interview*

To ensure that participants understood the purpose and potential outputs of the study, and that they were comfortable with the publication of data in the form of ‘quotes’, each respondent was asked if they had any questions about the research or how their data would be used upon the completion of their interview. This was considered important as it is recognised that the relaxed approach adopted in narrative interviews can lead participants to forget the purpose of the interaction and disclose information they had not intended to (Chataika, 2005).

Participants were also given a debrief sheet (Appendix 5) providing an overview of the study and researcher contact details to support this process. Further to this, they were given a sheet outlining contact details for specialised support services, the charities acting as gatekeepers, and NHS Carers Direct (Appendix 6).

Within 48 hours of the interview, I made comprehensive notes, both freehand and electronically (Appendix 7), and developed a short biography of each participant. As most narratives were highly complex, non-chronological accounts of multiple, often over-lapping, emotional events, it proved challenging to keep track of the over-arching story during the interview. Writing a biography shortly after the interview helped to address this issue, by contextualising the information shared, aiding comprehension of the basic elements of each participant’s narrative, e.g. what, where, when, who, and how. These concise documents proved particularly useful when communicating with those participating in longitudinal interviews. All communication with these participants between interviews was also logged in this document. Prior to the follow up interview I used this document to re-familiarise myself with their story. This knowledge, I believe, helped me to quickly re-establish rapport with these individuals in the second interview and encouraged them to disclose a detailed and frank narrative.

Transcription

I transcribed the audio-files using the programme Express Scribe. Effort was made to preserve participants wording, grammatical inference, colloquialisms and dialect where possible. All transcripts were anonymised through a process of replacing names with pseudonyms and removing key locations and other identifiable features. The process of transcription, though aided by the Express Scribe programme, took significantly longer than I had anticipated. Initially, I had hoped to complete each transcript within two weeks of the interview, as I believed that proximity to the interview would result in a more accurate transcript. However,

at times this approach proved difficult to sustain. In reality, transcripts were completed between one and six weeks after the interview, depending on the length of recording, complexity of the content, and number of interviews being conducted and transcribed at any one time. I am aware that this delay in transcription could be thought to jeopardise my iterative approach somewhat. However, I do not believe that this was an issue, as I was continually familiarising myself with the data in other ways, including producing extensive notes (see above) and thematic mind maps (see Section 4.3.3), and thus remained cognisant of the key emerging themes throughout the data collection period.

4.3.3 *Data analysis*

As previously described, iterative thematic analysis was used to analyse the data collected in this study. Braun and Clarke detail five phases of thematic analysis as: (1) familiarising yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, and (5) defining and naming themes (2006, p. 87). These stages largely reflect the analytic approach adopted in this study, outlined below.

4.3.3.1 *Data familiarisation: preliminary coding and thematic mind maps*

Data collection and analysis were concurrent. In the early stages of fieldwork, I immersed myself in the raw data, listening to recordings, reading and re-reading the transcripts, as well as writing extensive notes and biographies on each participant. I also spent time examining two personal diaries, written around the time of the transplant procedure, sent to me by participants (Jacob and Matthew). These documents were unsolicited and were offered freely by their owners (Jones, 2000).²³ Though all of these activities afforded some degree of data familiarisation, the most significant method proved to be the practice of transcribing the audio-recordings. During this familiarisation stage, sections deemed worthy of further attention, referred to as “codable moments” (Boyatzis, 1998), were logged as “pre-codes” (Braun and Clarke, 2006). A code refers to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way” (Boyatzis, 1998, p. 63). Data are considered codable when they strike the researcher as interesting in relation to the research question (Braun and Clarke, 2006). While some pre-codes were deductive, informed by existing theory, such as Hochschild’s emotion work (1979), the majority were inductive at this stage, meaning that they were rooted in the data (Braun and Clarke, 2006). This process

²³ Permission was acquired to use direct quotes from these diaries as data within the body of this thesis, if and where relevant.

allowed me to determine recurrent codes, which facilitated the development of initial analytic ideas. Throughout data collection, I used mind maps to keep track of, and collate, key codes into preliminary themes. Continual, iterative, development of these thematic mind maps aided data collection, as it informed future interview prompts and offered insight into potential “avenues of inquiry” (Pope *et al.*, 2000, p. 114). The final set of preliminary thematic maps centred on twelve themes:

- Communication and decision making
- Coping and wellbeing
- The donor and donor family
- Emotions
- Identity
- Lifestyle change/loss
- Public perception and awareness of transplantation
- Relationships (for example see Appendix 8)
- Roles and responsibilities
- Space and environment
- Support
- Time
- Uncertainty and risk

By familiarising myself with participant data at an early stage in this way, I was able to compare accounts, and thus identify, and subsequently question, deviant accounts - those that appeared to “counter to the emerging propositions” (Pope *et al.*, 2000, p. 114).

4.3.3.2 *Assessing preliminary themes: systematic coding*

Upon the completion of data collection, my attention turned to assessing the validity of the preliminary themes identified using thematic mind maps. To achieve this, I felt that it was important to systematically re-code the data set (transcripts, diaries, researcher notes). To ensure I used a robust approach, compatible with my research style and the format of the data collected, I trialled a number of different methods. Initially I coded data by hand, adding codes to printed transcripts and/or physically cutting up and sorting sections of the transcripts into folders. Recognising that this approach was not conducive to the timely retrieval and comparison of data, I altered my approach to involve the use of computer programmes. At first I used Word, coding my data by means of the ‘add comment’ function and cutting and

pasting sections of text on related themes into separate documents. However, after deliberation, I decided that the most effective way to systematically code and compare the data set as a whole would be to use data management software, namely the programme NVivo 10. Further rationale for using this programme is provided in Section 4.3.4.7.

Figure 4 details an example of the coding process undertaken using NVivo 10. Where possible I aimed to take a holistic, rather than line by line, approach, in order to preserve the context of the quote (Braun and Clarke, 2006; Saldaña, 2009).

Data section	Code
<p>...we spent the next 2 or 3 years backwards and forwards to [transplant centre] just jumping through hoops to get on that transplant list, 'cause you know we saw that, it was our only option, of us getting... I know, sorry, I talk about it as 'us' because from day one it was a team thing do you know what I mean? It was a joint decision.</p>	<p>Time - duration Perseverance/'Deserving' 'Choice' Terminology: 'we'/'us' Committed family Presence/Involvement in care</p>

Figure 4: Example of the coding process

A large number of codes were generated, to fully reflect the nuances in the data (Pope *et al.*, 2000). In addition to narrative content, codes denoted narrative structure, grammatical inferences, and language used.

4.3.3.3 *Reflecting on and refining themes*

Once I had coded all data using NVivo, I used the revised set of codes to refine the twelve preliminary themes developed at an earlier stage (see Section 4.3.3.1). Aware of the benefit of using visual representations when considering data at a broader level (Braun and Clarke, 2006), and keen to explore the links between codes and broader themes, I utilised the process of mind mapping for a second time. This process involved a significant degree of trial and error, with maps being reviewed and reformulated on numerous occasions until the “candidate themes” were felt to form a “coherent pattern” (Braun and Clarke, 2006, p. 91). Figure 5 illustrates an early-stage thematic mind map on the theme of loss.

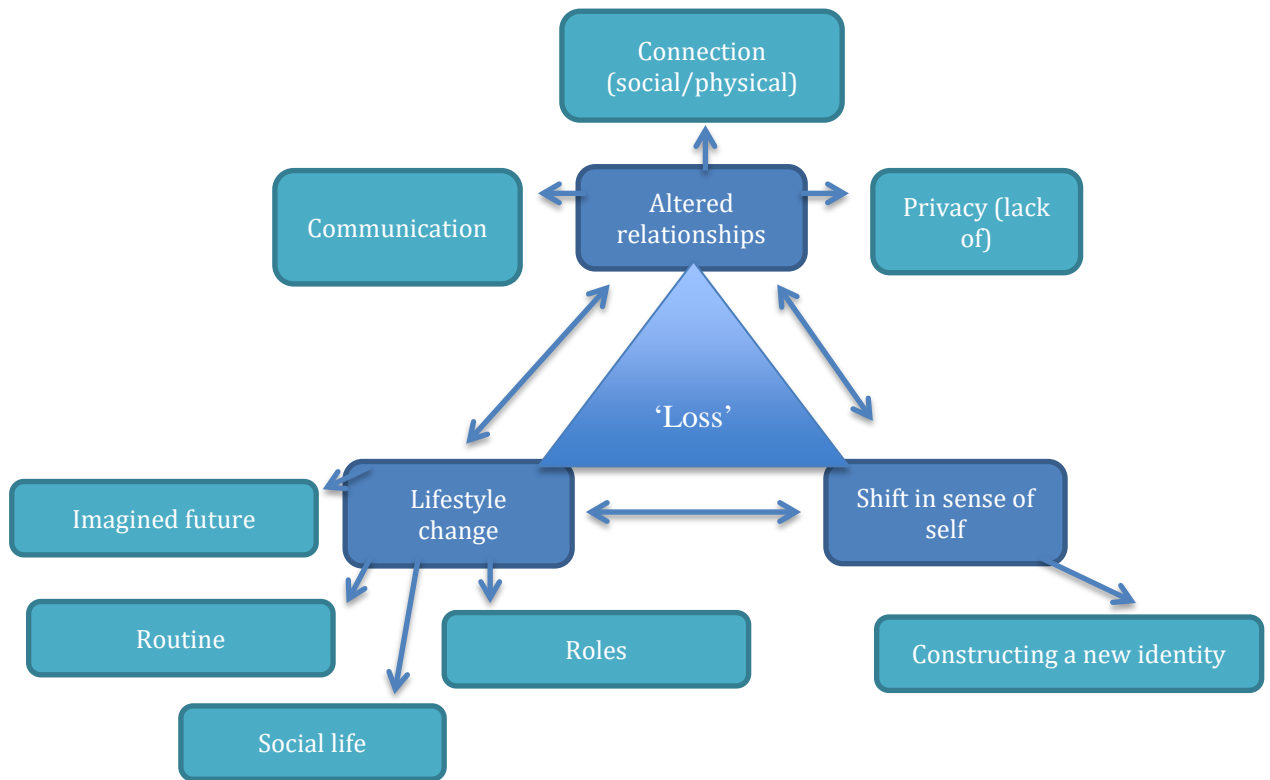


Figure 5: Early-stage thematic mind map on the theme of 'loss'

Though laborious, this approach proved instrumental for identifying stand-alone and interlinking themes. Writing about the themes using these mind maps aided the development of my analysis, by allowing further exploration of the relationships between themes and areas of overlap. Each draft of written work helped to progress my analysis, facilitating the refinement of working titles into formal and concise headings (Braun and Clarke, 2006).

4.3.4 Reflexivity and situated ethics

The following section details a reflexive account of the research, to emphasise key differences between how I originally planned to conduct this research and what happened 'in the field', and the ethical challenges faced throughout the research process. For the purpose of clarity, I structure this account in eight subsections, entitled: (1) sampling issues, (2) respecting participants, (3) interviewing multiple individuals, (4) researcher wellbeing, (5) sensitive interviewing, (6) managing assumptions, (7) the NVivo dilemma, and (8) anonymity and representing participants.

4.3.4.1 Sampling issues

Aware of the variance within the potential participant population (depicted in table 9), I was keen to ascertain a diverse sample that would reflect a broad spectrum of experiences.

Characteristic	Variants
Relationship with patient	Partner, parent, sibling, child, friend Living with or supporting Relationship status: good/poor, variable/static
Patient presentation	Acute, chronic or congenital condition Hospitalisation prior to transplant (short-/long-term)
Transplant type	Heart, liver, lung, heart/lung First transplant, re-transplant (liver)
Transplant stage and outcome	Pre-transplant Assessment: number of assessments, conditionality, suspension Waiting: number of months, number of false alarms Post-transplant Patient survival: recovery status, time hospitalised, (participant reported) quality of life Patient death: proximity to transplant, cause of death
Social factor	Age, sex, employment status, health status, financial situation, social support
Other	Distance from transplant centre, donor relationship (view of), involvement in transplant community

Table 9: Key variables within participant population

Purposive sampling is widely acknowledged to be the best way to achieve such variance (Ritchie *et al.*, 2014), however, this approach proved difficult to enforce in this research context. As I was asking interested individuals to contact me, rather than selecting participants to contact from a pre-set pool, I was largely unable to control the characteristics of those within my sample. A key characteristic that proved difficult to control was the time since their relative's transplant. Originally I decided to interview individuals whose relative had been transplanted within the last two years, to manage the impact of recall bias, a well-known criticism of qualitative research which states data collected a significant period of time after the event may not be as rich as that collected sooner (Bell, 2005). However, despite stating this cut-off point in the inclusion criteria on recruitment materials (Appendix 9), I was routinely contacted by individuals whose experience fell outside of this time limit. In light of this, I decided to conduct some exploratory interviews with individuals who did not meet this inclusion criterion. Upon comparing the data of these individuals with those who met the original inclusion criteria, I determined there was little difference in the quality of the data collected. In fact, the accounts of those interviewed a significant time after their relative's

transplant were often just as, if not more, revealing than those collected from individuals within months of the transplant. By comparison, relatives of individuals who had recently undergone transplantation appeared to struggle to give a comprehensive overview of their experience, and focus on how the process had affected them, rather than the patient. As time did not appear to have a negative impact upon the data collected, I removed exclusion criterion.

As a result of the issues discussed, the sampling strategy implemented in this study was more akin to convenience or opportunistic sampling, a method by which the selection of participants is largely influenced by who is accessible to the researcher (Marshall, 1996). Convenience sampling is often viewed as less desirable than other sampling approaches (Suri, 2011), however, it was appropriate in this study as it ensured the recruitment of a suitable sample of participants who were willing to discuss a sensitive, personal subject at length. The sample achieved using this approach was relatively diverse in nature (see table 10). Had this not been the case, I would have attempted to recruit additional participants using a purposive approach, to ensure the sample was reflective of the heterogeneity of the participant population.

Pseudonym	Time since transplant (at final interview)	Relation to Tx patient	Transplant type	Condition leading to transplant	Length of wait (approx. to nearest month)	No. of false alarms	Patient recovery	Interview format
Claire	N/A (waiting)	Partner	Heart	Chronic (Cardiomyopathy)	11 months (at final interview)	0	N/A (waiting)	Longitudinal Face-to-face One-to-one
Matthew	3.5 months	Partner	Heart	Chronic (Cardiomyopathy)	2 months	0	Discharged after 6 weeks.	Retrospective Face to face One-to-one
Rosalynn	4 months	Sister	Double lung	Acute (Pulmonary Hypertension)	<1 month	0	Experienced complications – further surgery required. Discharged after 2 months.	Retrospective Telephone One-to-one
Isabelle*	4 months	Partner	Double lung	Chronic (Pulmonary fibrosis)	8 months	1	Experienced complications - further surgery required. Discharged after 4 months.	Longitudinal Face-to-face 1 st : one-to-one 2 nd : group
David*	4 months	Brother	Double lung	Chronic (Pulmonary fibrosis)	8 months	1	Experienced complications - further surgery required. Discharged after 4 months.	Retrospective Face-to-face Group
Lesley*	4 months	Sister-in-law	Double lung	Chronic (Pulmonary fibrosis)	8 months	1	Experienced complications - further surgery required. Discharged after 4 months.	Retrospective Face-to-face Group
Deborah*	4 months	Mother	Double lung	Chronic (Pulmonary fibrosis)	8 months	1	Experienced complications - further surgery required. Discharged after 4 months.	Retrospective Face-to-face Group
Katy	6 months	Daughter	Liver	Chronic (Alpha-1-antitrypsin deficiency)	7 months	1	Discharged after 1-2 weeks.	Retrospective Telephone One-to-one
Erin	6 months	Partner	Liver	Chronic (PSC)	9 months	0	1 st TX: some initial rejection. Discharged after 2-3 weeks. 2 nd TX: Experienced complications - further surgery required. Discharged after 4 months.	Longitudinal Face to face Dyadic
Elaine	6 months	Mother	Heart	Congenital (Congenital heart disease)	20 months	6	Discharged after 3 weeks.	Longitudinal Telephone One-to-one

Jo	6 months	Partner	Liver	Acute (Infection)	<1 month	0	Discharged after 2 weeks. Re-admitted since with signs of rejection and infection (discharged after 3 weeks).	Retrospective Face-to-face One-to-one
Louise	8 months	Partner	Double lung	Chronic (Pulmonary Fibrosis)	2 months	5	Experienced complications - further surgery required. Discharged after 4 months.	Retrospective Face-to-face Dyadic
Anna	1 year	Partner	Double lung	Chronic (Severe emphysema)	7 months	0	Not discharged. Died 3 months post-TX.	Retrospective Telephone One-to-one
Jacob	1 year	Partner	Liver	Chronic (Hepatitis C)	2 months	0	Discharged after 2-3 weeks.	Retrospective Telephone One-to-one
Lindsay	1.5 years	Partner	Double lung	Chronic (Alpha-1-antitrypsin deficiency)	7 months	5	Discharged after 2-3 weeks.	Retrospective Face-to-face One-to-one
Evaline	1.5 years	Mother	Liver	Chronic (PSC)	5 months	0	Discharged after 1-2 weeks.	Retrospective Face to face One-to-one
Lucy	2 years	Friend	Double lung	Chronic (Emphysema/pulmonary hypertension)	5 months	1	Discharged after 1 month.	Retrospective Telephone One-to-one
Olivia*	2.5 years	Sister	Liver	Chronic (PSC)	24+ months (Briefly suspended)	1	Discharged after 2 weeks.	Retrospective Face-to-face One-to-one
Ellen*	2.5 years	Mother	Liver	Chronic (PSC)	24+ months (Briefly suspended)	1	Discharged after 2 weeks.	Retrospective Face-to-face One-to-one
Scott	2.5 years	Partner	Heart & Double lung	Congenital (Congenital heart disease)	24+ months	1	Discharged after 6 weeks. Readmitted since with severe infection (discharged after 6 weeks).	Retrospective Telephone One-to-one
Lynda	2.5 years	Partner	Liver	Chronic (PSC)	12 months	5	Discharged after 1-2 weeks.	Retrospective Telephone One-to-one
Amelia	3 years	Mother	Heart	Congenital (Congenital heart disease)	6 months	0	Experienced complications – further surgery required. Discharged after 4 months.	Retrospective Face to face One-to-one

Julie	4 years	Partner	Liver	Chronic (Scarring from prescription medication)	<1 month	0	Discharged after 2 weeks.	Retrospective Face-to-face One-to-one
Marie	10 years	Mother	Heart	Acute (Complications following heart surgery)	<1 month	0	Not discharged. Died a week post-TX.	Retrospective Telephone One-to-one

Table 10: Participant details ascending by time since transplant (*related to another participant, discussed the same relative)

4.3.4.2 *Respecting participants*

Aware of the personal and sensitive nature of the data I was asking individuals to share, I was keen to respect and express gratitude to participants by agreeing to include them. As I began to reflect upon the data collected I increasingly found myself in awe of participants for their willingness to share details of such a distressing time in their lives. This admiration, coupled with concerns that refusal to include participants could result in disempowerment (discussed in studies exploring the ethical dilemmas of conducting sensitive research e.g. Liamputtong (2006)), meant I became increasingly reluctant to turn away individuals expressing interest in the study. I am conscious that this approach to recruitment could be deemed ‘overly inclusive’, however, I strongly believe that it was important to remain open to participants to avoid causing undue harm.

4.3.4.3 *Interviewing multiple individuals*

Originally, I had hoped to recruit participants on an individual basis, to one-to-one interviews, as I was aware that participants are more likely to control what they disclose in a dyadic or group interview (Byrne, 2004; Morgan *et al.*, 2013). However, this was not always possible. Six participants requested to be interviewed alongside other family members, the transplant patient in two cases²⁴ and a small group of family members (totalling four individuals). While I was not keen to deviate from the one-to-one format, my primary concern was to ensure participant comfort and so I agreed to conduct two dyadic, and one group, interview(s) in these select cases. Mindful of literature discussing the potential for harm when interviewing family members together (Funk and Stajduhar, 2009; Eisikovits and Koren, 2010), I exercised caution in my approach within these interviews, refraining from what could be deemed ‘excessive probing’. Though I am aware that dyadic and group interviews are not widely recommended for research on sensitive topics, I do not believe that they were detrimental in this research context. On the contrary, I believe that they proved beneficial in some instances, encouraging shy or reluctant individuals to take part in and engage with the interview in a way that they would not have done if they took part in the research independently (Edwards and Holland, 2013). Relatives often worked together to relay the narrative, reminding each other of key events - which on occasion proved integral to their narrative and significantly influenced the direction of the accounts provided. Further, interviewing family members together gave me an interesting insight into the family dynamics, data that I could not access

²⁴ Transplant patients were present at, and participated in, two interviews. However, as previously discussed, data from these individuals has not been included within this thesis for clarity purposes.

via one-to-one interviews. This reflects the accounts of other qualitative researchers studying family caregiving, such as Torgé (2013) who argues individual interviews can obscure “the perspective of the family unit, the complexity of family caregiving and how families produce joint accounts of illness” (p. 102).

4.3.4.4 *Researcher wellbeing*

When planning this study I decided to limit the number of interviews I conducted to two or three a week, to allow time for the development of preliminary analysis between interviews and to prevent physical, mental, and emotional exhaustion, widely documented consequences of conducting qualitative research (McCosker *et al.*, 2001; Johnson and Clarke, 2003; Dickson-Swift *et al.*, 2007; Bahn and Weatherill, 2013; Boden *et al.*, 2016). While this approach worked relatively well on the whole, there were occasions where it proved difficult. The time-dependent nature of the transplantation process meant that scheduling interviews with longitudinal participants was particularly challenging. As the waiting list is inherently unpredictable, interviews with individuals in the pre-transplant phase were prioritised and scheduled for the next available opportunity, regardless of how many other interviews were planned, to ensure I was able to capture their account before they received a successful call from the transplant team. Consequently I sometimes found myself trying to do too much simultaneously and this, coupled with the emotionally taxing nature of the interview content, proved stressful at times and had short-term implications for my personal wellbeing. This was somewhat unavoidable, however, as I would have struggled to access certain data had I delayed these interviews. Cognisant of the potential for negative personal implications, I took steps to preserve my wellbeing, including: taking regular breaks, debriefing with my supervisors after each interview, and engaging with peer support within the Institute of Health and Society (IHS).

4.3.4.5 *Sensitive interviewing*

The potentially sensitive nature of the interviews was another element of the research that I had considered in some depth prior to commencing my fieldwork. I was aware that discussing family relationships, particularly the ill-health and/or death of a family member, may be distressing for the participant, thus I was keen to adopt a sensitive approach to data collection to prevent causing unnecessary harm. To do this, I broached topics I deemed potentially difficult in a tentative manner and intensively monitored participants’ responses (what was

said, how it was said, and their facial expressions), to determine how comfortable they were. This was more difficult in telephone interviews, due to the lack of face-to-face interaction, however, changes in participant tone, sighs, and hesitation proved to be good indicators of distress (Sturges and Hanrahan, 2004). If at any point the participant became noticeably agitated or upset, I assessed their willingness to continue and reminded them they were free to refrain from answering or could stop the interview at any time. In all cases, participants took a couple of moments to gather themselves and continued. It became apparent that participants felt it was important to share their story, regardless of how upset they became, and thus I did my best to respect and facilitate this throughout the data collection process. As the interviews progressed I became accustomed to expressions of 'negative' emotion from participants. I realised that I was often fulfilling the role of "friendly stranger"; giving participants the opportunity to offload to an interested individual who was not intimately involved in, and thus had no control over, their life (Cotterill and Letherby, 1994). This proved useful for data collection as it allowed participants to air their grievances without fear of repercussion. However, fulfilling this role proved problematic at times as I struggled to preserve the researcher-friend boundary, particularly with participants recruited to longitudinal interviews. Communicating with participants over several months, rather than on a single occasion, meant that I became increasingly attached to, and emotionally invested in, these individuals. This attachment proved difficult to manage at times, particularly when exiting the field. I was aware that ceasing communication after the follow-up interview was vital, as it sent a clear message to participants about the researcher-participant relationship; however, I found it challenging to adapt to this shift. It was difficult to 'let go' of participants and I often had to resist strong urges to seek updates on their situation, mirroring the experience of researchers discussed by Exley (2004), Foster (2004), and Dickson-Swift *et al.* (2006).

4.3.4.6 *Managing assumptions*

Aware that participants can judge researchers in relation to their appearance, demeanour, and/or allegiances, I was conscious of the impact I may inadvertently have on the data collected (Mishler, 1986; Bowling, 2002; Green and Thorogood, 2009). One factor that I believe did influence participant response to an extent was my affiliation with the charities I had used as gatekeepers. At times my allegiance with charity groups, known to have a good relationship with the local transplant centre, appeared to affect the data that I was able to collect, as participants seemed reluctant to express negative sentiments about their experience. I attempted to minimise the impact of this by asserting my neutral position and restating that

the intention of this study was to explore all elements of the transplant experience, positive or negative.

In addition to participant assumptions, I was conscious that I too might make erroneous assumptions during the research, in relation to participant appearance/behaviour/demographic profile etc., which could jeopardise the methodological rigour of this study. To avoid this, I engaged in a continual process of reflection and self-criticism. I made extensive notes following each interview, reflecting upon the findings and my positionality, in an attempt to remain as objective as possible (Seale and Silverman, 1997). This practice proved valuable, as it allowed me to reflect upon and document my impressions of the exchange (re. environment, flow, interruptions) and participant (re. physical characteristics, mood, rapport) for future reference. Further, this provided a useful space to document initial thoughts on the data, such as key themes to address in subsequent interviews. As well as reflecting upon my approach and thoughts independently, I also did this with my supervisors in monthly meetings and with a larger group of qualitative researchers during 'data sessions'.²⁵ By assuming this reflexive stance early on, I endeavoured to remain aware of the impact of my own subjective influence on the collection and interpretation of the data (Birks *et al.*, 2008). Other strategies adopted to ensure the methodological rigour of my work included: listening to interview recordings on numerous occasions to confirm ideas and the context of quotes (Mays and Pope, 1995; Seale and Silverman, 1997), searching for and querying deviant cases against more established findings (Mays and Pope, 1995; Seale and Silverman, 1997), and use of NVivo to systematically re-code the data set to reduce the possibility of overlooking or wrongly disregarding data (Mays and Pope, 1995; Seale and Silverman, 1997).

4.3.4.7 *The Nvivo dilemma*

Though I made steady progress in my analysis using a diverse approach of mind-maps, and hand- and digital coding, over time I became concerned that this approach was not rigorous or systematic enough. To ensure I felt confident that I was not inadvertently overlooking or wrongly discarding data, I decided to recode the data set using data management software. I was aware of the potential disadvantages of using software to code qualitative data, including vulnerability to technical issues and the risk of over-coding (St John and Johnson, 2000), however, I deemed these risks acceptable in light of the reported benefits, particularly the

²⁵ 'Data sessions' refers to a bi-weekly meeting of qualitative researchers (n=~6-12) within the IHS during which the group collectively analyse sections of an anonymised transcript. My data was shared with this group on three occasions.

level of flexibility, structure, and degree of transparency researchers are thought to achieve using such programmes (Pope *et al.*, 2000; Lu and Shulman, 2008). Using NVivo helped to alleviate my concerns, by facilitating the analysis of all of data (transcripts, notes, and participant diaries) on one platform. Though this process was helpful, recoding my data with NVivo proved incredibly time consuming and ultimately the codes created did not differ much from those I had prior to using the programme. Considering this, it could be argued that use of NVivo was an unnecessary resource-intensive step in my analysis. Nevertheless, I believe it proved beneficial by helping to boost my confidence in my analysis and avoid ‘cherry picking’ quotes or making overly ambitious or unfounded claims (Pope *et al.*, 2000; Lu and Shulman, 2008).

4.3.4.8 *Anonymity and representing participants*

In recording and writing about participants I faced numerous challenges associated with issues of anonymity, and how best to represent individuals and communicate their stories. Effort was made to preserve participant anonymity through careful handling of participant records, the use of pseudonyms, and thoughtful presentation of identifiable information (e.g. names/places/occupation etc.) in transcripts and written work (Larossa *et al.*, 1981; Corbin and Morse, 2003). At times it proved difficult and time-consuming to successfully anonymise documents without losing the integrity of the data (Saunders *et al.*, 2015). Indeed, in some cases it became clear that it would be virtually impossible to conceal participant identity without drastically altering their account. Recognising the importance of preserving the integrity of data, alongside the potentially negative implications (social, financial, legal, and political) of breaching confidentiality in this research context (Corbin and Morse, 2003), I determined the most appropriate course of action was to withhold certain illustrative examples from this thesis.

4.3.5 *Limitations*

This section draws together the limitations of my methodological approach. Arguably, the most significant limitation of this study is rooted in the way that participants were sampled and recruited. As has previously been discussed, this study was conducted using a convenience sampling approach, a method often criticised for its lack of rigour and strategy (Polkinghorne, 2005). While I recognise that adopting this approach could leave this study open to criticism, the challenging nature of this work meant that this decision was somewhat

unavoidable. Steps were taken to limit the effect of this on rigour of this study, including closely monitoring the characteristics of participants to ensure the sample was varied, both in terms of demographics and transplant experience. As previously outlined, I had always intended to conduct additional purposive sampling if this was not the case. However, as my supervisors and I deemed the sample to be largely heterogeneous, it was not felt necessary to conduct additional purposive sampling to 'fill the gaps'.

The decision to recruit through charities could be argued to be a limitation of this study, as these groups largely controlled who I was able to access and thus the type of participant I was able to recruit. Unbeknown to me when starting this research, charity membership was largely comprised of transplant recipients more than five years post-transplantation. This complicated recruitment in two key ways. Firstly, as these charities had little interaction with family members, I had to rely on transplant recipients as secondary gatekeepers. Not only was I depending on the charities to efficiently pass research information to their members, I was trusting on the individuals who received this information to share it with their family. Aware of this, I ensured all of the recruitment information was sensitively worded, with the transplant recipient in mind, in the hope that this would encourage recipients to share it. Secondly, as membership predominantly comprised transplant recipients, it proved difficult to reach and recruit family members of individuals awaiting a transplant via these groups. Alternative recruitment strategies were developed to capture this demographic, based on the advice of group members, such as placing recruitment materials in charity-run accommodation that is available to families throughout the transplantation process. Unfortunately, these strategies did not boost recruitment of participants to longitudinal interviews.

Another potential criticism, in relation to recruiting through these charity groups, is that this approach could have led to the recruitment of a skewed sample of engaged and relatively well-supported individuals. Indeed, this was a personal concern at the beginning of the research, as I was keen to gain insight into how supported family members felt, by their social network and the transplant team, throughout the transplantation process. However, interviews revealed that participants were not necessarily involved in or aware of the charity groups. Though some participants interacted with these groups (attending events, posting on social media), most recounted following charity activities from a distance, and a handful professed that they knew very little about such groups.

One limitation of this research that proved comparatively difficult to address was the fact that this study only seemed to appeal to family members who responded in a ‘supportive’, socially acceptable, way throughout the transplant process. Though I had heard anecdotes of family members who had responded negatively when their relative fell ill and required a transplant while shadowing health professionals in the transplant clinic²⁶ (e.g. well partners leaving the ill partner when they learned they needed a transplant), I struggled to recruit anyone willing to discuss such an experience. This is somewhat unsurprising given the social expectations surrounding how relatives ought to behave when a family member is unwell, as individuals who responded differently may have feared that they would be negatively judged. This fear of being judged also seemed to influence the participation of relatives of individuals requiring a transplant due to risk-related behaviour. Though I spoke to one individual whose partner required a liver transplant as a result of contracting hepatitis C through drug use, I was unable to recruit anyone whose relative was placed on the transplant list for conditions related to excessive alcohol consumption or smoking. Though frustrating, this recruitment issue is not all that surprising considering the social stigma surrounding conditions associated with such behaviour.

4.4 Chapter summary

Prior to describing the methods I used in this study, I discussed the methodological beliefs underpinning my approach. With each subsequent section I addressed the methodological decisions I made, from my approach to sampling through to the method of data analysis I chose and the reasons for this. Following this, I reflected upon key methodological and ethical challenges faced. To conclude, I presented potential limitations of my methodological approach, outlining the ways that I attempted to limit the negative impact of these and ensure I adopted a rigorous approach throughout this research. In the following three chapters, I present the data collected using this approach in three empirical chapters. To aid the reader’s comprehension each of these chapters focuses on a distinctive element of transplant life discussed by participants, starting with their clinical experiences. Following this I focus on participant accounts of their family life, specifically their roles and relationships. The final empirical chapter explores the social impact of transplantation, in relation to ‘existing’ and ‘emerging’ social networks.

²⁶ For further detail on time spent shadowing transplant professionals, see Chapter 2, Section 3.2.1 (footnote 14)

Chapter 5. Encountering the clinical world of transplantation: Spending time in the transplant centre and interacting with the transplant team

In this chapter I focus on participants' experiences within the transplant centre. Particular attention is paid to the extent to which family members felt acknowledged by the transplant team, regarding their role in their relatives care and their personal support needs. I present and discuss data chronologically, under the headings pre- and post-transplantation, to illuminate the extent to which experiential elements appeared to change over time, and the impact of this upon family member wellbeing (physical, psychological, and emotional) and sense of self. Prior to presenting empirical data, I provide an overview of the participant group for contextual purposes.

5.1 Participant overview

Twenty-four individuals were recruited to this study. Twenty participants were women and four were men. Twenty-three individuals were from the UK and one was from the south of Ireland. These individuals discussed experiences of six transplant centres. Four types of transplant were discussed: heart (n=5), lung (n=9), heart/lung (n=1), and liver (n=9). Most participants were parents or partners (n=18), though a smaller number were siblings (n=4), an adult child (n=1), or friend (n=1). While the participant group includes one non-relative, I use the term 'family members' throughout this thesis for clarity purposes and in light of contemporary definitions of 'family', which are broad and generally refer to individuals who share similar goals and resources (physical and emotional). Four participants were recruited prior to their relative's transplant and were interviewed longitudinally on two occasions, between six and nine months apart. Twenty participants were recruited after their relative's transplant and were interviewed retrospectively about their experience. Various interview formats were used with participants, at their request, including: one-to-one (n=21)/dyadic (n=3)/group (n=1), and telephone (n=10)/face-to-face (n=15). For more detail, refer to table 7 in Chapter four.

Table 11 presents an overview of some of the key participant characteristics to aid the reader in contextualising data presented in the subsequent empirical chapters.

Participant characteristic	Category	No.
Age at time of interview (years)	18-24	1
	25-30	0
	31-40	0
	41-50	7
	51-60	6
	61-70	8
	70+	2
Gender	Male	4
	Female	20
Employment status	Employed full time	8
	Employed part time	3
	Self-employed	4
	Retired	6
	House wife	2
	'Carer'	1
Relation to transplant patient	Partner	12
	Parent	6
	Sibling (biological & in-law)	4
	Child	1
	Friend	1
Transplant type	Heart	5
	Lung	9
	Heart/lung	1
	Liver	9
Perspective/involvement	Retrospective	20
	Longitudinal	4
Transplant outcome	'Successful' transplant	21
	Waiting	1
	Bereaved	2

Table 11: Key participant characteristics

5.2 Pre-transplantation

In this section I present participant accounts of their experience of the clinical world of transplantation at key pre-transplant stages, including 'the assessment', 'the call', and during 'the operation' (for further detail see Chapter 2).

Most participants, particularly parents and partners, first encountered the transplant centre and their relatives' transplant team while accompanying them to the transplant assessment - a process to determine an individual's suitability for a transplant. The assessment process appeared to mark the beginning of a steep learning curve for these family members, as it was

the point at which they began to understand the complexity of the transplantation process and what was expected from them as a 'carer', as the following quotes²⁷ illustrate:

The first [assessment]... that was the first experience of how complicated that process [transplant] is really. (Erin, 49, partner)

...at that time [the assessment] I didn't really know anything about them [transplants]. I didn't really understand what, um, the risks were and all the rest of it [...] I think at that point it really started to hit home for me that, this was serious stuff. (Lindsay, 52, partner)

[At the assessment] staff made it very clear that it ['carer'] was a very important role for somebody to be taking. And um, you know, that we would be making life or death on behalf of our, of, of, of the person going through the transplant experience. So it was like "Oh my god!" (Lucy, 51, friend)

While respondents agreed that this process opened their eyes to the reality of waiting for and/or living with a transplant, individual experience of the assessment appeared to differ substantially. A number of participants, such as Lynda and Lindsay, recounted that they found the assessment to be a well-structured, useful experience, which left them feeling more knowledgeable about their relatives' impending transplant:

[The assessment] was very, very well done. We came home with an extensive booklet explaining everything you could want to know about [the liver transplant]. Um, and a lot of stuff which probably a lot of people don't want to know... I read it from end to end, and so did [partner]... we were very aware that you can get called in and then various things can go wrong, either the organ's not suitable or somebody who was on ITU and expected to move out doesn't, and therefore there's no ITU bed free, or the theatre space gets taken up and you get sent home... intellectually we knew all about that. (Lynda, 68, partner)

The booklets [provided at the assessment] gave the bigger picture and helped reinforce everything they'd told us over those three, what- four days. That was a huge amount of information to take in. The hospital assessment was good because every time [partner] had a test there was a lot of time hanging around afterwards where you could then, between you, get your heads around what, little parts of it, so by the end of the four days they'd actually covered most things and [partner had] been able to ask any questions and had them answered during the process. So it was a good, good way of doing it and backed-up by these two booklets. (Lindsay, 52, partner)

In contrast, the accounts of some participants revealed that they struggled with the way that the assessment was conducted. Isabelle, for example, reported that she found it very difficult to process, and subsequently remember, the volume of information that the transplant team shared with her and her partner during this time:

At the assessment...they [staff] go through everything with you, it is information overload... I only remember [information] because I wrote it all down... I think that [information provision] needs to be more precise, as opposed to going through all this

²⁷ Throughout this thesis quotes have been abbreviated in two ways. The ellipsis '...' has been used to indicate the omission of a few words, while '[...]' denotes the omission of a more substantial section of text.

reams of stuff in the space of two hours and your head is battered because you don't remember it... I think that needs to be more concise. (Isabelle, 43, partner)

Isabelle stated that she believed that way that the transplant team relayed important information to families during the assessment could be improved, to prevent individuals from becoming stressed and overwhelmed as she did. Supporting this, Anna noted that she felt that the way information was communicated with families during the assessment needed to change; believing that poor communication had left her partner with erroneous expectations that she was left to manage over time:

...every time we went [for an assessment, partner] wanted an answer. He wanted to know yes or no, "Am I getting it or not, am I getting it or not?" He could not understand-, he got very frustrated you know? You'd go and they'd [the transplant team] ask for something else [another test] and then something else. You know he thought that it was sort of a way of putting him off, they [the transplant team] were putting him off, he just wanted a yes or a no straight away, he just didn't have the patience so I found that difficult... there's so much that you have to be tested for, and so many y'know hoops you've gotta jump through...I don't think [partner] understood the process. I don't think it was explained very well [by the transplant team]. That ok, you're coming for assessment, but it might take another two years before you meet the criteria to go on the list. You know, just because you're coming for assessment, you're not gonna get a yes or a no. It's a goal that you're working towards, not a definitive result. (Anna, 48, bereaved partner)

These quotes illustrate that the assessment process can be a challenging clinical encounter for family members, as it can be felt to exacerbate, rather than relieve, the care burden that they felt as their relatives' health declined. Anna's account, for example, implies that a significant part of supporting a relative through this process was working to manage their emotions, to bolster the psychological impact of potentially, or actually, being told 'no'. This was all the more taxing because participants were simultaneously struggling to manage challenging personal emotions at this time. Elaine, for example, recalled that she felt extremely anxious during her son's assessment, as she was constantly worried that each test could prove that he was not suitable for a transplant:

[The assessment] was very difficult in that each test we didn't know if this was the test, the test on his liver – would this be the one that would turn him down for transplant? And you know, his kidneys, how were they holding up? Yeah, 'cos he's on a huge amount of medication for the last 20 years, you know. Will this be the one [test] that will stop him from being on the list? (Elaine, 61, mother)

However, the emotional toll participants experienced throughout the assessment did not necessarily diminish upon receiving a 'yes'. Lindsay revealed that, contrary to what she had envisaged, she did not feel relieved, but more distressed, when she learnt of the transplant team's decision to add her partner to the transplant list:

I thought I would be relieved, but I actually spent the whole weekend crying, most of the weekend, because it was just coming to terms I think with the fact that, you think you wanted it but you didn't want it, that's difficult to explain really. But um, that was quite, that was quite hard. I didn't expect to feel like that. I think I thought you know I'd be really pleased that he was gonna go on the list and it was quite a shock to think that actually, I am pleased but, but I'm not, just because the risks and things... (Lindsay, 52, partner)

This account reveals that family members can experience emotional dissonance (Hochschild, 1979) (see Chapter 3, Section 3.2.5.4 for definition) when their relative is placed on the transplant list, as they struggle with the internal conflict of simultaneously feeling optimistic that their relative may one day have a better quality of life, and anxious about the risks associated with a transplant.

Mirroring the divide in assessment experiences, participant accounts of interaction with the clinical team during the wait for a transplant varied. A number of participants reported that they felt somewhat overlooked by the transplant team during subsequent visits to the transplant centre:

[I felt] no one [in the transplant team] was talking directly to me. They were talking about my husband rather than my personal feelings in all of this [...] I certainly didn't feel included. At all. (Julie, 57, partner)

I'm there I'm kind of going, "Oh, hi" you know, making all the [effort] and whatever, and, and they [the transplant team] don't want to talk to me because it's not me that's having the transplant. (Elaine, 61, mother)

[Relatives] can be left on the outside a bit, a lot you know. There's been, sort of, a lot of decisions where [the transplant team] only talk to the patient and you're kind of there as a spare part, you know? It's very excluding. (Scott, 43, partner)

These accounts reveal that the patient-centered approach adopted by the transplant team during the wait for a transplant can leave family members feeling invisible in the eyes of the clinical team. This perceived exclusion seemed to leave family members feeling ambiguous about their role and questioning why they were encouraged to accompany their relative, as their involvement felt like an afterthought rather than an essential component in the process. This is reflective of other research that reveals that family members typically do not feel included by staff members in acute care settings (Morris and Thomas, 2001; Young et al., 2002; Wilkinson and McAndrew, 2008; Wingham et al., 2017). Partners, in particular, commented that the format of appointments left them feeling unable to ask questions; reinforcing the sense of exclusion that they felt. Julie and Claire commented that the constant presence of their relative, in particular, acted as a deterrent:

It's all wrapped up in data protection [doctor-patient confidentiality...] You can't go and ask for an appointment with your husband's doctors without him being there [...] I think from the beginning [of the transplant process...] most [family members] would really appreciate a space to talk, without the patient there. Because there are things you just cannot ask or say when they're present. (Julie, 57, partner)

...if you're talking about them [relative] in front of the doctors, do they [the ill relative] get the impression, well, you don't care for them? Or, you know, it's all getting too much for you and they're a burden to you? So to me it's like a double-edged sword [...] sometimes you don't always understand what's going on [...but] you can't voice your opinion in front of your other half [in case you upset them...] It's really hard at times. (Claire, 59, partner)

These quotes show that anxiety about adding to their relative's distress can prevent individuals from asking questions of the transplant team. Claire's use of the term 'double-edged sword' illuminates the extent to which family members can feel caught between their desire to air their concerns and the felt need to shelter their relative from the challenging issues playing on their mind. To remedy this, participants, Claire and Julie included, noted that they would have appreciated the opportunity to speak to staff members on their own; however, they recognised that this would be difficult to facilitate in light of constraints on staff time and issues surrounding doctor-patient confidentiality.

Not all participants described feeling excluded from clinical conversations. On the contrary, a number of respondents reported that they felt the transplant team recognised their presence and tried to include them where possible. Lynda and Isabelle, for example, stated:

I've always gone with him and I've always gone into the room with him and the consultants and the registrars [in the transplant centre] knew we went as a couple, they'd always shake my hand, they'd always look to me [...] I'd take a copy of a list of questions. I'd sit there and I'd just make sure all the questions were asked and that I'd write things down so that I could remind him of it when we got home. So they always included me as part of the team, this was team [surname], we were in this together [...] I felt they treated us as a team, so they were obviously focused on [partner] but I was included in any of the discussions, the debates, things about treatment and you'd say to them "Can I ask you a question?", "Of course you can!" And there was always time for questions. (Lynda, 65, partner)

[At appointments] I always have a notepad with me... I sit and read through it again ...you know, the questions I've asked and what they've said to me [... I say to the transplant consultant] "I'm writing this down mind! I hope you realise that. I'm gonna get you to sign these notes afterwards!" Little comments like that makes me feel more comfortable and I think sometimes it makes the staff feel more comfortable, 'cos I think it's hard for them [...] to me if they feel more comfortable with you, you can approach them more [...once] you've got that relationship with people... you reap what you sow and if you're nice, it pays dividends. [Partner thinks] like that as well, so we're liked as a couple. (Isabelle, 47, partner)

Keen to be acknowledged, Lynda and Isabelle recounted working hard to present a positive image of themselves to the transplant team, that of agreeable relatives – or co-carers - who were invested in the process and eager to learn how they could help. Strategies that they used to achieve this included: attending and preparing questions for appointments, asking questions, visibly documenting what they were told, and using humour to make others feel comfortable. This behaviour is illustrative of the way that family members performed emotion work (Hochschild, 1979) (see Chapter 3, Section 3.2.5.4 for definition) to present a positive ‘front-stage’ image (Goffman, 1959)²⁸, or ‘face’ (Goffman, 1955)²⁹, as they viewed this as integral to developing a good relationship with the transplant team and ensuring inclusion in future clinical discussions.

With the exception of interim assessments, the next time family members reportedly encountered the clinical world of transplantation was when the transplant coordinator contacted their relative about the availability of a donor organ. Most participants recounted that receiving this call was a “surreal” experience, as the following quotes illustrate:

[The day that the call came] was really kind of surreal because you, you're prepared for this for so long and you get to [the transplant centre...] you're waiting for the nod to say 'yes, it's definitely going ahead' and that's kind of, that's stressful in itself ...'cos there's a chance of life. So everything, everything hangs on that. (Anna, 48, bereaved partner)

[Getting the call] was a, a very surreal experience... we [travelled to the transplant centre and] sat in this, this ward, this room on the ward, this bedroom, all in silence, all looking at different corners of the room, you know. We didn't, didn't know what to say really and we were just in our own worlds [...] then quite quickly the process started moving and it just felt like 'yeah, this is actually happening now', you know? (Scott, 43, partner)

While receiving a call was felt to be a positive step in the transplant journey, this event appeared to constitute a source of stress for family members, particularly when their experience did not match with that which they had envisaged. Julie provided a key example of this:

[The transplant team] told us the sort of expected route to transplantation would be like we'd get a call probably tea time the night before, we'd come in, they'd be all ready, I could stay with [partner] on a night, we'd go to theatre the first thing the next morning. Give or take you know, that's not always a perfect thing. We'd get a call, it would be from [the coordinators] and then when [partner] went to theatre I could go for a coffee with [social worker] or whatever. None of that happened. Now I'm not, I'm not holding that as a tablet of stone, but... We got called at five in the morning by

²⁸ ‘Front-stage’ image refers to the behaviour the functions to “define the situation for those who observe the performance” (Goffman, 1959, p. 32).

²⁹ ‘Face’ is defined as an “image of self delineated in terms of approved social attributes” (Goffman, 1955, p. 213).

someone we didn't know...we were sound asleep. That blew us away... When I got to the hospital it was absolutely all systems go because they wanted him in the theatre by about 10.30, um and it was just mind-blowing the speed at which everything happened. (Julie, 57, partner)

Staff provision of an 'expected route' appeared to be a strategy used to prepare family members for, and reduce their concerns about, what lay ahead, however, for some it appeared to do the opposite. For Julie, the disparity between this route and her personal experience seemed to leave her feeling ill-equipped to deal with what happened, adding to the stress of this event. Another source of stress appeared to be the uncertainty surrounding whether the call would result in a transplant or turn out to be a 'false alarm' (see Chapter 2, Section 2.3.4.1 for detail on false alarms). With this uncertainty in mind, participants appeared unsure of how to respond to the call. Reports of feeling numb and experiencing a sense of disbelief were common, particularly among those who had been through a false alarm previously:

[After the sixth call] we went in [to the transplant centre] and like I say, I really, I didn't feel anything, it was really bizarre really, because I just thought 'we're gonna go home' [...coordinator] came in around about half six in the morning and said, she actually came in with a pre-medication and I just sort of looked at her in absolute amazement. (Lindsay, 52, partner)

[Son] woke us up at six to say that the hospital had called... we rushed over there ... we spent the whole day in the hospital saying, "I wish they would hurry up and send us home, for God's sake"...So when they finally said it was a go, it completely side-, completely shocked us because we never thought this one was going to work. Never. It just did not arise. (Elaine, 61, mother)

...the registrar came in at about seven in the morning, I think half seven. He said, "Oh the organ's on the way" and I think he looked, he looked puzzled as to why we weren't actually quite ecstatic. We just said, to him, "Look we've been here five times before. Until the surgeon says it's all systems go we just can't get excited, we can't believe it." (Lynda, 65, partner)

These quotes illustrate that family members can feel sceptical of the call and reluctant to believe that it will progress to transplant surgery. Such scepticism appeared to emanate, at least in part, from the emotion work family members performed to protect themselves and their relative from the disappointment of another false alarm. For some, this scepticism seemed so deep rooted that they consequently felt indifferent or aggravated about being called and the subsequent wait for the verdict regarding the viability of the donor organ.

Respondent accounts of their reaction when their relative was taken to the operating theatre revealed that family members rarely think about and plan for this time while awaiting a

successful call. It was common for respondents to note that they did not know what to do when staff left them alone:

I sort of stood outside the hospital in limbo then because I didn't know really what to do [...] I kept thinking 'well do I go home? Or do I stay here?' ...I decided to go home ...I didn't really want [to be around] anybody...had a bath, tried to sleep and just got up in the end and paced the floor really [...] It really was the longest day. (Lindsay, 52, partner)

[Staff took partner into theatre] and a nurse comes to me and she says, "Would you like to stay in a room on your-?" I thought 'I don't know what I want to do.' (Matthew, 68, partner)

Mirroring these accounts, it was common for individuals who lived relatively close to the transplant centre (<2 hour commute) to recount that they felt conflicted between the desire to stay at the hospital, to ensure they were near if something went wrong, or to return home. Most reported that they did eventually decide to return home to an environment that was familiar and offered a sense of comfort, a decision reportedly supported by the transplant team:

...I assumed I would be up there [at the hospital during the surgery]. And they've [the transplant team] said, "No, we've got to look after you as well. So we would rather you didn't [stay]. There's no point in you being here." (Isabelle, 43, partner)

[Coordinator] says to me, "Don't wait in the hospital. You live nearby, go home." (Julie, 52, partner)

Unsurprisingly, individuals who lived further afield, who had opted to temporarily relocate to on-site charity-funded accommodation or alternative accommodation nearby, did not report facing such a dilemma. However, their accounts did reveal that they struggled significantly during this time as they were often separated from their usual support network and found it difficult to relax in unfamiliar and/or clinical surroundings:

[When partner] went down to theatre, they [staff] just kind of leave you, you know, 'Oh, we'll get in touch with you when he's out of theatre'...I spent those twelve hours just pacing the hospital, I did not know what to do with myself, I didn't know where to go. I was sat outside the theatres [...] it was] absolutely horrendous. (Anna, 48, bereaved partner)

[When he was in surgery] I came out of the hospital and walked up and down the park... It was a Sunday so [the coordinators] weren't there and [social worker] wasn't there. I didn't have anybody. So I walked up and down the park. Up and down. Up and down. (Louise, 61, partner)

[When partner went to surgery son and I were] sat in a waiting room... just kind of left to our own devices in many ways [...eventually the transplant coordinators came and gave us a key to a flat] which was just, you know, what we needed at that point [...but it was] absolutely freezing cold... I didn't really sleep, waking every fifteen

minutes or so... It was a very surreal experience really. I wasn't sure what to do.
(Scott, 43, partner)

Individuals who had temporarily relocated appeared to feel a greater need for support from the clinical team while their relative was in the operating theatre than those who commuted, and thus did not necessarily appreciate being 'left to their own devices'. The light-touch approach adopted by the transplant team seemed to leave family members feeling somewhat overlooked, once again. This is concerning in light of the complex range of emotions that participants reported experiencing while their relative was in theatre. Jacob, for instance, reported struggling with the uncertainty of this experience:

[It felt like I was in] purgatory. It was purgatory...are you going to make it into heaven or are you going to be- ascend downstairs? You know basically it was, it was purgatory...it's exactly purgatory, exactly. (Jacob, 68, partner)

By drawing parallels between these two experiences, Jacob emphasised the profound sense of distress that he felt during this uncertain period of time. For some, this distress appeared to be exacerbated by the perceived lack of contact from the transplant team while their relative was in theatre. Scott and Jo recounted that limited communication during this time increased the sense of anxiety that they felt. As the hours passed with no word from the transplant team, they feared something had gone wrong:

[I was] waiting for this phone call to hear something. I woke up in the early hours, still no phone call [...] about seven o'clock... I spoke to the transplant coordinator who was mortified that I'd not been telephoned at midnight by the consultant, or surgeon, to tell us they'd done the operation and everything was fine! And um it was like, 'My God. Just my luck that no one would have phoned.' [...] That's always stuck with me [...] that niggling feeling that I, I wish somebody would have at least phoned me up and told me it was all ok, you know? Because it would have saved a lot of anxiety.
(Scott, 43, partner)

I'd been promised that, you know, they'd phone me [when the surgery had finished] and they didn't [...] I was thinking 'something's gone horribly wrong, it really has gone horribly wrong, it shouldn't be lasting this long.' [...] Actually it was ok and they just hadn't phoned me up... it was the worst three hours. (Jo, 50, partner)

Limited and/or slow communication from the transplant team while their relative was in theatre, and upon the completion of the surgery, appeared to remind family members of their lack of control over the situation and their relatives care within the transplant centre, reiterating their sense of being an 'outsider' (Becker, 1963).³⁰

³⁰ In this thesis, the term 'outsider' refers to individuals who "stand outside the circle of "normal" members of the group" (Becker, 1963, p. 15).

Above, I have explored participant accounts of their experience of the clinical world of transplantation at key pre-transplant stages. Throughout, I have outlined ways that these experiences appear to affect family member wellbeing and sense of self. Next, I present participant accounts detailing their experience within the clinical world of transplantation post-transplant. As in the previous section, I comment on the extent to which individual wellbeing and sense of self seemed to alter as a result of such experiences. Pre- and post-transplant accounts are presented side-by-side in this way to illuminate the extent to which, and in what ways, participant's experience of the clinical world of transplantation appeared to change over time, as their relative progressed, or not as the case may be, through the transplantation process.

5.3 Post-transplantation

In this section I present participant narratives of their experience of transplant centre at crucial post-transplantation stages, including 'the recovery' and after their relatives' discharge.

More often than not, the Intensive Care Unit (ICU) was the setting of family members' first post-transplant encounter with the clinical world of transplantation, with many participants recounting that they visited their relative in the ICU a matter of hours after the surgery was complete. It was common for individuals to report that they struggled during such visits, as they were not accustomed to the format and atmosphere of the ICU. For Marie, the difference between the ICU and other clinical settings was so stark that she likened it to "another world" (Marie, 50, bereaved mother). Reflecting wider qualitative literature (e.g. Engström and Söderberg, 2004; Urizzi and Corrêa, 2007; McKiernan and McCarthy, 2010), the accounts of several interviewees revealed that they found spending time in the ICU physically, psychologically, and/or emotionally challenging. Scott, for example, recounted that he struggled physically with anxiety and nausea, so extreme that he found it difficult to sit at his partner's bedside:

...I remember just going in to the, the intensive care, I was just going hot and cold, I felt really nauseous. The whole thing, with all these pipes everywhere. I don't, I don't really deal with anything like that that well [...it was a] claustrophobic sort of feeling I was getting, you know, so I just needed to get outside, get some fresh air and try and keep me stomach down really because I felt really sick and nauseous... (Scott, 43, partner)

Louise reported that she too struggled to sit with her partner, as her limited understanding of ICU technology and staff routines left her feeling distressed:

...that whole episode of going into the intensive care unit... these machines right round the walls, you're just absolutely in a panic. All these gadgets and this nurse is looking at all these monitors right around and you're afraid of talking to the girl in case you're distracting her, you know? And he [partner] was just lying there... it was awful [...] I couldn't sit there [in ICU] for five minutes without crying... it was so stressful... watching this nurse put all of this medicines into those tubes underneath him and drains and every five minutes something was beeping. So I was up a height, worrying about all this beeping... it was like torture... I just couldn't sit there too long. You know and watch it? Because the least wee movement or beeping, these things, anything just set me off. (Louise, 61, partner)

Louise's use of the term 'torture', coupled with her assertion that she exercised caution when she spoke in fear of distracting the nurses, illustrates the extent to which family members can feel stressed and anxious within the ICU. For some, this sense of discomfort was amplified by their relatives' appearance. Lindsay and Rosalynn reported feeling shocked by how lifeless their relatives looked:

[Staff had] explained everything [about ICU but] he was on life support and it was a shock. I think what shocked me more than anything was his colour, because he was so, so grey, so cold... suppose he looked dead, that's what you expect [a dead person to look like]. He was just very, very grey... that stuck in my head... I'd expected all the machines and everything but I hadn't anticipated he was going to look dead [...] his colour, and his skin sort of looked waxy sort of and I was thinking, you know, 'Oh is that [life support machine] really keeping him alive?' (Lindsay, 52, partner)

After her sister's transplant, Rosalynn went to visit her in the ICU. She found this a difficult experience, noting she looked "shocking", like she was "dead on a ventilator". Rosalynn commented that, despite her training (to become a nurse), she did not feel mentally prepared for this scene and would have appreciated more warning from the staff. (Rosalynn, 47, sister – paraphrased interview content recorded during and after the interview)³¹

These excerpts suggest that there is a significant difference between what family members expect their relative will look like after 'life-saving' transplant surgery and the reality of this experience. Several participants reported feeling taken-aback by how they felt, as they had not anticipated such a response. Katy, for example, noted:

[Mum and I went to see dad] in intensive care and that was horrible because he had all like tubes coming out of him and he was like really, really ill [...seeing him] was horrible... I thought I was gonna be fine because I'm quite good at dealing with things but as soon as I saw him I nearly burst into tears and that was, that was a shock to me 'cos I'm like very able, able to deal with things, quite strong. Um, but just having all wires attached to him and he's half-awake, um, I found [that] hard. (Katy, 24, daughter)

³¹ Throughout the empirical chapters, paraphrased notes have been used in the place of quotes for Rosalynn as technical issues prevented the capture of an audio recording of the interview.

This example demonstrates that exposure to the ICU can challenge family members' perception of themselves, as they learn of their ability to cope with scenes and sensory experiences to which they are rarely exposed. In some cases the shock that family members experienced appeared mitigated by support from members of the transplant team. Partners who attended the ICU alone, such as Louise and Lindsay, were particularly appreciative of such support:

[I have] nothing but praise again for [the transplant] team [they] are brilliant, there is no doubt about it. [Partner] received absolutely wonderful care, but they were also very good at making sure I was ok as well [...They] were absolutely brilliant... really good at keeping, telling you everything, answering all your questions [...they] treated you like, like an adult really and just, just told you the facts as they were. It was really good. (Lindsay, 52, partner)

...the transplant nurse and social worker were excellent. I, I don't know what I would have done without those two girls... if it wasn't for them ones I don't know how I would have got through it to be honest with you, especially the social worker. Like she would come every day to see me [in the ICU], and would talk me through everything. (Louise, 61, partner)

From these quotes it is apparent that, in addition to the hospital environment, interactions with hospital staff could have a significant impact on family member experience of the transplant centre, influencing it either positively – as the above examples illustrate – or negatively. Contrasting the data presented above, a number of respondents reported that they found it difficult to communicate with staff while their relative recovered in the ICU. One barrier to this was noted to be the use of medical terminology in conversations with them and other staff members within earshot. Marie, for example, recounted becoming increasingly frustrated with the use of “doctor language”, of which she had little understanding:

[Staff would say] "Her bloods are this" and "this is that" [it was] a different language... they talk in a different language. For me, every day I went in, she [daughter] just looked the same in this intensive care, she wasn't speaking and wasn't herself and they would bombard you with, "Her counts are low" or something's high or something's this or that. Just tell me what, what does it mean? You know, don't speak to me in doctor language! (Marie, 50, bereaved mother)

Similarly, Isabelle recounted feeling confused by medical terminology, and frustrated by how “stupid” the use of such terms made her feel:

[The staff] use [terms] which you don't understand but it's because it's an everyday term to them- [like] pneumothorax – I had no idea what that was [...] Even straightforward terms, are not straightforward. And then you've got to [ask what it means and] you feel stupid. (Isabelle, 47, partner)

From these examples it is possible to argue that medical terminology can be felt to prevent good communication and be perceived as somewhat exclusive by family members, as it

reminds them of their outsider status. This reflects existing health research, which suggests that the use of medical terms can confuse patients and their family (Wittenberg-Lyles et al., 2013). However, not all respondents reported finding the use of medical terminology confusing, and thus exclusionary. By coincidence, several participants worked for, or had previously been employed by, the health service and thus possessed a relatively good understanding of medical terminology. Rosalynn, for example, recounted that her nursing training meant she understood and was able to ‘translate’ terms that the transplant team used for her sister, to ensure she was fully aware of what was going on. Relatives of individuals who had been ill for a significant period of time prior to their transplant (>5 years) seemed similarly unfazed by staff use of medical terminology, as they appeared to have developed a proficient understanding of this vocabulary over time. Amelia, for example, noted:

One of the most common things I'm asked when [son is] in hospital is "Are you a nurse?" (Laughs)... you do you pick up things over the years that you know certain words do or certain tests, what's going on. (Amelia, 43, mother)

Participants in this position seemed to somewhat value the use of medical terminology as a way to efficiently illustrate their medical expertise and consequently bolster their ‘front-stage’ image (Goffman, 1959) as a knowledgeable individual who should be viewed as an ‘insider’ in the clinical setting.

As well as medical terminology, visiting rules appeared to influence the extent to which family members felt included in their relatives’ recovery. Several respondents reported struggling with the “regimented” nature of the ICU:

...the intensive care area was much more regimented [than the ward]... [staff] would control how people would move in and out and stuff and very often [visiting] times it was difficult for me because I couldn't get in there and help her, I couldn't sit with her. Or they, they'd say you, you know, you need to leave and that, that made it difficult to be more supportive... I was looking forward to when she could progress and get out of there basically because I thought, it's just hard you know. They let you in for just a few minutes and then, um, they'd say, "Oh she needs to sleep again." Which is fine but um, yeah it was just a different atmosphere entirely. (Lucy, 51, friend)

Rosalynn reported that she felt that the ICU staff were very strict about visiting hours, meaning that she was only allowed in to see her sister from 2pm. She noted that she would often go over to the hospital much earlier than this and sit in the relative’s room, waiting. Though this gave her the opportunity to meet other families who were going through similar experiences, she found sitting and waiting very difficult and often struggled to fill the time. (Rosalynn, 47, sister – paraphrased interview content recorded during and after the interview)

These quotes reveal that the ‘strict’ ICU visiting policy appeared to hamper participants felt ability to see their relative and remain involved in their care in the initial post-transplant

period. By restricting their involvement, such rules appeared to further reinforce the sense of exclusion family members felt within the transplant centre, leading them to feel more like 'spare parts' than essential partners in their relative's care.

Accounts of family members who temporarily relocated to be near to the transplant centre revealed that they were particularly susceptible to feeling excluded during their relatives' recovery, as they simultaneously felt invisible both in the eyes of the clinical team and their established social network (see Chapter 7 for detail), from who they physically separated. Scott and Anna relayed that they felt that living in accommodation on the hospital site had a detrimental impact on them over time:

You're not in your own home and you're- it's kind of normal but not normal [...] It's a very strange place to be in [...] Every day is the same you know, you get up, you go to the ward, you come home - back to the flat and you go to the ward again... there's no friends there to talk to or to catch up with. (Scott, 43, partner)

[Over time] you lose touch with reality [...] you're living in this bubble where there's no kind of contact with the outside world as such (cries), which had a real kind of detrimental effect on me [...]. It isolates you because you're going back to one room, you know and you're sat there, just you and your thoughts [...] the only people you talk to: doctors, nurses, people in the canteen, maybe the odd visitor, you know, everyone is connected to the hospital... that's all anyone talks about - hospital, hospital, death, dying... (Anna, 48, bereaved partner)

Though staying on-site allowed them to remain close to their relative, meaning they were arguably more likely to be included in their relatives care than those who commuted from home, it was recognised to have personal costs. These accounts reveal that family members can struggle with being separated from the comfort of their home environment and feel isolated from their life outside of the transplant centre. Recognising this as a risk, some participants stressed that they tried to maintain some distance from transplant centre, to give themselves some down-time:

...you need to relax and you need to get away from the hospital. You need space. I would've, I would have went crazy [staying in the charity-funded accommodation]. I would have went stir crazy [...] in that situation, you need to be away from that [the transplant centre], you need to be away. You need to be able to get out, go out of the hospital, out of the grounds. (Amelia, 43, mother)

I spoke to some families at the time who were travelling from quite a distance and they needed to stay at the hospital but I think for me it was important to go in, be fresh ...it was important for me to leave [go home] and to be fresh, and to maintain that enthusiasm for recovery. I think if I'd stayed in the hospital I would have just got exhausted and wound down. (Olivia, 49, sister)

On the other hand, however, a few participants appeared to view the charity-funded accommodation as offering exactly that: a place for them to escape the pressures of the hospital ward, without having to 'leave' their family member. Jo, for example, noted:

[Being allowed to stay in the charity flat] was possibly the single most useful thing that happened for me during the whole process [...] just having this little place I could go and crash out in because I was sleeping at very odd times. I was, you know, not able to sleep at night and then I'd come over all exhausted at two o'clock in the afternoon or something and just having this place five minutes walk down the corridor where I could, I could go and be away from other patients and you know, have a shower or cook a bacon sandwich on my own, watch rubbish television, sleep. Um, I think that was the single most useful thing that the whole kind of transplant team did for me. Umm and I did, I did share it [the accommodation] with a couple of other people while I was there and they, they said the same thing [...] it made so much difference. (Jo, 50, partner)

By providing a space in which family members could engage in routine activities, such as cooking or watching TV, on-site accommodation appeared to enable family members to achieve a small sense of 'normality', despite the abnormal circumstances. In this way, relocating to be near the transplant centre could be viewed as having a positive, rather than solely detrimental, impact on individual wellbeing.

As time passed, family members typically recounted that they spent less time at the transplant centre and interacting with the transplant team. For most this happened gradually, as their relatives' health improved and they were subsequently discharged home. At this point, family encounters with the clinical world of transplantation typically reverted back to the format that they had experienced earlier in their transplant journey: attending clinic appointments alongside their relative and conversing with the transplant team remotely, via telephone or email. Matthew summarised this, stating:

[We were told] "Well you're being discharged today you've gotta come to out-patients tomorrow" (laughs), "and at the end of the week as well." [...] what tends to happen is at the end of the outpatients we come home, we have to ring back the next day to find out the test results and whether any medication changes are to be done and um also we'll be given when the next appointment will be [...] appointments are] not so frequent now. Um, the last appointment, which was last week... was a fortnight gap and we've almost got a three week gap until we go for the next one. So they are, they are starting to stretch out. (Matthew, 68, partner)

Though family members typically reported that interaction with the clinical world of transplantation diminished overtime, respondents were aware that the nature of the transplant meant that they, as a family, remained somewhat tied to the transplant team for the remainder of their relative's life. The somewhat permanent nature of this relationship appeared to influence the way that family members behaved in the presence of the transplant team post-

transplantation, particularly their willingness to be open about negative feelings and/or experiences related to their relative's transplant. It was not uncommon for family members to report that they continued to conceal their low-mood and negative feelings (e.g. anxiety and stress) from the transplant team. Erin, for example, noted:

...They [the transplant team] just think I'm alright now. Now that he's been discharged I think they just think I'm alright [...when they ask I say] "Oh yeah, everything's fine." ...I would just say everything was fine. That I was alright. It's easier. (Erin, 49, partner)

Erin's account reveals how family members continued to perform emotion work in order to manage the impression that the transplant team had of them, and how they were coping, post-transplantation.

5.4 Chapter summary

Throughout this chapter I have presented respondents' accounts of their experience within the clinical world of transplantation, more specifically their experience of spending time in the transplant centre and interacting with the transplant team throughout the transplantation process. I have illustrated how time spent in the transplant centre was typically felt to be a stressful and anxiety-inducing period, as family members struggled with multiple unknowns, including the potential for false alarms and unfamiliar environments e.g. ICU. Spending time in the transplant centre was felt to be an emotionally draining experience for family members, as they expended a great deal of energy attempting to manage how they felt as well as the emotions of the individuals around them, including the ill relative and staff members. Support from the transplant team was noted to fluctuate throughout the process, but was felt to be particularly poor while their relative was away in theatre.³² Limited staff interaction during this time was particularly difficult for those who had temporarily relocated to be close to the transplant centre, who were thus less able to tap into their existing support network.

Several elements of their experience within the transplant centre appeared to leave family members feeling excluded from the process, including the: patient-centred nature of conversations, persistent use of medical terminology (which they often did not understand), and 'restrictive' visiting hours. To negate these feelings, some family members endeavoured

³² While this chapter has detailed a number of issues that family members reported experiencing and areas that they felt could be improved, it is important to stress that most family members appeared satisfied or happy with their experience of the transplant centre. The disparity between positive and negative data within this chapter can be explained somewhat by the well-known human inclination to remember and focus on negative rather than positive emotions, impressions, and experiences (Baumeister, Bratslavsky, Finkenauer, and Vohs, 2001; Vaish, Grossman, and Woodward, 2008).

to establish themselves as an 'insider' in the eyes of the transplant team by working to present themselves in a positive light, as a 'good' or even 'expert' carer (Mac Rae, 1998; Allen, 2000; Pickard, 2010). To do this they performed emotion work, concealing negative feelings and insecurities about their ability to care, and physically demonstrated their commitment to their relatives' care, by: dutifully attending appointments, preparing and asking questions, clearly documenting clinical advice, and exhibiting their knowledge of their relatives' condition. By spending time in the transplant centre, family members were able to develop strong relationships with their relatives' transplant team and establish a central role in their relatives care, as 'co-carers'. Maintaining this position over time was recognised to be challenging and require work. To do this, family members worked to sustain a positive face around the transplant team, by continuing to perform emotion work informed by feeling rules (Hochschild, 1979) about being a 'good carer' (Mac Rae, 1998; Pickard, 2010), such as remaining positive and prioritising the needs of the care recipient above their own.

Chapter 6. A balancing act: Negotiating the impact of transplantation on family life

In the previous chapter I explored how family members were affected by their experience of the transplant centre. In the next two chapters I move on to focus on how, and to what extent, the transplantation process was reported to affect participants' life outside of the hospital. In this chapter I explore participant accounts of family life, particularly family roles and everyday family activities. While I realise that these elements of family life interlink and overlap in many ways, for clarity purposes I address them separately within this chapter. As in the previous chapter, I present and discuss relevant data chronologically, focusing first on the pre-transplantation experience before moving on to discuss post-transplantation accounts. Throughout, I give particular focus to the affect that changes to family life had on family member relationships, personal wellbeing, and sense of self.

6.1 Family roles

All participants reported experiencing a change in household, financial, and care roles during the transplantation process. What follows is an account of the extent to which participants' roles altered from the norm as their relatives' health changed. First, I focus on participants' accounts of life pre-transplant; to illustrate how family roles can be disrupted in the lead up to the transplant. Following this, I present participants' post-transplant accounts, to illuminate the extent to which this sense of disruption can change or persist after transplantation.

6.1.1 Pre-transplantation

In this section I explore how family roles were affected by chronic illness prior to the transplant. Data from individuals whose relatives received a transplant following the rapid onset of an acute illness are not presented here (three participants excluded: Rosalynn, Jo, and Marie – see table 6, Chapter 4), as these participants did not report a significant change in family roles prior to the transplant operation.

Many participants discussed altering the division of labour within their households as their relative's health deteriorated. To preserve family functioning, respondents noted that they assumed responsibility for activities that their relative had previously undertaken but now struggled to fulfil. Partners who had previously shared practical and financial household roles

with their spouse appeared particularly affected by this change. Erin recounted that she adopted a greater proportion of household roles as her partner's health declined:

...he was going little by little, taken little by little away, um, my time at home, for doing things became bigger and bigger. I would be cutting the grass... he couldn't take the dog for a walk so I would get up early and go for a three mile walk before I went to work. (Erin, 49, partner)

Likewise, Lynda noted that she undertook the majority of the household chores as her partner struggled with exhaustion:

He never went food shopping again 'cos he just couldn't cope with wandering around the supermarket, he hadn't got the energy [...] I was actually trying to keep the household running with priorities of food on the table, clean clothes to put on, you know, clean bed linen what have you... the dog needed to be walked and whereas [partner] would take the dog or I'd go or we'd both go, he couldn't take the dog for a walk because he couldn't, he, he was so tired and worn out and frail [...] I would be taking the dog as well but only for a short walk in case the call came... sometimes I got to resent the dog, I'll be honest about it, it's just one chore too many (Lynda, 65, partner)

The amount of time that participants reported spending on household activities varied, however, it generally appeared to increase as their relative's organ failure progressed. Several participants recounted that they spent more time doing housework, as their relative became less able to contribute and their symptoms intensified. Julie noted that her partner's encephalopathy,³³ caused by his liver failure, meant that she spent more time cleaning up after him, as he struggled to control his movements:

[He lost] his coordination, so spillage. I was washing clothes, mopping up carpets (Julie, 57, partner)

Jacob's diary revealed that he assumed the responsibility for changing the bed sheets, as his partner no longer had the strength to do so:

I tried to change the sheets. "Why can't you do it right? Why can't you?" So much ointment, the sheets become greasy and stick to her body every night, gathering up in infuriating ridges that won't be smoothed... Gathering crumbs too from the day in bed. I still change them, but it had been her job in our earlier life to change the sheets and she feels ashamed that she has not the strength to do it now. (Jacob, 68, partner – diary entry³⁴)

For some couples, like Jacob and his partner, disagreements about how to do jobs 'correctly' appeared to result in tension. However, this was not the case for all. Claire provided a

³³ Hepatic encephalopathy – a disease affecting the brain - is a major complication of cirrhosis, characterised by a myriad of neurological manifestations. Symptoms include abnormal movements, seizures, disorientation, slurred speech, and personality changes (Cordoba, 2011; Mullen and Prakash, 2012).

³⁴Entry from an unsolicited diary, examined to inform analysis (see Chapter 4, Section 4.3.3.1 for more detail).

counterexample, noting that although she and her partner disagreed on how to mow the lawn, she did not feel frustrated by his attempts to direct her:

...if we do the garden, he tends to trim the edge for us and I do the lawn and I don't do the stripes right so I get wrong. So he's sitting watching, "You haven't-" (laughs). But you know so we try and help each other out that way and do things (Claire, 59, partner)

In addition to fulfilling more household roles, several participants noted that they also became the main financial provider, as their partner took sick leave or retired early from work. It was not uncommon for respondents to discuss feeling under pressure to continue earning, to ensure their family remained financially stable during the wait for a transplant. Anna, whose partner had to give up his job, revealed:

...it was really difficult... Life goes on so everything is going on while all this [transplant] is happening. You still got to keep your day job going, you still got to, bills still got to be paid and you know everything's still got to tick over. (Anna, 48, bereaved partner)

This pressure was particularly apparent in the accounts of self-employed participants, who were unable to take paid leave from work (annual or sick leave). Jacob, who ran an entertainment business alongside his partner prior to her illness, recounted that the pressure to sustain an income meant that he often had to prioritise work over providing care for her:

I had to go to work abroad... the first three months were not really too bad and so I didn't feel too bad about going away, but after that [her health] started getting much, much worse [...but] we needed to earn a living. You know we don't, we don't have savings, we have debt and we have to pay, you know, have to pay stuff so I, I couldn't stop working... it was very hard. (Jacob, 68, partner)

Though he did not want to leave his partner when her health was so uncertain, the financial pressure the couple were under meant that he felt he had little choice. This illustrates how family members can experience role conflict³⁵ in the lead up to their relative's transplant, as they struggle to balance the competing demands of household, financial, and care activities.

Partners acknowledged that adopting the role of main financial provider not only affected their capacity to fulfil other roles, such as that of carer, it could also affect their relationship with their partner. Isabelle recounted that the role reversal that her and her partner experienced became a source of tension, as he struggled to adjust to the loss of his work identity:

³⁵ Role conflict is a term that has been used to describe the difficulty individuals experience when "juggling their other roles or household activities with the duties of supporting a person with an unpredictable chronic illness" (Wingham et al., 2017, p. 5).

...he gave up work which he took badly to for the first three months. He took badly to the fact that I was at work, he was sitting waiting for me to come home from work. Initially I did not want to do anything else apart from go home from work because I thought I can't [leave him]... he was sat [at home] and I felt guilty [...] roles have reversed because I'm working and he's not, so that, you struggle with that, he does. And I have to be so conscious of it to still give him his place, if that makes sense? Um, I involve him in my job, I involve him in what I'm doing and I'll say, "What do you think I should do regarding this? What do you think? What do you think?" So he doesn't feel useless. (Isabelle, 43, partner)

Though she initially found it difficult to navigate the effect of this role change on her partner's self-esteem, over time Isabelle appeared to feel able to buffer these negative feelings by actively including him in her work decisions. By giving him a sense of purpose and influence in this way, Isabelle seemed able to ease the sense of guilt that she felt about usurping his role as the main financial provider. However, not all reported responding in this way. In contrast to Isabelle, who rose to the challenge and appeared willing to accept and manage the emotional implications of assuming this role, Lindsay recounted that she felt resentful toward her partner for his decision to retire early:

...it was only my income coming in, so there was quite a lot of pressure there as well about how am I gonna manage this? [...] I resented that he'd given up work and I still had to work and pay the mortgage and things and that's awful to, to feel that resentment, but there were times I really did resent-, I sort of said to him "Well if you hadn't smoked then you might not have triggered this off and then you'd be alright and..." So, which isn't, isn't nice to admit but I did... that wasn't fair on him, he had an illness, he didn't ask to be ill. Um, but I couldn't help feel, feel resentment at times for him being ill, really for the impact that that illness had. (Lindsay, 52, partner)

Lindsay's account reveals that family members can struggle with the assumption that they will assume the roles relinquished by their relative as their health declines, as they do not always feel willing or able to do so. Individuals in this position seemed to experience emotional dissonance (Hochschild, 1979), as their negative emotional response, anger and resentment in Lindsay's case, was felt to conflict with feeling rules associated with being a 'good carer': that one *should* feel/respond with compassion and empathy (Savulescu et al., 2006). Expressing negative thoughts and/or emotions left family members feeling guilty, as they were conscious that their situation could have a negative impact on their relative's psychological wellbeing.

In addition to changes in household and financial roles, all participants acknowledged that their roles changed to reflect their relatives' increasing care needs. Participants recounted performing numerous care-based activities (personal, medical, and emotional) for the ill relative in the lead up to their transplant. Personal care activities included tasks such as

feeding and washing their relative, as the following quotes from Julie, Louise, and Katy demonstrate:

...the year before transplant well I was definitely a carer then. He couldn't dress himself, he couldn't, he needed help in the shower and all sorts of things [...] His whole coordination went... eventually we got to the stage where he really wasn't eating, and I got to the stage where I was having to almost feed him because the hand wasn't taking food to the mouth. (Julie, 57, partner)

He couldn't shower by himself, I had to make sure I was standing, using the shower with him. Not inside the shower, I'd be standing there helping. (Louise, 61, partner)

...things like making sure he eats at the right time and um, like, making sure his clothes are clean and changing his clothes. (Katy, 24, daughter)

As well as addressing their relative's personal care needs, participants often assumed responsibility for managing their medication regimen and encouraging them to attend, or accompanying them to, hospital appointments. Anna, Julie, and Olivia provided key examples:

[I was] the driving force behind it [partner's care]. I was the one who kind of made sure he went to all of his appointments that he took all his medications, that he done everything that he was asked to do [by the transplant team]. (Anna, 48, bereaved partner)

...he wasn't really walking. We were using a wheelchair. Um, so by necessity I was with him, and going into the clinic rooms with him. (Julie, 57, partner)

He [brother] liked somebody at the appointment because he couldn't listen properly to some of things that were being said, so he needed somebody there to support him. (Olivia, 49, sister)

Visible caring activities, such as those discussed above, were not the only caring behaviours family members reported performing. Much of the care work that participants discussed within their interviews was 'invisible' in nature, meaning that it was not obvious to others, including the care recipient. One such activity frequently discussed by participants was the felt responsibility to continually monitor their relative's physical condition. Several interviewees reported that their minds became preoccupied with observing their relative's physical health, as they felt responsible for ensuring they remained fit enough for the transplant. For example, anxious that her son's condition could decline at any time, jeopardising his chance of a transplant, Elaine reported that she expended a great deal of time and energy monitoring his physical condition:

...I'm all the time vigilant, watching, [thinking] 'Is he well enough?' Because if he gets a dose of something and he gets the call, they won't do it, you know, if he gets suddenly ill they might take him off the list. (Elaine, 61, mother)

The sense of remaining 'alert' that Elaine alludes to here was also prevalent in the accounts of others, as the following quotes from Erin and Lynda illustrate:

It felt you were always on duty [...] you're just so on alert all of the time, and watching for things [symptoms]... I was living on that high anxiety. (Erin, 49, partner)

...I was always on the alert because, you know, I'd hear him move around and I'd be thinking 'Is he alright? Is he in pain? Is this gonna mean putting him in the car and a drive over to the transplant centre?' (Lynda, 65, partner)

Another, less visible, element of the care often discussed by participants involved attempts to monitor and subsequently manage their relative's emotional wellbeing. Most participants reported observing a decline in their relative's mood as they waited for their transplant.

Accounts of despondency and depression were common:

...He told me that he wanted to stop taking tablets... and just let nature take its course. Now I never thought of him, I never thought of [partner] being like that (cries)... he's always been strong. (Claire, 59, partner)

...he was very, very depressed. He very rarely left the house. (Anna, 48, bereaved partner)

...things started to kind of decline quite rapidly in terms of health. She became quite depressed... her mood began to plummet. (Scott, 43, partner)

While participants often noted that they understood why their relative felt this way, they nonetheless seemed to find their relative's changing moods concerning and difficult to live with. In light of this, a number of respondents reported seeking ways to improve their relative's mood and boost their outlook on life. Strategies used to affect this change included: taking day trips, arranging social activities, and encouraging their relative to continue working or studying. Ellen, for example, reported helping her son to continue working by taking him to, and collecting him from, his place of work every day:

...he [son] never stayed off work at all. I used to take him in every morning, and bring him back, um, partly because I feel so that if you can keep a bit of normality in life, you know, if you go on the sick and just permanently sit in a chair, it doesn't do anybody any good... it was much better for him to work. (Ellen, 74, mother)

Isabelle recounted encouraging her partner to go out to eat at a local restaurant, where the staff were aware of, and catered to, his needs:

...we still do that [go out for dinner at a certain restaurant]... he's got his little electric concentrator, they [staff] make sure we get a seat by the plug. They make sure we're not up the stairs so he hasn't got the stairs to cope with... it makes him feel normal and I think that's so important (Isabelle, 43, partner)

The underlying premise of these strategies appeared to be an attempt to help their relative feel 'normal'. One way that family members worked to do this within the home was by suggesting that their relative continue helping with household jobs, where possible. Lynda and Claire both reported that they encouraged their partners to cook, when they appeared able, as this was an activity that they enjoyed:

I used to try and spot when he was having a good day and say "Fancy cooking a steak for tea tonight love?" you know "Yeah, ok." Sometimes by the time he got there he was failing and struggling and so I'd say "Well you do the steak and I'll do the vegetables." It was anything to try and keep him engaged with life because it was closing down all the time. (Lynda, 65, partner)

...the only pleasure now he's got is like going in the kitchen and pottering and doing his own thing and I think if I take that off him as well, what else has he got? [I can see him] sit down, panting, "Do you want a hand?" "Um-hm." Then I'll go and give him a hand but I will not purposely go in the kitchen and interfere because I think, well if he's enjoying himself [himself] then he's alright. (Claire, 59, partner)

By responding in this way, participants appeared to be working to negate the disruptive impact of illness upon their relative's sense of self (Moore and Gillespie, 2014). In addition to encouraging their continued involvement in everyday activities, participants often also appeared to manage their relative's emotional wellbeing by engaging in emotion work (Hochschild, 1979). It was not uncommon for respondents to discuss concealing negative emotions, such as anxiety, fear, and resentment, from their relatives. Jacob and Erin provided key examples:

I obviously couldn't show her that I was terrified. Her whole approach was to be positive, so I was being positive too. We were both hiding stuff from each other like nobody's business. I mean basically we both wanted to sit down shuddering and wailing but that's just not on really is it? Well it certainly doesn't help. (Jacob, 68, partner)

...I slept in the other bed and I found that quite useful... because I could be emotional where he wasn't, without him knowing. So that was quite beneficial [...] before it would be in the bath, I would go in the bath to cry [...] it's the safest thing to do I think. I don't cry in front of him [partner]. (Erin, 59, partner).

Erin's approach of suppressing her emotions until she was alone in the bath is reflective of strategy reportedly adopted by family members caring for a relative with dementia (Mac Rae, 1998). One of the prime motivating factors for controlling displays of emotion in this way seemed to be a desire to ensure that their relative did not feel guilty about the wider implications of their poor health. Claire noted she was reluctant to cry in front of her partner, as she did not want him to feel burdensome:

...I don't like to talk to him about it [emotions]. That's why I would never do this [cry] in front of him, because I couldn't because I don't want to burden him with thinking that maybe he thinks he's a burden to me. (Claire, 59, partner)

Though the tendency to conceal emotions from the ill relative was predominantly apparent within the accounts of partners, other family members also described trying to mask how they felt in the lead up to their relative's transplant. Katy, who lived some distance from her family during her father's transplant, reported hiding feelings from him, and other family members:

It [the transplant] wasn't something that we discussed. When we were all there and together we tried to focus on like more positive things because I think everyone worried about it individually [...] I wouldn't discuss it [feelings] with my mum. I think 'cos I suppose my mum or my dad realising that I was really upset, then they'd be even more upset and even more stressed with the situation [...] the emotional side of things I didn't, I wouldn't have discussed with my brother because I think that would make him worse and more worried. (Katy, 24, daughter)

These quotes illustrate that family members often incorporated emotion work (Hochschild, 1979) into their care role, concealing negative emotions from their ill relative and other family members, to protect them from the reality of how they were feeling. This behaviour appeared to stem somewhat from a desire to maintain face (Goffman, 1955) as a strong individual, able to cope with the situation. For Katy this seemed particularly important, as she seemed concerned that if she appeared to be struggling, her parents may start withhold information from her in an attempt to protect her from further emotional distress. It was relatively common for participants to report hiding information from those deemed to be 'fragile' in this way, typically children and elderly parents, as demonstrated below:

...we didn't tell his father or my mother, who was still alive at the time, because they were both quite elderly and we hoped they would never have to know [about the transplant]. (Lynda, 65, partner)

...we've kept a lot of things from the girl's [granddaughters] and especially the eldest gets so angry that we're not telling her anything... I'm just like piggy in the middle here because I know [daughter] doesn't want them to worry but at the same time they don't want to be kept in the dark so it's a bit of a dilemma in that respect really, especially with the eldest. (Evaline, 67, mother).

I didn't tell my sons much... before we [partner and I] just used to get on with it together and not involve them. To the fact that when he went in for his transplant I told the eldest son, I says, "Y'Dad's got the call he's going in. Are you coming?" He say's "Oh I'm going to work." I says, "Well you do realise this may be the last opportunity you'll get to see him, you know, he could die?" He goes, "Oh right!" ...I don't think [he understood], because, we kept it really to ourselves. (Erin, 49, partner)

Though the decision to hide information was made in the best interests of others, it could prove problematic at times. Evaline's account reveals that this decision could have a

detrimental effect upon family relationships, generating feelings of anger and resentment at being “kept in the dark”. Likewise, the quote from Erin suggests that downplaying the seriousness of the situation from others within the family could backfire on occasion, as it meant that they were not aware of, and thus did not respond as expected, during times of need.

Several participants stressed that their involvement in personal, medical, and emotional elements of care fluctuated over time, to reflect their relative’s non-linear deterioration and their own personal circumstances. Respondents often noted that they did not necessarily need to provide all elements of care at any one time; they may be providing emotional support but not medical care, for example, and vice versa. Stressing the variability of the care role, Elaine noted:

[Caring is] seen from the outside as being just one hat, but I think in our situation it’s a multiple of hats that we [partner and I] take on and off, um, as the situation arises and, and depending on his [son’s] health. It depends on what we’re seeing as benefit.
(Elaine, 61, mother)

The fluctuation in their care role meant that family members traversed back and forth between the identities of ‘carer’ and ‘family member’, never fully identifying as one or the other. Balancing their ever-changing care role, and its visible and invisible components, alongside other responsibilities (household, financial, and/or parental) was acknowledged to have personal costs. Several participants reported that their wellbeing, physical and psychological, suffered as they attempted to stretch themselves between competing obligations. To manage this, some sought professional help pre-transplantation:

I got very tired... I was ploughing on through it and I thought 'no, I'm not coping' so I went off to see the GP [...] He [partner] felt guilty and he felt bad because I was tired. He felt very angry and upset when I went back on the medication [anti-depressants] because this whole process was doing this to me. (Lynda, 65, partner)

Like Lynda, Lindsay and Amelia also revealed that they visited their GP and were prescribed anti-depressants pre-transplantation. This illustrates that role change, alongside other elements of disruption, can challenge family members’ ability to cope, increasing their support needs during the wait for a transplant.

In this section, I have presented ways in which family roles can be disrupted and are adjusted as the family wait for a transplant and the impact of this on family member wellbeing,

relationships, and sense of self. Next, I explore post-transplant accounts to determine the extent to which family roles are able to return to 'normal' following a transplant.

6.1.2 Post-transplantation

In this section I explore the extent to which, and in what ways, family roles were felt to change in the post-transplantation period, and how family members responded to this change. First, I explore participants' accounts of providing care for their relative following their transplant, before presenting changes in household roles.

All participants acknowledged that they devoted a significant amount of time to the care role in the month following their relative's transplant, as they supported them in their recovery. Respondents reported undertaking a range of personal, medical, and emotional care activities while their relative was hospitalised, and at home after their discharge. Though their relatives were receiving medical care from staff while they were in hospital, most interviewees said that they still felt responsible for much of their personal and emotional care needs. Several participants reported that their relatives did not let the ward staff wash them, and thus this job fell to them, as the following quotes illustrate:

He [partner] wouldn't let them [staff] clean him or anything like that. He found it really difficult using a commode... it took me ages to get him over that. He was so reliant on me, so reliant on me. (Anna, 48, bereaved partner)

At her sister's request Rosalynn took over much of her personal care from the nurses, such as washing and changing. The nurses relaxed visiting hours to allow Rosalynn to care for her sister in this way. This continued for a couple of months, until her sister was transferred to another hospital. (Rosalynn, 47, sister – paraphrased interview content recorded during and after the interview)

He [partner] made me go into the [ward] shower with him and he sat on the seat while I washed him. (Louise, 61, partner)

Some acknowledged that they felt responsible for providing the majority of emotional support. Lucy summarised this by stating:

...as much as the hospital staff could help and support in their professional roles, the, the kind of real nurturing had to come from someone like myself or family member, because they would be the ones who would have to pick-up if [friend] was feeling depressed or if she was crying or, you know, struggling with her body. (Lucy, 51, friend)

Family members, and friends in the case of Lucy, typically reported being heavily involved in the care of their relatives while they recovered in hospital, thus it was not the case that all of their relative's care needs were fulfilled by hospital staff. They felt the need to be present at

the hospital during their relative's recovery, which often meant that the care role took precedence over other roles that had previously been central in their everyday life. A prominent role that participants appeared to struggle to balance alongside their care role was that of parent (to children who were not the organ recipient). This was particularly prevalent in the accounts of respondents who stayed near the transplant centre, rather than at home with their children, in the weeks following the surgery. Amelia, Lucy, and Rosalynn all discussed the challenges of this:

...although we're not far away [from home], it's [the transplant centre] not home you know? It feels far when you're, when you'd like to just run and give your kids a cuddle. (Amelia, 43, mother)

I'd get phone calls from my daughter and she'd be like, "Mum I want you to come home! I miss you, I want you!" So, you know I keep telling her, "It's only a few more days, it's alright. It's gonna be a few more days." So the pressure was intense for, for me because I was obviously committed to [friends] situation, I wouldn't, I wouldn't let her down but um, my own home, you know things at home were obviously a little bit topsy-turvy as well because obviously me being gone and everything. So yeah it was really, [a] very, very intense time. (Lucy, 51, friend)

Rosalynn reported that she found the whole process very exhausting and struggled with how segregated she felt from own life while staying near the hospital. She found it particularly difficult to be four hours away from her son, aged eight. Though she tried to keep in touch as much as possible, she recognised phoning was not the same as being at home. Rosalynn noted that her sister expressed deep guilt about "taking her away" from her family, feelings which she appeared to struggle to manage. (Rosalynn, 47, sister – paraphrased interview content recorded during and after the interview)

These quotes illustrate the internal battle some participants experienced when their felt need to care for and support their relative began to conflict with other roles within their life. This role conflict appeared to result in feelings of guilt, for some, as they struggled with not being able to devote as much time and energy to other roles to which they felt committed, such as parent (as the above examples illustrate). This sense of guilt was also reported in relation to roles outside of the family, such as employee, as the following quote from Lindsay illustrates:

I did worry a lot about having time off to look after him...the social worker in hospital said 'see your GP and you'll be signed off sick', which is fine but I felt really guilty because I don't like taking sickness absence, unless I'm actually sick, and it wasn't me that was actually sick. (Lindsay, 52, partner)

Lindsay's eagerness to distance herself from the 'sick role' (Parsons, 1951)³⁶ appeared rooted in a strong desire to maintain 'face' (Goffman, 1955) within her work environment, as a hard-working and committed employee.

After their family member's discharge, most participants reported that they continued to fulfil the role of carer. Several respondents noted that the intensity of this care role took them somewhat by surprise, as they had given little thought to life post-transplantation prior to the operation:

I hadn't anticipated how tiring it would be when he came home; I was so focused on the transplant... [Afterwards I] was taking him to the GP, I was also having to help him shower, I was helping to empty that drain... I was doing the dressings [...] every day was taken up... I had to learn the pill regime and get to know that and by the time I'd helped him with the shower, checked the pills, done the GP run or gone up for more medication or taken him up to the nurse [... I was] thinking 'I am absolutely shattered.' (Lynda, 65, partner)

I didn't expect to feel this tired [after the transplant] but I really am... [Partner] is extremely weak. [I'm] Trying to hide my fear. Smoking too much. Sweating with the work. (Jacob, 68, partner – diary entry³⁷)

These accounts illustrate the high volume of care-based tasks family members faced in the aftermath of their relative's transplant, and the potentially detrimental impact of this upon individual wellbeing. In addition to the physical burden, several participants discussed being affected psychologically by the responsibility of caring for their relative at home after their transplant, recalling moments they felt anxious or stressed. Louise recounted worrying over her partner's medication regime:

He [partner] couldn't do his pills. I had to do them for him. He just didn't, didn't know about it... they were an absolute, and I'm not exaggerating, it was that size [motions with hand], and I was terrified of getting these things wrong, you know? (Louise, 61, partner)

Scott reported that he became very concerned about keeping his house clean, to ensure his partner did not contract an infection:

[I] really went to town with the cleaning, I was cleaning every day... all the different floors of the house. We've got a three storey house, like an old house you know, takes a lot of cleaning and mopping, sterilising all the work surfaces. So that kind of went a bit overboard, tubs of hand gel everywhere, you know, the alco-hand gel. (Scott, 43, partner)

³⁶ The sick role is a status that gives individuals certain rights and obligations, including: 1) the person is not responsible for assuming the sick role, 2) the sick person is exempt from performing some or all of their 'normal' social duties (e.g. work-/family-related), 3) the sick role is a temporary phase; individuals must try to get well, and 4) to get well, individuals need to seek and accept appropriate medical care. (Parsons, 1951).

³⁷ Entry from an unsolicited diary, examined to inform analysis (see Chapter 4, Section 4.3.3.1 for more detail).

Similarly, Olivia reported that her mother, Ellen, became more fastidious about keeping the house clean:

Mam and dad's house is always clean anyway, but I think my mam, even more so, needed to scrub everything, nothing lying around, no dust, everything behind closed doors, nothing on benches. Everything had to be just *so*, because she wasn't going to risk any infection. (Olivia, 41, sister)

For some, this anxiety appeared to be rooted in how dependent they felt upon the transplant team and the perceived safety of the transplantation centre. Lindsay, for example, expressed that she felt anxious about leaving hospital and being solely responsible for her partner's care:

...you're worried that you haven't got the back-up of the medical team. Even though they're only on the end of a phone, it's all new and you don't know what to expect in terms of-, although they tell you all the signs and they educate you both when you're in hospital about what to look for and the signs to be concerned about and things-, um, you're looking for every little thing. If he sneezed it was like [gasp] "Oh, do you think you're getting a cold? Do you think that's it now?" ...I get anxious about things now that in the past would never really have bothered me. Um, and that's carried on even though it's about 18 months since transplant. (Lindsay, 52, partner)

The enduring uncertainty surrounding her partner's health meant that Lindsay felt compelled to continue monitoring his condition for some time after his transplant, in a similar way to how she had done prior to his surgery. This suggests that the pressure that family members feel to monitor their relatives' health does not necessarily diminish following the transplant surgery. Indeed, Julie recounted that she was still monitoring her partner's wellbeing more than four years after his transplant:

...now [four years on] it's not personal care. It's monitoring discretely his wellbeing. (Julie, 57, partner)

As indicated by this quote, the care activities undertaken by family members were noted to change over time. Most participants acknowledged that as their relative became stronger they began to take responsibility for their own care:

[He keeps saying] "... I can go and get my own medication I don't need you to go and pick it up for me." So the pressure was lifted in that I didn't have to do all [...] Eventually, I suppose around March time after transplant, he said "I'm perfectly capable of going to clinic on my own, you don't need to come with me and hold my hand anymore." So I stopped going. (Lindsay, 52, partner)

Likewise, the volume of household duties that family members were required to fulfil typically decreased over time as their relative became stronger and able to resume their domestic responsibilities. Later in her narrative, Lindsay recounted that her partner was keen to contribute to household roles following his lung transplant:

[He did] the cooking and things and starting to potter around doing bits of housework and things, and wouldn't let me iron and things I thought 'this is great, I'm all for this!' (Lindsay, 52, partner)

Jo, too, noted that her partner was quick to resume household chores, such as cooking, only a couple of months after receiving a liver transplant:

[Partner] has got stronger and started doing stuff like housework and cooking... and really likes doing that [cooking]... being able to pull their own weight. (Jo, 50, partner)

While some, like Lindsay, appeared relieved as their care duties diminished and household roles returned to 'normal' over time, others reported struggling with their relative's growing independence and the impact that this had upon their everyday life and sense of self. This was particularly prevalent within the accounts of mothers, who had been providing care for their child for a significant period of time prior to their transplant surgery. Amelia, for example, recounted that she felt a sense of loss as her son's health improved and he no longer appeared to rely on her:

...as he started to feel a lot better, it's nearly like withdrawal symptoms you know? I don't know what to do with meself, you know? [...] I wouldn't call it a need or an addiction- but it's just it [caring] was always something that was part and parcel of our routine. There wasn't a day went past when I wasn't having to do something medical or clinical [...] I'm a bit lost because we'd spent all his life running, and it was mainly me, running to and from the hospital and clinics to appointments and out-patients [...] you don't miss it, you definitely don't miss it but there's definitely a void. There's definitely a void from what you, what you're used to doing [...] it's a big change in your life [...] it's been wile [very] hard for me to let go. He wants to be so independent and things like that, very, very hard. Even tomorrow's clinic, I'll be there but in the background - it's horrible (laughs)! (Amelia, 43, mother)

Elaine also reported struggling to negotiate the change in her carer role as her son began to lead a more independent life:

Like there [son] came in the door, flying in the door, got that bicycle out, now he hadn't ridden a bicycle since he was 12, right? ...Should I be worried? (Laughs) I don't know (laughs). But can I get into the car and drive behind him and make sure? Where, where does my role as carer, caregiver sit on that? [...] When do you step back? When do you stop saying, "Have you taken your medicine?" All of those things [...] I've been caring for [son] for the last 20 years... I suppose my priorities will always be for his health and happiness. In so far as I can for him, for as long as I can. (Elaine, 61, mother)

Reflecting wider literature in transplantation and other care contexts (Ullrich et al., 2004; Bray et al., 2014), mothers seemed to particularly struggle to relinquish the role of carer after their child's transplant as they were habituated to devoting the majority of their time to

meeting their child's care needs. However, interview data revealed that this struggle was not specific to mothers. Some partners and siblings also reported experiencing a sense of loss as their care duties diminished. Jo stated that she found it difficult to adjust to her partner's recovery and growing independence, as the carer role had given her a sense of purpose during a difficult time of unemployment:

[Caring] gave me a kind of purpose because it gave me something to do that was positive, rather than sort of sitting around and being emotional... having [partner] to look after gave me, I mean it absolutely gave me purpose. There wasn't any room for anything else [...] I had to take [partner] everywhere. So I was very much a carer at that point which I'm not really now. I mean [partner] went off to work on a bus (laughs), which is great, it's great but it also makes me feel slightly pointless. (Jo, 50, partner)

Rosalynn appeared similarly saddened that her sister no longer sought her support as her health improved:

Rosalynn stated she is less involved in her sister's care now than she was while she was hospitalised. Though Rosalynn was keen to continue attending the assessments, her sister now takes a friend with her. Rosalynn finds this difficult, noting she "hates" not being there and that she is "jealous" of her sister's friend. (Rosalynn, 47, sister – paraphrased interview content recorded during and after the interview)

These quotes reveal that family members can experience emotional dissonance (Hochschild, 1979) as their relatives recover and regain their independence. While they typically experience emotions that are socially expected in response to recovery, such as happiness and relief, they can also feel low about the impact of their relative's recovery upon their care role. For some, including Amelia, Jo, and Rosalynn, it was clear that the role of 'carer' had become a valuable, positive part of their identity and that the loss of this role affected how they viewed, and felt about, themselves as life returned to 'normal' following their relative's transplant.

As well as the carer role, family members also acknowledged that they were conscious of what their relative's recovery meant for the household roles they had grown accustomed to. While some appeared keen to allow household roles to revert back to 'normal', others acknowledged they were reluctant to relinquish certain responsibilities. Louise, for example, stated that she was adamant her partner would not resume control of all the household roles he had held prior to his illness, as she no longer wanted to be dependent on him:

[When he became ill] I had to take over. You know, you just, you just have to. And even the kids said, "I don't know how you did that Mummy. Did you do that on your own?" You know, stupid things, you know, but it's because he did *everything*. And I

just let him, you know. I'd never do that again, believe me. Never do that again.
(Louise, 61, partner)

This example demonstrates the transformative potential of family illness, which has previously been documented in studies exploring personal and familial implications of poor health (Carel et al., 2016). By disrupting their usual roles and routine, illness can offer family members unique insight into the structure of their family life and how amenable it is during times of change. In doing so, it can provide individuals with an opportunity to reassess the workings of their family unit, to ensure it is robust and able to cope with their relative's uncertain future health.

Not all participants reported that family roles eventually returned to 'normal' post-transplantation. Some family members reported that though they hoped to re-establish 'normal' family roles post-transplantation, this had not happened as their relative was not willing or able (physically/psychologically) to resume certain household roles. For example, Julie noted that, four years after her partner's transplant, she continued to do a number of household chores that had previously been 'his':

...there's all sorts of things he used to do in our marriage, things he would take care of, and I notice more and more now, there's things he leaves to me [...] in the past four years I've realised how dependent my husband's become on me. Um, there's been a loss of confidence since transplantation. So there's an initial relief that you're living, that you're going to be able to do some degree of normal again, you're going to be able to do some of the things, many of the things you did before. But equally I think there's been a loss of confidence about things he was confident about doing before, now I notice he doesn't do. (Julie, 57, partner)

Julie's account illustrates that the physical and/or psychological effect of living with a transplant can mean household roles remain changed for some time, meaning roles that were originally believed to be temporary became a more permanent part of their life and sense of self. This shift can have significant consequences for family member's envisaged future life (Barken, 2014; Aasbø *et al.*, 2016), leading them to experience biographical disruption (Bury, 1982) (see Chapter 3, Section 3.3 for definition).

6.2 Everyday activities

In this section I present ways in which everyday family life can be affected in the lead up to, and following, a transplant. I use the term 'everyday activities' to represent a combination of family-based activities that were considered part of 'normal' family life by participants, such as the ability to: go shopping, dine out, and take day-trips or foreign holidays.

6.2.1 *Pre-transplantation*

Below, I explore the extent to which family members' ability to participate in everyday activities was affected by their relative's health, and the limitations imposed due to transplant waiting list policies and practices (see Chapter 2, Section 2.3.3).

All participants reported that changes in their relative's health disrupted their ability to plan and engage in everyday activities, with and without their ill relative. Activities with a physical element, such as shopping and going out for dinner, proved particularly challenging to engage in as a family. Those living with the ill relative appeared to feel most restricted by this, particularly partners:

I would leave him parked in a seat [near the shops] because he didn't have the energy to walk around and I would run into a shop and come back, "Are you alright?" Run to another shop and he would say, "Just take your time" but I, I couldn't do that. (Erin, 59, partner)

...we had a little walk around [local park] and he managed to walk a bit further than he should have done [...the next day] he was really tired, he was really, really tired and he just didn't want, he, he wanted to go out but he couldn't, physically he couldn't and we just spent the day at home [...] all of the things that we used to like doing, he's been restricted. (Claire, 59, partner)

...we used to go into town, have lunch on the outside of town, then get the taxi in, few drinks in two wine bars and that was what we did. And we loved doing it. Didn't drink a lot, we just liked the fact we were in the centre of town, talking to people and it would be the same people and they'd come over and talk to us and we can't do that anymore. (Isabelle, 43, partner)

[We] went from being, us having a normal life to him being, you know, so restricted and basically housebound [...] every time we left the house we had to take so much stuff with us... it was just such a palaver. We couldn't do anything social really. Couldn't just go into a restaurant, you know, 'cause he needed all his oxygen and everything and then you'd have to make sure that you had a seat near the door um, because you know he would get claustrophobic because there's not natural air, you know? So, couldn't go to the cinema, or anywhere where there were loud, large crowds or... It was, just, didn't really have much of a life. (Anna, 48, bereaved partner)

[Encephalopathy] has a profound effect on your family life. We couldn't go out. We couldn't stop in restaurants or at pubs. (Julie, 57, partner)

That these individuals felt increasingly restricted by their partner's poor health is perhaps unsurprising given the entwined nature of partner's lives. Though they themselves were not physically limited, their accounts reveal they were living a less active life, largely restricted to their home, in order to tend to their relative's needs. This is reflective of other studies conducted on care in other contexts, including studies on caring for the chronically ill and those receiving palliative care (Payne et al., 1999; Eriksson and Svedlund, 2006). This sense of restriction appeared to have a detrimental effect on family members' sense of self and psychological wellbeing, as they felt less able to engage in activities (independently and/or alongside their relative) that had previously been integral to their identity and thus struggled to achieve a sense of personal fulfilment. Elaine passionately articulated this:

I want to get on with my life, where's my life? [...] I feel my life is getting more and more restricted with him... because I'm not working, I'm here to collect him. I drop him to college, I collect him from college [...] It means I'm sitting here waiting for him to come home, and what am I doing with my life in the interim, you know? ...how can I turn around and do study when I have this hanging over me? I just can't! I don't have the resources. (Elaine, 61, mother)

As her son's health deteriorated, Elaine's life became increasingly focused on helping him maintain a 'normal' routine, leaving her with little time and energy to invest in activities that she had previously enjoyed. This case illustrates that family members can, in a sense, become as restricted as their ill relative as they prioritise their relative's needs above their own.

Though this sense of restriction is known to be common within all caring experiences, family members living with, or providing care for, relatives awaiting a transplant are arguably restricted to a greater degree, as they also have to adhere to the limitations imposed due to transplant waiting list policies and practices. Two conditions that appeared to exacerbate this sense of restriction were: the need to be contactable at all times, and within a commutable distance of the transplant centre. The former requirement meant respondents were cognisant of maintaining good telephone coverage. Issues with network coverage, particularly concerns surrounding signal 'black-spots', appeared to worry most participants and influence the extent to which they felt able to visit new places. Lynda, who lived in a rural area, noted that this affected her ability to go out for meals:

...if you wanted to go out for lunch somewhere, um, I'd have to ring the place before and say "Can you get a mobile signal inside your pub, your restaurant?" and if they say no... you think no [...] it just got a bit irritating. I just, I wanted to take him out

for lunch for his birthday, where can we go? All these restaurants "oh we haven't got a mobile signal", "no we haven't got signal"... (Lynda, 65, partner)

Similarly, Erin reported feeling anxious about visiting places that she knew had poor coverage, such as shopping centres:

Being on call... sometimes I felt angry [about it and that] our lives had changed that much. That you couldn't go anywhere, you couldn't go out of [phone signal range], you know, if we went to the [shopping centre] sometimes you can't pick a signal up, so that causes you anxiety. (Erin, 49, partner)

These quotes reveal the frustration that family members felt as a result of how small their world became as they sought to remain in areas with good telephone network coverage.

The necessity to remain within a commutable distance of the transplant centre also appeared to exacerbate the sense of limitation participant's experienced while waiting for the transplant. Several respondents recounted they felt less able to plan family holidays abroad:

...we can't leave to go away on a holiday or anything, because we have to be here for his transplant and that has been so difficult on us... the idea that you cannot go away. Now technically he could come off the list and, um, we could go off, but we can't take that chance. (Elaine, 61, mother)

[We used to] go abroad all the time. We used to do long weekends [partner] misses that. He misses going away... of course we can't go that far... There's no point in him coming off the list just to go on holiday, I can't see the point in that. (Isabelle, 43, partner)

It was common for participants to note that they felt it was too risky to suspend their relative from the waiting list in order to go on a holiday abroad. Reluctant to plan foreign holidays, several respondents recounted arranging breaks closer to home as an alternative, with the proximity of the transplant centre in mind. For example:

...we went away in a caravan to places that were within sort of an hour and a half of the [transplant centre]. Just in case. So we went over to the [caravan park] and things, so we did do things, we did try and carry on as normal as we could. (Lindsay, 52, partner)

...we managed to get a few days to [the seaside], because obviously you can't travel too far. You've gotta be within a certain amount of miles in case you do get the call, so we just decided to go to [the seaside] for a few days. (Claire, 59, partner)

Other participants reported taking trips to national parks or holiday resorts relatively close to the transplant centre. Indeed, Evaline noted that her daughter received her successful call while they were on a family holiday at one such resort. Only one participant recounted planning and embarking upon a foreign holiday during the wait. Cognisant that this may be

their last chance to travel abroad and make memories as a family, Scott noted that he and his partner decided it was worth suspending her from the waiting list to take their son on holiday together:

...we did, you know, make the decision to go back to America and we just came off the list for two weeks and just went. Spent the whole two weeks really, um, trying to fill our head with some happy memories... (Scott, 43, partner)

This deviant case suggests that families do not unequivocally prioritise the transplantation process over the perceived needs of the family during the wait for a transplant. To an extent, this behaviour can be interpreted as an attempt to manage the ill relative's identity, by focusing on aspects of their identity independent of their poor health. By continuing with their family tradition of an annual trip to America in spite of his partner's illness and position on the waiting list, Scott and family appeared to place his partner's familial identity - of wife and mother - above her identity as an ill person and prospective transplant recipient.

6.2.2 Post-transplantation

In this section I explore the extent to which participants felt able to resume everyday activities after their relative's transplant surgery. As in the previous section, I consider both the impact of their relative's health, and limitations imposed due to transplant policies and practices.

In the initial months of recovery, clinical expectations (guidelines and/or stipulations) appeared to influence participants' willingness to plan and participate in everyday activities, in particular the necessity to attend regular clinic appointments. Matthew reported that he initially struggled with the regularity of these appointments:

...we had not been pre-warned about how often you would have to go to outpatients at first. We'd had various talks on what you can and can't do and what to expect and all the rest of it, but not [about outpatients...] that created difficulties...but we got round them. (Matthew, 63, partner)

Ambiguity surrounding the scheduling and duration of these appointments meant family members often struggled to plan ahead. Most participants, Matthew included, reported that the impact of this waned over time, as the number of appointments lessened in line with their relative's recovery. Participants reflecting on clinic appointments a number of years after the transplant did not appear to view them as disruptive to everyday life, rather a key part of it:

...the clinics, him coming to clinic, we are used to a routine. We know what we're doing... it's just routine. It's one of them things that has to be done. (Amelia, 43, mother)

This illustrates the extent to which elements of the transplantation process can become part of a 'new normal' established by family members following the transplant surgery.

Uncertainty surrounding their relative's future health was a cause of concern and affected how willing they were to plan and participate in everyday activities after their relative's discharge. Such concern was particularly apparent in the accounts of those whose relative had struggled to recover from their transplant surgery. Isabelle, whose partner had experienced a particularly turbulent recovery, noted:

...we've planned nothing because I don't want to. So- [partner] keeps saying, "Get a cruise booked!" I'm like, "No, no. No, no, no. I want you home and know you're ok. I don't want to tempt fate." I don't [want to plan]. Because you just sort of start to pick up and then there's something else. (Isabelle, 43, partner)

Participants' continuing uncertainty surrounding their relative's health appeared to influence their willingness to plan and participate in everyday family activities post-transplantation, as they felt unsure of what was achievable or how these activities may compromise the recovery process. While for some, like Isabelle, this uncertainty seemed to be rooted in their relative's poor recovery, for others it appeared to stem from personal concerns regarding their knowledge of their relatives 'new' condition. A number of participants appeared anxious that they no longer knew enough about their relative's condition and thus would not be able to identify, or know how to respond to, any issues. Erin, for example, stated:

...he hasn't got the same illness, I don't know what to expect, I don't know what to look for. And he was never very good at telling me if he was bad [in pain]. (Erin, 49, partner)

This anxiety was particularly prevalent in the accounts of family members whose relative had a transplant after a long-term chronic illness, such as Elaine, who cared her son for over twenty years prior to his heart transplant:

I had, now, no way of judging how sick he was, because this was, this was we were in the Garden of Eden and I had no way of knowing how sick he was. I couldn't judge! Whereas beforehand, I knew all the symptoms of heart failure, I knew all the things [...Now] I could not tell if he was sick or well, I didn't know what I had fallen in to, I felt like I had fallen in to some rabbit hole, into an alternative universe and I [did not feel] able for this. (Elaine, 61, mother)

As these accounts illuminate, family members can feel troubled by the sudden change in their understanding of their relative's health state. This felt loss of expertise appeared to affect how participant's confidence in caring for their relative, which in turn seemed to compromise their ability to relate to their 'carer' identity, thus altering their self-perception. The implications of this shift in one's perceived understanding upon family member's resilience and ability to

cope have been documented in other research contexts, for example studies conducted with those caring for relatives with mental health issues (Wilkinson and McAndrew, 2008).

Most participants acknowledged that over time they became able to participate in many everyday activities that they had previously enjoyed, as life returned to 'normal'. Amelia recounted she became more socially active as her son recovered from his transplant:

...he is more active now than he has ever been... I'm not worried about him as much [...] I didn't have a social life [before his transplant, but after] I actually joined a boot camp through Facebook, a boot camp! And I done running at a boot camp... [and the other night] I went to the cinema with a couple of the girls [friends]. (Amelia, 43, mother)

Others reported that they had been able to plan and go on holidays as their relatives' health improved:

...we've been away and there's been no ill effect and we've been away twice and she's really, really enjoyed it. And it's just kind of brought us back to some kind of normality in many ways because its things we used to do all the time without even thinking about it, you know? (Scott, 43, partner)

...we've had a few holidays [since the transplant]. We went to Thailand last year... that was our philosophy, we had to live and enjoy our lives. (Erin, 49, partner)

However, not all respondents felt able to resume their previous lifestyle. A number of interviewees reported that their relatives' on-going physical and psychological issues meant they were unable to plan and participate in the everyday activities that had previously been central to their 'normal' life. Jacob recounted that his life had become restrained in the year following his partner's transplant, as she continued to struggle with how her life had changed:

...now we're trying to hide away from everyone because, because everything has changed so much [...] She's still hugely worried about everything... she's really stiff, her body's sore, she you know- it's really hard for her [...] She can't drink and um, she can't really party [...] we've definitely become more insular. Definitely [...] She just wants to go and hide and lie in and um cry to be honest some of the time... now I tend to go out to the pub for a meal by myself and she'll stay at home and that's bloody horrible because, you know, we love each other. (Jacob, 68, partner)

Similarly, Julie reported that her partner's confidence remained low four years post-transplant, affecting her ability to visit her elderly mother or take day trips without him:

...things he was confident about doing before, now I notice he doesn't do them unless we do them together. Um, I notice that sometimes when I'm out of the house and I might say, "Taking my 90 year old mother to see someone, I'll be an hour." It turns into three hours, she wants to go to the shops on the way home and when I get home he's quite, um, what appears to be angry and maybe a bit resentful but I, I actually think that's loss of confidence. (Julie, 57, partner)

These quotes illustrate that family members can continue to feel as though their life is limited after their relatives' transplant surgery. While Jacob's sense of limitation appeared to be rooted in the fact that he was no longer able to do certain things with his partner, Julie's sense of restriction stemmed from feeling guilty about doing things without her partner. For both Jacob and Julie, the felt or actual constraints upon their ability to live a 'normal' life appeared to have a negative effect on their relationship with their partners.

6.3 Chapter summary

Throughout this chapter I have discussed some of the main ways family life is affected during the transplantation process. In the lead up to the transplant, family members adopt greater and/or new roles, as their relative's health deteriorates and they become less able to contribute. In addition, respondents reported spending an increasing amount of time tending to their relative's physical and emotional care needs, a shift in their relationship that had implications for individual's sense of self. Fulfillment of multiple roles can prove taxing, both in terms of time and energy, affecting family member wellbeing. Further, family member ability to engage in everyday activities that previously constituted a key part of 'normal' life is restricted somewhat by their limited ability to leave the house, either independently or alongside their ill relative, as their relative's care needs always take priority. The change in roles and everyday activities can lead to tension and resentment between participants and their ill relative, as the family struggle to adjust to the way their lives have changed as a result of illness and the wait for a transplant.

Following the transplant, many family roles and everyday activities shift back to 'normal' over time, as the ill relative's health gradually improves and they become more independent. This shift, though welcomed by some family members, appeared challenging for others. Some participants seemed to experience disruption as a result of this change. This was particularly prevalent among family members who had grown accustomed to fulfilling, and had begun to identify with, the role of 'carer', who often professed a sense of loss as a result of relinquishing this role. However, family life did not return to 'normal' for all participants post-transplantation. Ongoing physical and psychological issues experienced by the ill relative meant that family roles and the ability to participate in everyday activities remained changed for some for a significant time post-transplantation.

Chapter 7. Keeping up appearances: Social interactions and support throughout the transplantation process

In this chapter I present respondents' accounts of interactions with their social network, and assess the extent to which these interactions were felt to be supportive, throughout the transplantation process. In the context of this thesis, the term 'social network' refers to the 'web of social relationships surrounding an individual' (Umberson and Montez, 2010, p. S54). Two constituents of this 'web' are considered here, participants' 'established' social circle - their extended family, friends, colleagues, and neighbours - and an 'emerging' social circle, comprised of other families involved in the transplantation process. Reflecting the previous chapters, I present data under the headings pre- and post-transplantation to illuminate the extent to which participant's social interactions and felt social support changed over time. Throughout, consideration is given to how social exchanges appeared to influence participants' wellbeing and sense of self.

7.1 Established social network

In this section I explore participant accounts of interactions with their established, or 'normal', social group pre- and post-transplantation. Particular attention is given to reports pertaining to extended family and close friends, however, I also comment on exchanges with neighbours and colleagues where appropriate. In relation to these groups I comment on the perceived availability of social support, practical and emotional, throughout the transplant trajectory.

7.1.1 Pre-transplantation

Family members discussed interacting with a number of individuals within their established social network in the lead up to the transplant. It was particularly common for them to discuss encounters with members of their extended family and close friends; however, they also recounted interactions with colleagues and neighbours. Starting with accounts pertaining to extended family, I explore participants' accounts of such exchanges, focusing particularly the how such interaction appeared to affect individuals' experience of social support.

Extended family were recognised to be key sources of practical and emotional support in the lead up to the transplant. More often than not, the source of such support was noted to be siblings and parents. By comparison, support was rarely sought from children, whether young

or old, likely because of a desire to ‘protect’ these individuals (see Chapter 6, Section 6.1.1). The practical support documented by participants ranged from help with general household maintenance, to childcare, to taking responsibility for updating others:

[My dad is] just so good, he's backwards and forwards to our house all the time. He's 73 but he, he's fitter than [partner], you know, so if something needs doing, he'll come and do it. (Isabelle, 43, partner)

[My] sister at home basically had [my] two kids, the two smaller kids [while I was at the transplant centre]. [She] done everything with them [...sister] was basically like a PA. I would send her a text every morning and every evening and I think she had over 100 people she would send a text to you know for to send it on. (Amelia, 43, mother)

By adopting this responsibility, Amelia’s sister appeared to relieve her of the burden of communicating updates to invested, often anxious, peers; allowing her to focus her time and energy on her son. Other participants, such as Erin, acknowledged that their relatives also helped to relieve this burden, by assuming the role of ‘informer’:

[Partner’s] brother would come down a lot. He was good actually. He would give everybody the updates... (Erin, 49, partner)

As well as practical support, respondents recounted receiving emotional support from their relatives. Jo, for example, noted that her brother acted as her key emotional support while her partner was in surgery:

I phoned [brother] up the night before, the day before [the surgery]... and said, “Look [partner is] critically ill and needs a transplant.” He said, “I’ll come up.” He dropped everything, got on a plane and turned up... he spent the whole day with me and it was exactly what I needed and wanted. (Jo, 50, partner)

Similarly, Elaine reported that despite their often-difficult relationship, her sister was a good source of emotional support during the wait for her son’s transplant:

I’m lucky in that I have my sister... while, um, we have hammer and tongs rows at times, she has been a great support to me. (Elaine, 61, mother)

These quotes reveal that involvement in the transplantation process can have a positive impact on wider family relationships, encouraging individuals to come together and support one another. However, not all accounts were positive. Some participants reported that they did not feel able to seek practical or emotional support from their extended family. Claire, for example, reported that she did not feel she could turn to her stepdaughter for support, as she was evidently finding it difficult to come to terms with what was happening to her father:

[Partner’s] daughter’s not very good [at supporting me]... she’s really in denial and when he told her last year that, you know, he was quite poorly, [she said] “Oh I don’t want to know, I don’t want to know.” I don’t think she can cope with the thought of him having a heart transplant [...one time] I got meself [myself] upset, and she says, “Oh I can’t talk about it, I can’t talk about it.” (Claire, 59, partner)

Similarly, Anna reported that she did not feel supported by her partner's family, as they did not appear to understand, nor were they willing to accept, the seriousness of his illness:

[Partner] was really ill in ICU and I phoned his family and said, you know, "He is really ill, I'm worried. I think you need to come and see him". They sent his brother... his words to me when he left were, "I dunno what you're going on about, he's not that bad. He looks alright to me." ...They just thought I was making it out to be worse than it was. (Anna, 48, bereaved partner)

These accounts reveal that though family are often assumed to be the most appropriate source of support at times of crisis, in the context of transplantation this is not necessarily the case. This was particularly prevalent among individuals who were not physically or emotionally close to their extended family. Lindsay, for example, reported the physical distance between her and her family, and the emotional distance between her partner and his family, meant that she struggled to access physical and/or emotional support from them while awaiting his transplant:

I've got no family in the area [...] well mum lives in [another country] so didn't see much of my mum. Um, his [partner's] dad is very focused on themselves really... my own brother lives down south so I didn't see much of him [...] as I say [partner]'s family, they were never, his dad was never, I think there was a bit of friction between [partner] and his dad... they didn't have a close relationship. (Lindsay, 52, partner)

Likewise, Julie noted that the distance, emotional and physical, between her and her partner's daughters meant that she did not feel able to seek support from them. Nor did she feel able to reach out to his sister, as she was dealing with her own personal family crisis at the time:

[...Partner] has two daughters, at that time we had no contact with them, they were away from [hometown] and he was not in touch with them [...partner] had a sister but she was bringing up four kids on her own because her husband died of cancer, so you know in terms of decision making, it was mine. There wasn't anywhere else to go with that. (Julie, 57, partner)

This quote illustrates that participant's reluctance to turn to family members for support was not solely dictated by physical and/or emotional distance, but could be rooted in the knowledge that their transplant experience was not occurring in a vacuum; that those around them could be facing personal and/or family issues and thus may not have the resources to support them.

In situations where family were not available, or deemed to be appropriate, respondents reported turning to other connections within their social networks for support, namely: friends, neighbours, and/or work colleagues. As with relatives, respondents stated that they received both practical and emotional support from individuals within these groups. Friends and neighbours were often called on for practical support:

I don't drive, and people were driving me up and down to the hospital... anybody and everybody would come to the door and ask me did I need a lift to the hospital, [we have] very good neighbours. (Louise, 61, partner)

Once [partner] was on the transplant list, various friends here said, "We can come and help." One in particular has helped an awful lot and so people were coming in at Easter when we were quite busy, beginning of April [friend would] come virtually every day and helped me with the [business] because [partner] could do nothing by this time. (Matthew, 63, partner)

...if he was in hospital for assessments or anything, I used to go [away]... just have a few days break from that and other people used to visit him in hospital so we could have the chance to be away from it. (Ellen, 74, mother)

[While I was away for work] there were two friends, two women that we'd known for a long time in [home town] that looked after [partner]. (Jacob, 68, partner)

While, on the whole, participants appeared open to offers of practical support from non-relatives, a number appeared to struggle to accept this support. Isabelle, for example, noted:

I'm just so independent... I mean next door's, "Bring your ironing round, I'll do it." "No, no, its fine, I can cope." So I'm very guilty of that and I've got to be aware of that. Because they want to help and I've gotta let them because if I don't, they might not offer again. (Isabelle, 47, partner)

In contrast to her previously reported comment about accepting practical support from her father, this quote reveals Isabelle appeared to feel uncomfortable accepting such support from others in her social network. Mirroring wider research on the family response to caregiving (LaValley, 2017), Isabelle's discomfort appeared to be rooted, somewhat, in the perception she held of herself as an independent individual who did not need help from others. This quote further reveals that family members can feel compelled to respond positively to and/or accept offers of practical support, as they harbour concerns that not doing so may threaten relationships and jeopardise future offers of social support. Reflecting Isabelle's account, Lynda recounted similarly struggling to accept offers of practical support from non-relatives:

[...Friend] was saying, you know, "I'll take [partner] home 'cos I've got the car here and I'll bring your shopping, I'll deliver the shopping for you." And I said, "Oh I'm fine doing the shopping." [He said] "Yeah but you've got better things to do with your time, you need to relax, not do the jobs. I can bring the shopping round." I'm thinking 'It is relaxing for me walking up the village to the butchers to get me out of the house just for five minutes!' (Lynda, 65, partner)

Rather than making her feel supported, this offer appeared to compound the sense of isolation that Lynda was experiencing by emphasising how little individuals within her social network understood about how she felt. These accounts reveal that family members can experience emotional dissonance (Hochschild, 1979) in response to offers of support from non-relatives, as they struggle with the conflict between their frustration and feeling rules associated with

offers of social support: that one *should* feel grateful (see Chapter 3, Section 3.2.5.4). To manage this and preserve fragile social ties during a time of such uncertainty family members performed emotion work (Hochschild, 1979), by masking how they truly felt about offers of support with expressions of gratitude and a friendly exterior. This is illustrative of another way family members were managing their ‘front-‘ and ‘back-stage’ selves (Goffman, 1959) in the lead up to their relatives transplant.

As well as practical support, respondents discussed receiving emotional support from their friends, neighbours, and work colleagues:

I had a very, very supportive boss [...] I'd send him a message, didn't matter what time of day or night it was, he gave me his private mobile and I could message him [...] He has been absolutely brilliant about things [...] I explained to him how you know one minute everything could be rosy and that and the next minute it could all change very, very quickly and we have to live with that and he gets that. He, he's really good. I think he's actually done his own research as well. (Lindsay, 52, partner)

[When partner was admitted to hospital] I called up a very close friend who dropped everything and just came over... he didn't come in to the meeting with the surgeon with me but he was kind of around for me to drip over [cry to] afterwards (laughs). (Jo, 50, partner)

[A close friend] was very supportive... I don't see him very often, it's usually on the phone, if I get on the phone. It's like having a counselling session really. (Erin, 49, partner)

[Partner and I] got tremendous support from the village here, the people would always say "How's [partner], how's he doing?" You know, they'd want to know about things and want to know about transplants and you know all the processes that most people know nothing at all about, but sometimes it didn't get beyond that. (Lynda, 65, partner)

These quotes show that participants valued, and were comforted by, the emotional support offered by colleagues, friends, and neighbours while awaiting their relative's transplant. However, it was not the case that they felt well supported by all social interactions. Lynda's admission that "sometimes it didn't get beyond that" reveals that, on occasion, family members felt that the support offered by others was somewhat limited and superficial in nature. Claire similarly reported that though she was surrounded by people, she did not always feel well supported by them as they focused overwhelmingly on her relative's health and prospective transplant, rarely asking about her and her needs:

...sometimes you do feel isolated and you do feel lonely and you've got, you've got friends yes [...but my friend will] ask you how you are and then she's, she's conscious about [partner]. "He's looking, he's not looking too good today." He's not this and he's not that. And I think, 'Do you not know I, I know that?' I mean I've got it every

day... Sometimes I feel I've been pushed to one-side (crying) and it's all, it's all about [partner]. Which it is! But I'm the other half of [partner]... I feel I've been pushed to one-side and no one thinks about me. (Claire, 59, partner)

This quote illustrates the extent to which growing social interest in the ill relative could frustrate and upset family members, as it left them feeling invisible within their social circles and thus unsure of where to turn for support. This experience reflects that of family members in other illness contexts, such as those caring for individuals with cardiomyopathy and dementia (Dickson *et al.*, 2010; Cardiomyopathy UK, 2017). Over time this sense of invisibility appeared to disturb participants' self-perception, as they felt increasingly socially defined, or 'labelled' (Becker, 1963), as 'a relative of an individual awaiting a transplant', rather than in relation to other factors. Some accounts revealed that the acquisition of this new label could have a destructive impact on valued social relationships, as the following quote from Elaine illustrates:

I have one particular friend whose son [has been on the] same trajectory from congenital heart point of view [as my son]... they both have a very similar diagnosis... We were both living with our son's being terminally, um, with the prognosis that it was terminal in their 20s. Then [my son] got offered the transplant and [hers] didn't. And it was very strange to see what it did to our friendship. We had been propping each other up for the last 10 years and suddenly it changed [...] I miss that friendship. It would have changed if one of the boys had died, we both knew that...you can't keep up the friendship if one of them dies, it's just not possible because your child is alive and their child is dead... this changed it in the same way. The, going on the transplant list, it was as if her child was dying and [my son] was potentially living. And that, that completely surprised me. (Elaine, 61, mother)

This account reveals that being labelled as 'a relative of an individual awaiting a transplant' may have a detrimental impact on family members' ability to connect with their established social world. Elaine evidently struggled with this change, as it led her to question where she belonged socially now that her son was simultaneously no longer classified as 'dying', but nor was he certain to live. This sense of social liminality (Turner, 1969)³⁸ appeared to differ somewhat from that experienced in other illness contexts with more linear, predictable treatment pathways, such as cancer (Jordan *et al.*, 2015).

Relationships outside of their respective illness communities were also reportedly affected in the lead up to the transplant as, having little exposure to individuals with life-threatening illnesses, other people seemed to struggle to witness their relative's deteriorating condition. Scott reported that a number of friends withdrew from him and his partner as a result:

³⁸ Turner (1969) defines liminality as being "betwixt and between" two states (p. 95), thus liminal persons are ambiguous individuals who elude clear classification.

[Friends] just stopped coming around [...] It [social life] kind of just dried up really, and um I think just people didn't feel comfortable in coming around because there was nothing to tell them. It's not that we led this riveting lifestyle [...] People were backing off... I don't think it was them being selfish or anything, I just think that people struggled to deal with what was happening, they struggled to see how [partner] was, because she was declining rapidly. I mean, she lost a heck of a lot of weight, had this wheelchair when we went out, and people just couldn't believe it really. They were mortified, just watching her slowly die. (Scott, 43, partner)

Similarly, Lynda recounted that some family friends appeared to cut ties with her and her husband while they waited for his transplant:

...some friends actually didn't keep in touch, they didn't phone, they didn't email [...] people say, "Oh yeah, yeah, we'll come round" and then don't. I would get- I, with some folk, with a couple of friends, yeah I felt- never said, to them- but I felt very angry. (Lynda, 65, partner)

These excerpts highlight the extent to which the family member social ties can be detrimentally affected by the social inclination to distance oneself from reminders of illness and death, often detailed in research on the family experience of chronic illness, disability, and bereavement (Chapple *et al.*, 2004; Breen and O'Connor, 2011; Lawn *et al.*, 2013). While some family members, like Scott, understood and appeared to accept this response, others, such as Lynda, clearly felt hurt and angered that their peers were avoiding them during such a difficult time. Several respondents recounted attempting to prevent peer withdrawal by consciously limiting how often they discussed their relative's illness or transplant experience in the presence of others, thereby evading the stigma associated with chronic illness. This was particularly prevalent in the accounts of individuals whose relative was on the waiting list for over a year. Elaine, for example, reported actively avoiding discussing her son's transplant with her friends, as she was cognisant of 'boring' them:

I don't share a lot about it now, insofar as, because we've gone into the second year of transplant, waiting for transplant, people have lost- the novelty of it has kind of died away... our friends are bored with our lives. They are bored, completely and utterly bored. And to be honest, I can't blame them. Because it's always been one crisis or another [...] On the sixth call, we didn't even bother telling anybody, because what was the point? What is the point? We've decided now, if the transplant goes ahead...we will wait until it goes and then we will let people know. Because there is absolutely no point in, in just, yet again, intruding on other people's lives. (Elaine, 61, mother)

Likewise, Scott noted that he avoided talking about his partner's illness and impending transplant with his friends, as he was conscious that doing so might 'push' them away:

I didn't want them [friends] to have to live our problem almost... I didn't want other people to have to sit and listen to our problems in life, I didn't think that they'd come round to listen to this [...When friends came around] I would not want to be talking about transplant and ill-health, I'd try and talk about something else really you know. I

always kind of, I suppose in the back of me mind I always thought, 'If we start talking about this too much, it will push people away' [...] in many ways I kind of felt like I, I wanted to keep it to myself a little bit, in some ways, because I didn't want to kind of, having to repeat myself... in an odd way you, there's a tendency to keep things, um, and I don't know whether this does kind of border on depression and self-loathing sort of thing but just to, to keep it to yourself so only you have to consume the problem and other people don't have to listen to it. (Scott, 43, partner)

From these quotes it is clear that family members are cognisant that their experience may lead their social network to view them as burdensome. By concealing the true reality of their experience from their peers, Elaine and Scott appeared to be performing emotion work to prevent others from feeling uncomfortable around them. These examples suggest that family members can prioritise the preservation of their social image and peer relationships over their need for support. While this approach may have had positive impact on their social ties, the same cannot be said for their individual wellbeing as they began to internalise their emotional struggles.

Widespread social misconceptions concerning the transplantation process appeared to further exacerbate the sense of social isolation that participants felt in the lead up to their relative's transplant. It was common for participants to report that members of their established social network had a poor or erroneous understanding of the transplantation process and what it meant for the ill individual and their family:

...everybody thinks it's [admission to the waiting list] an automatic, and "Sure why wouldn't he be considered?" and "Why wouldn't he-?" you know? ...everybody thinks it's so simple and I just wish it was as simple as that for us. (Elaine, 61, mother)

[Friend] said to us, "How long will you wait?" I says, "We could wait weeks, months, years. We've been waiting since April now." [...] "So that means you've just gotta sit and wait?" I says, "Uh-huh." I says, "There's no given time. It's not as if you can go to Tesco's and buy them off the shelf!" (Claire, 59, partner)

Participants also reported struggling with social misconceptions surrounding what a transplant patient 'should' look like. It was particularly common for family members of chronically ill individuals who did not rely on visible medical aids (e.g. a wheelchair/oxygen tank) to recount that others commented on how their relative did not appear 'ill enough' to need a transplant:

[Partner] doesn't look ill [...] When you say he's on the lung transplant list people think, 'Well, why?' You know but I think it's because what's going on inside, not what's visual. (Isabelle, 47, partner)

Limited public awareness of the variable and often hidden nature of chronic illness appeared to frustrate and trouble family members. This was particularly apparent in the accounts of

relatives of liver transplant patients, who often reported feeling affronted by the erroneous social misconception that their relative's condition was the result of alcohol abuse:

...one of the hard things, was, I mean [son has] never been a drinker, I mean he doesn't have, he doesn't touch alcohol... he's never, ever had anything to drink... But everybody as soon as they knew he was going on the transplant list, you know, they would say "Oh is it alcohol related?" (Ellen, 74, mother)

[After hearing the words 'liver transplant' a neighbour] sort of went on about his friend who had unfortunately drank his way through his second liver and stuff so the assumption was there. "Oh yes I know about alcoholics, it's ok." And I kind of thought, 'Oh, ok. We're gonna have that then are we? Oh.' (Jo, 50, partner)

Though alcoholic liver disease is one of the conditions that can lead an individual to require a liver transplant, this condition was not the cause of liver failure for any of the relatives of participants within this study (for an overview of liver conditions leading to transplantation see table 1, Chapter 2). The sense of frustration resulting from this perceived stigma mirrors that reported among individuals living with lung cancer, who are often presumed to have developed their condition as a result of smoking (Hamann *et al.*, 2014; Maggio, 2015). To manage this perceived stigma, several participants reported adopting a defensive approach when informing others of their relative's impending liver transplant. Erin, for example, recounted:

...there's a stigma isn't there? A lot of people think its drink related and it's not. They don't realise the amount of causes [of liver disease...] I used to say um, "But it's not 'cos of drink!" I felt as if I had to say that. (Erin, 49, partner)

The urge to inform others that their relative's condition was not alcohol-related appeared to be rooted in a desire to disassociate the family from the stigma associated with alcoholism, thus preserving their relative's 'high moral status' (Charmaz and Belgrave, 2013) as blameless and deserving of a transplant. Authenticating their relative's sick role (Parsons, 1951) (see Chapter 6, Section 6.1.2 for definition) in this way appeared particularly important for family members, as it acted to validate their care role in the eyes of others.

The social misconceptions discussed above appeared to leave participants feeling misunderstood by, and thus somewhat isolated from their peers. Indeed, Scott commented that sometimes he felt so alone in his experience that it was as if he were "living on an island" (Scott, 43, partner). Interviewees indicated that they struggled to respond to misconceptions about the transplantation process. Elaine, for example, recounted that she felt conflicted by a strong desire to educate others about transplantation and an awareness that others may not want to know about, or be able to comprehend the reality of, this experience:

I find myself trying to educate people about transplantation 'cos they're all basing it on Holby City, or um, Casualty or something like that where it's all da-da and we run in and we do it [...] I don't know whether I am talking through me hat or whether they were listening to me out of politeness [...] I used to expect too much from people to, to understand it and they really don't. And I mean there's my sister, who is involved and still doesn't understand it. Why should I expect somebody else outside to understand how complicated it is, you know? (Elaine, 61, mother)

This account illustrates that family members can feel the need to lower their expectations of others, to limit the sense of frustration and isolation they felt when confronted with the social misconceptions about transplantation.

7.1.2 *Post-transplantation*

Participant accounts revealed that offers of support from their established social network were felt to peak in the weeks following the transplant, while their relative recovered in hospital. Friends and neighbours, in particular, were acknowledged to offer practical support during this time:

...when [son] had his operation and we were visiting in the hospital you know, the fortnight that he was in, every day that I came home there was something on the step. Somebody would do a stew or somebody would do a, you know, spaghetti bolognese and they would just leave a little note saying, 'It's already cooked, just warm it up' ... There was loads of deeds of kindness, people just helped out so it was lovely. (Ellen, 74, mother)

...when she [friend who lives near the hospital] knew that [brother] was in [hospital], she said, "You can park on my drive anytime!" ... It's expensive at the hospital [...] if you're visiting for long periods, having to go regularly, it's very, very expensive. (Olivia, 49, sister)

...there were people who, maybe more peripheral to our lives, who, who kind of came out of the woodwork and said or did things at times of, of great emotion that were just right [...for example] the flat we [lived] in was up 44 stairs [...] a very kind neighbour on the ground floor said, "Well we're going away for a fortnight, do you want to come back to our place?" So that solved that [issue]... we went back to the ground floor flat. (Jo, 50, partner)

In addition to this, several participants recounted that their friends continued to support them in the day-to-day running of their household and/or family business while their relative recovered in hospital, as the following quote from Matthew illustrates:

[As they had done before the transplant, friends] would come over and, and um help me [with the business]. So I was getting quite a bit of help, which meant I could go every day to the hospital. (Matthew, 63, partner)

Though some respondents discussed receiving practical support from members of their extended family during this time, these reports were relatively infrequent. Lynda and Katy provided two rare examples:

[I called] my sister-in-law [about the dog...] her husband drove to our house, collected the dog, collected the crate and her food and everything and took her to the kennels and dropped her off. (Lynda, 65, partner)

My mum went [to the hospital] and stayed [nearby]. Luckily my auntie lives right near the hospital, so she was able to stay there without having a hotel or anything. (Katy, 24, daughter)

On the whole, participant accounts indicated that extended family were keen to offer emotional support in the weeks following the transplant, as the accounts of Anna and Lesley reveal:

[Son] was driving backwards and forwards [to the hospital], he used to come up and visit me um, you know. He, he was really worried about me... he would work all week and then come up at weekends. (Anna, 48, bereaved partner)

[After the transplant] we came probably for about four weeks almost permanently...we stayed in hotels near the hospital initially then we rented a place [...] we didn't want to go home because we just didn't feel as if we could leave Isabelle... it was very difficult [...] I think for the first few weeks, if Isabelle had not had us, it would have been horrendous. (Lesley, 63, sister-in-law)

Participants who did not have strong familial connections, or who lived a significant distance from their extended family, reported seeking emotional support from close friends:

[I told one friend when partner had his transplant, she] and I are very close and she's been through some serious highs and lows in her life and we get it. We get it when people need to talk and we get it when people don't, they just need a hug... other friends got some of the story but not the rest of it. (Julie, 57, partner)

[The day after the surgery] my best friend came up and I've known her since I was eleven... I phoned her up and I kind of wept at her down the phone, "I think she's going to die! I can't cope with it on my own!" and she said, "Ok, I'll come up for the weekend." And she came up for the weekend. (Jo, 50, partner)

The accounts of Julie and Jo reveal how selective family members can be when choosing who to seek emotional support from, with both turning to close friends who they had known for a significant period of time.

The data presented above illustrate that family members felt relatively well supported by their established social connections while their relative recovered in hospital post-transplantation. However, this sense of support did not seem to last. Social support was felt to dissipate

somewhat when their relative returned home. Elaine recounted that she felt social input diminished because the excitement surrounding her son's transplant had blown over:

...everybody was in touch with us the first month [...] he went from everybody being in touch with him the first month, to nobody being in touch with him. He had cousins came out of the woodwork, contacting him in the first month and then everybody just got on with their lives basically. The excitement of it all was over. (Elaine, 61, mother)

This account reveals that the novelty of the transplantation process was felt to play an important role in generating social interest and subsequent offers of support. As the novelty, or "excitement" as Elaine phrased it, wore off social support was felt to wane. Accounts revealed that this was somewhat influenced by social misconceptions surrounding transplantation, most notably the belief that transplantation is a curative procedure. Respondents evidently felt frustrated by this misconception as they recognised that it led people to believe that their relative was out of the danger zone and able to live a normal life, when this was often not the case:

[Family] were just thinking 'Oh that's it now, he's sorted, move on brilliant.' I don't think they realised that you're having to live every day with this fear that um, things can change and it isn't, it isn't like 'oh yes that's it now let's move on' um, that you do have to carry on living with that, that fear of something happening. (Lindsay, 52, partner)

...people say, "Oh, I must call in and see if [partner] wants to go to the pub." Well [partner] doesn't want to go to the pub, do you know? ...He's not out of the woods. He can get an infection. He can get a rejection. He can get very ill, very quick. (Louise, 61, partner)

[Friends had] brought this child around with a sniffing cold and hadn't paid any attention to the fact that [partner] just had her transplant and can't be near anybody like that you know? So that kind of caused a lot of friction for me [...] we did have some other friends who were persistently getting coughs and colds, who just didn't seem to understand that they couldn't come in the house [...] there were a couple of groups of friends I really took a dislike to because of that. I mean things are all right now, they've resolved but it took a long time. (Scott, 43, partner)

Limited social understanding of the reality of life post-transplantation appeared to constitute a source of stress for family members, as it left them feeling misunderstood by, and thus intellectually isolated from, others in their social network. This sense of intellectual isolation appeared to have implications for some family member's sense of self, as they felt disconnected from those that they previously identified with, and their wellbeing, as they no longer felt understood and thus supported by those that they would usually confide in during difficult times. This sense of social isolation appeared exacerbated by the positive social perception of transplantation, which left family members feeling pressure to maintain a

positive, 'grateful', face (Goffman, 1955) when discussing transplantation with others. Erin and Elaine, for example, reported feeling compelled to appear happy and grateful about their relative's transplant, despite struggling with the challenges their families continued to face:

...you feel as if you should be grateful... [I keep saying] "We grateful. We very grateful!" ...I feel as if we, we exist and we plod on, we pretend [to be ok] (cries). (Erin, 49, partner)

[It's] kind of a shorthand thing that you *have* to express gratitude [...you can't] complain about anything because it comes across as being ungrateful. (Elaine, 61, mother)

These quotes reveal that family members can feel obliged to manage their emotions and present themselves as feeling 'blessed', despite feeling somewhat 'bereft' about how their lives had changed, to adhere to feeling rules about transplantation, e.g. the belief that organ recipients and their families *should* feel thankful and grateful to the donor and transplant team involved in the procedure (see Chapter 3, Section 3.2.5.4).

This felt shift in social circumstance is particularly concerning when considered alongside participant accounts of their psychological state post-transplantation, as they reflected upon and attempted to process their experience:

[In the lead up to the transplant] I was so calm. It was afterwards. It was afterwards that it hit me, do you know what I mean? When it was over. (Louise, 61, partner)

...you go through the whole transplant process - and I think you do what's needed to do, it's a bit like adrenaline keeps you going type approach - and you get through it all and you come out of the other side and then all of a sudden it hits you, what you've gone through and what you're living with for the rest of your life as well [...] I didn't expect to feel the way I did when, when we got back so that, that was a shock... I don't think I expected to feel as anxious now at this stage [years afterwards]. I thought I'd be like this when it was all happening and I didn't, I actually coped very well at the time things were happening [...] it was after that the] transplant took its toll in terms of that perspective started to go and things and focusing on stupid things... it demolished my resilience. (Lindsay, 52, partner)

These data are congruent with research indicating that family members can develop anxiety following their involvement in the transplantation process, which can manifest into post-traumatic stress disorder (Stukas *et al.*, 1999; Farley *et al.*, 2007; Perez San Gregorio *et al.*, 2008; Heinrich and Marcangelo, 2009). Accounts revealed that family members felt particularly anxious post-transplantation about their relative's future health, as it was deemed fragile and uncertain. Amelia, for example, reported that her son's improved health and positive appraisals from others afforded her little reassurance about his future health:

No matter how many people reassure you, surgeons, consultants [say], "He's doing good, he's doing good. I'm happy, I'm happy." That's grand but I'm not 100% happy because he's been through so much and I know what his body's like... there's still that thing in the back of your mind, you know, that something is gonna happen. (Amelia, 43, mother)

Similarly, Jacob reported that he continued to harbour concerns about his partner's health:

[The transplant has] been done but it's not sorted, do you see what I mean? [...] There is a constant niggling at the back of your head that, that um- whereas before death was staring you in the face now it's just kind of hanging on her shoulder you know... there is this constant ghost of catastrophic illness sitting, sitting right bloody behind us. (Jacob, 68, partner)

These quotes reveal that family members tend to suppress their ongoing concerns post-transplantation, moving them to the 'back' of their minds. Such emotion work appeared to be part of their attempts to protect their ill relative's wellbeing and re-establish a sense of normality, within their family and among their peers, post-transplantation. These findings indicate that while it may not be obvious to others, family members can struggle psychologically for a significant period of time after their ill relative has 'recovered', and thus require more, longer-term, social and professional support than is currently offered.

By showcasing respondent's accounts of encounters with their established social network, I have provided insight on the extent to which they felt supported by, or isolated from, this group throughout the transplant trajectory. Throughout this section, I have illustrated that the transplantation process can have a significant impact on family members existing social relationships, meaning they often struggle to feel that they belong among their peers. Next, I explore the extent to which family member's interactions with a new or 'emerging' social network, namely other transplant families, worked to alleviate this sense of social isolation.

7.2 Emerging social network

In this section I explore participant accounts of interactions with an emerging social network: other transplant families. Particular focus is given to family member's willingness and ability to interact with this group, and the extent to which such interactions were felt to constitute a source of support and alleviate their sense of social isolation throughout the transplantation process.

7.2.1 Pre-transplantation

Participant accounts revealed that speaking to and/or spending time with other transplant families, who had experience and knowledge of the process, seemed to provide a sense of solace for some. Anna, for example, remarked that meeting other transplant families at the outpatient clinic helped her to feel 'normal' and less alone in her experience:

When you're at home... you do feel isolated and alone because nobody else is going through it, you know? Trying to get a lung transplant, it's so kind of out-there, it's not kind of, it's not an everyday thing. And that was what our life was, that's all we-, you know, trying to meet the criteria, trying to get that little bit of hope... when you get to the hospital everyone you talk to is going through a similar kind of thing and you, you feel normal because you're with people who understand, who are in the same position... that was really weird because you're so used to being different and then when you get to the hospital you're just, you're just one of many. You know, everyone is going through the same thing [...there are] people you can talk to and then you realise you're not going nuts, you know, this is normal to have these feelings. (Anna, 48, bereaved partner)

Opportunities to interact with other transplant families were valued by participants like Anna, as these individuals were felt to understand what they had been through and their fears for the future in a way that their established social network could not. As well as helping them to feel somewhat 'normal', networking with the transplant families was recognised to have other advantages, such as providing hope and inspiration, and insight into transplant-related events and resources (e.g. the transplant games³⁹ and support groups). Claire and Isabelle noted:

...we've got two good friends [a couple]... he's already had a heart transplant, so he's been a great inspiration. Just done the transplant games and everything, it's been brilliant [...] we're getting a closer bond with them and we go out with them [...] He told [us] about the heart transplant Facebook, on Facebook... I think it gives [partner] a little bit of hope sometimes when he sees the stories [on Facebook], the before and the afters. (Claire, 59, partner)

...we went to the transplant games and we were talking to a guy behind us and he- everybody's so friendly- um and he [said], "Can I just ask, who you're supporting?" Now obviously [partner] had his tubes on so he must have known it was lungs or heart anyway and we said, "Oh the [transplant hospital]. We're on the list." And he said, "Oh I had-" he had the same [transplant] as [partner needed]. He had his lung transplant four years ago. I said, "Do you mind me asking how old you were?" And he said I was 58, which [partner] liked that because it was somebody a similar age group to him. It wasn't a 21 year old girl... and the guy was there doing the discus, the shot-put, and the javelin. (Isabelle, 43, partner)

³⁹ The Transplant Games is an annual sporting event (UK and worldwide) at which individuals living with a transplant compete to win medals. Individuals participate in teams representing the transplant centre providing their care. The aim of this event is to raise awareness of organ donation.

This inclination to establish relationships with individuals with a shared experience is not a response unique to those living with or providing care for someone awaiting a transplant, rather it has been documented in a multitude of illness contexts and among the bereaved (Riches and Davis, 2000; Locock and Brown, 2010; Theed et al., 2017). Though a handful of participants discussed developing, and relying upon, other transplant families pre-transplant, most seemed to struggle to establish a connection with this group prior to their relatives' surgery. Distance and the time-/energy-intensive nature of the care role appeared to constitute key barriers to establishing these relationships:

...we're so remote, there aren't other people [experiencing transplant] in the area.
(Lynda, 65, partner)

[Pre-transplant] my mind-set was all around having to deal with his limitations... my life focused really around [supporting him] it was a completely restricted lifestyle... [Socially] I turned into an old lady really. (Lindsay, 52, partner)

In light of this, it was much more common for participants to describe developing relationships with transplant families post-transplant, while their relatives recovered in the transplant centre.

7.2.2 *Post-transplantation*

Several participants acknowledged that they developed supportive relationships with other transplant families they met while their relatives were recovering in hospital post-transplantation. While these persons were often virtual strangers, a number of participants reported feeling close to them by virtue of their shared experience. Louise described feeling “bonded” to other transplant families during the time she spent in the transplant centre:

...you do bond with most people. You get sort of become a family almost [... everyone] looks after each other [...] It's the people in the families, in the same position as yourself [that understand]... that's the only way to describe it. You have to be there. (Louise, 61, partner)

Family members appeared to benefit from interacting with other transplant families, as these individuals understood the transplant experience in a way that others within their social network did not. While, on the whole, participants appeared to value the chance to establish relationships with other transplant families, and the accompanying sense of support and camaraderie, downsides were also reported. One key drawback of developing supportive relationships with transplant families was reported to be the propensity to get “caught up in everybody's story” (Lesley, 63, sister-in-law). Later in her narrative, Louise recounted that

her bond with one particular couple meant she became swept up in their emotional journey, and experienced their highs and lows as well as her own:

...you go through their pain as well as your own [...one friend] would be crying to me and I'd be crying to him, whenever [partner] was sick... he was all upset for me because of what had happened to [partner], while I was upset for him when [his daughter] was up in intensive care. (Louise, 61, partner)

In some cases, emotional investment in other transplant families seemed to influence how respondents felt about, and responded to, their relative's recovery. Witnessing and becoming involved in others, often turbulent, transplant stories appeared to affect how Evaline felt about her daughter's relatively smooth recovery:

[It was hard] seeing other people's family who are far worse and my daughter surviving, you know... people you are living with [in charity accommodation], these people are in the same position but it isn't always a success story. (Evaline, 67, mother)

In addition to the socially expected emotions of happiness and relief, Evaline's account reveals that she felt somewhat guilty that her experience of the transplantation process had been more straightforward and positive than that of others she met in transplant centre. This suggests that family members can struggle with emotional dissonance (Hochschild, 1979) as a result of their emotional investment in the lives and experiences of other transplant families. Supporting this, Scott recounted that he found it difficult to manage the conflicting emotions he felt as his partner recovered but the relatives of others, who he now considered friends, did not:

[A friend] lost his wife and I started thinking... I had to stop myself from wanting to be really ecstatic to other people [about partner's recovery] because I was mindful that they might be going through a horrendous experience and that their relative or loved one might not pull through it [...] you don't know what the other patients are going through and when you're in a hospital environment, it's usually not good... I've met a lot of people going through some shocking trauma. (Scott, 43, partner)

To manage this, Scott and others in this position reported suppressing their happiness around other transplant families to avoid offending or upsetting those less fortunate than themselves. Emotion work such as this appeared to be central to family members' attempts to maintain face, as understanding and sensitive individuals, and consequently preserve delicate social ties. These quotes illustrate that interacting with other transplant families could constitute a double-edged sword in terms of support, as it could contribute toward, rather than relieve, the distress experienced by family members post-transplantation.

As had been the case with their established social network, support from emerging social networks was acknowledged to diminish over time. Whereas before and immediately after the transplant participants discussed turning to other transplant families for support, it was rare for them to mention interacting with this group after their relative was discharged from the transplant centre. The sense of connection that respondents reported feeling with other transplant families seemed to diminish when they returned home, as they were no longer bound by circumstance (transplant event/ICU experience) and environment (the transplant centre). In this sense, other transplant families appeared to constitute a transient source of peer support for family members, fixed to specific temporal and geographical facets of their transplant experience. This diverges from the experience of carers in other illness contexts, such as chronic kidney disease (Taylor et al., 2016), who reportedly view peer support not as rooted in a specific period, but something that could be tapped into at different time points. Unlike informal carers in other illness contexts, transplant families did not appear to bond with one another to such an extent that they formed a supportive community. In spite of their extensive involvement in the transplantation process, family member accounts revealed that they struggled to feel that they belonged at events run by and for the ‘transplant community’, such as the transplant games. When asked if she felt she’d become part of a community of transplant individuals, Olivia (49, sister) responded by saying “I’m just sort of hovering on the periphery”. Similarly, Scott recounted feeling as though he was on the outside of this community, peering in:

...I feel like I’m on the outside of the ring a little bit really... a lot of other people, the relatives [of transplant recipients], would probably say the same thing. The people who have gone through this process are in a niche kind of... it’s like a club really... it’s like they’ve got, got a special bond between them. (Scott, 43, partner)

This suggests that family members may lose a sense of their place within the transplant world as their relative regains their independence and the social expectation that they fulfil the role of ‘carer’ diminishes. While some seemed bothered by this change in their felt inclusivity within transplant circles, others appeared to welcome this as they had little desire to interact with or establish a relationship with the transplant community. Lindsay, for example, noted that she did not want to socialise with others who had been through transplantation, as she preferred not to share her problems:

[I] didn't really get involved in anything that [social] side of it [transplant]... I don't think I needed to either. (Lindsay, 52, partner)

Similarly, Elaine stated she was not keen to develop ties with those who had been through a transplant, as she wanted her family to move on and live a ‘normal’ life:

I don't want to have anything to do with his old life [...I worry my son is] in danger of becoming a poster boy [for transplant in congenital heart disease...] I want him to have a certain anonymity, to, um, to get on with his life now. (Elaine, 61, mother)

This quote reveals that some family members were keen to distance themselves, and their family, from the transplant community in order to protect their ill relative from being 'labelled' in relation to their condition and/or transplant experience. The propensity to distance oneself from the transplant community parallels research conducted in other health contexts, such as cancer, that highlights that ill individuals and their families often shy away from illness communities as they are felt to be overwhelming and can reinforce a sense of being different and abnormal (Locock and Brown, 2010).

7.3 Chapter summary

Within this chapter I have presented respondents' accounts of social interactions and offers of support to illuminate the social implications of supporting, or living with, a relative through a transplant. In the lead up to the transplant, family members reported receiving practical and emotional support from individuals within their established social network. Participants acknowledged that while they did not necessarily feel the need to accept all support offered to them, they had to respond carefully to such offers to prevent damaging social relationships. For many, this sense of support continued post-transplantation, particularly in the weeks following the transplant procedure while their relative recovered in hospital. As well as, or instead of, support from their established social network, some participants developed supportive relationships with other transplant families that they met in the transplant centre.

Not all social interactions were felt to be supportive. On the contrary, respondents often reported feeling somewhat misunderstood by, and isolated from, individuals in their established social network. Participant accounts revealed that they were subject to peer withdrawal and a sense of invisibility resulting from increased social focus on their ill relative. Social misconceptions of the transplantation process also challenged family members' sense of social belonging, by leaving them feeling intellectually isolated from those around them. To alleviate feelings of social isolation, participants worked to appear 'normal' around others, concealing the challenging reality of their transplant experience through emotion work informed by feeling rules surrounding the transplantation process. Though establishing relationships with other transplant families helped to ease the social isolation

experienced by family members to an extent, this support was transient and had emotional costs.

Social support provided by established and emerging social networks was recognised to diminish over time, in line with their relative's recovery, as social interest in the transplant waned and opportunities to spend time with other transplant families became less frequent. However, this diminishing support did not necessarily reflect family members' felt need for support. On the contrary, some respondents recounted that they felt a greater need of support after their relative's recovery than they did at the time of the transplant surgery. The disparity between their felt need for support and the support offered by their peers appeared to reinforce the sense of social isolation that family members felt throughout the transplantation process.

Chapter 8. Discussion

8.1 Introduction

In the preceding chapters I presented an analysis of family members' experience of the transplantation process by focusing on: accounts of time spent in the transplant centre and interacting with the transplant team; their personal life and dynamics within the home; and, their relationships with established and emerging social networks. In this chapter, I reflect on the extent to which, and in what ways, family members of heart, liver, and/or lung transplant patients are affected by the transplantation process in the UK; in terms of roles, relationships, identity, and wellbeing. To achieve this, I summarise and discuss the research findings in relation to existing literature exploring the family experience of illness, transplantation, and informal caregiving. Following this, I present the strengths and limitations of my research.

8.2 Summary and interpretation of key findings

To enable clear presentation of the core findings of my thesis, I have structured the following discussion around two key themes prevalent within the data chapters: 1) disruption and 2) impression management. Within each section, I outline what I mean by these terms and contextualise them in relation to relevant data from the empirical chapters.

It is important to reiterate that the vast majority of existing literature exploring the impact of transplantation upon the family originates from the USA. Some studies have been published in other parts of the world, most notably Canada, Brazil and Northern and Central Europe, however, there is a paucity of research exploring the family experience of transplantation in the UK. Thus, although many of the findings presented reflect existing research, they are original, as they have not previously been reported in a UK-context.

8.2.1 *Disruption*

Disruption was one of two key themes readily apparent within my data. I use the term 'disruption' to refer to challenges to the continuity, structure, and logic of an individual's every day and/or anticipated future life (Becker, 1997). Reflecting broader literature exploring the impact of illness and informal caring on family members (e.g. Corbin and Strauss, 1985; Karner and Bobbitt - Zeher, 2005; Barrett *et al.*, 2014; Olson and Connor, 2015), I

predominantly consider disruption in relation to family member roles, routine, and relationships. Throughout this discussion, I draw upon a growing body of literature which argues that Bury's (1982) concept of 'biographical disruption' (see Chapter 3, Section 3.3 for definition) is also a useful lens for understanding the experience of family members living with and/or providing care for ill relatives (e.g. Adamson and Donovan, 2005; Hasselkus and Murray, 2007; Bray *et al.*, 2014; Aasbø *et al.*, 2016). I use the term 'disruption' throughout this section, rather than the more specific 'biographical disruption', to represent the range of disruptive experiences described by participants. While some forms of disruption seemed to significantly affect participant's envisaged future and thus constitute biographical disruption, others did not fit with this concept as they were more transient and faded as the family progressed through the transplantation process.

I have structured the following discussion to reflect the format of the empirical chapters, focusing on disruption experienced by family members throughout the transplant trajectory in relation to: 1) clinical encounters (Chapter 5), 2) family life (Chapter 6), and 3) social response (Chapter 7). Figure 6 provides an overview of the main elements of disruption considered in these subsections. Throughout, particular attention is given to the impact of disruption on individual wellbeing and sense of self, and the extent to which this fluctuates over time or transplant stage (see Chapter 2, Section 2.3 for an overview of the seven stages of the transplantation process).

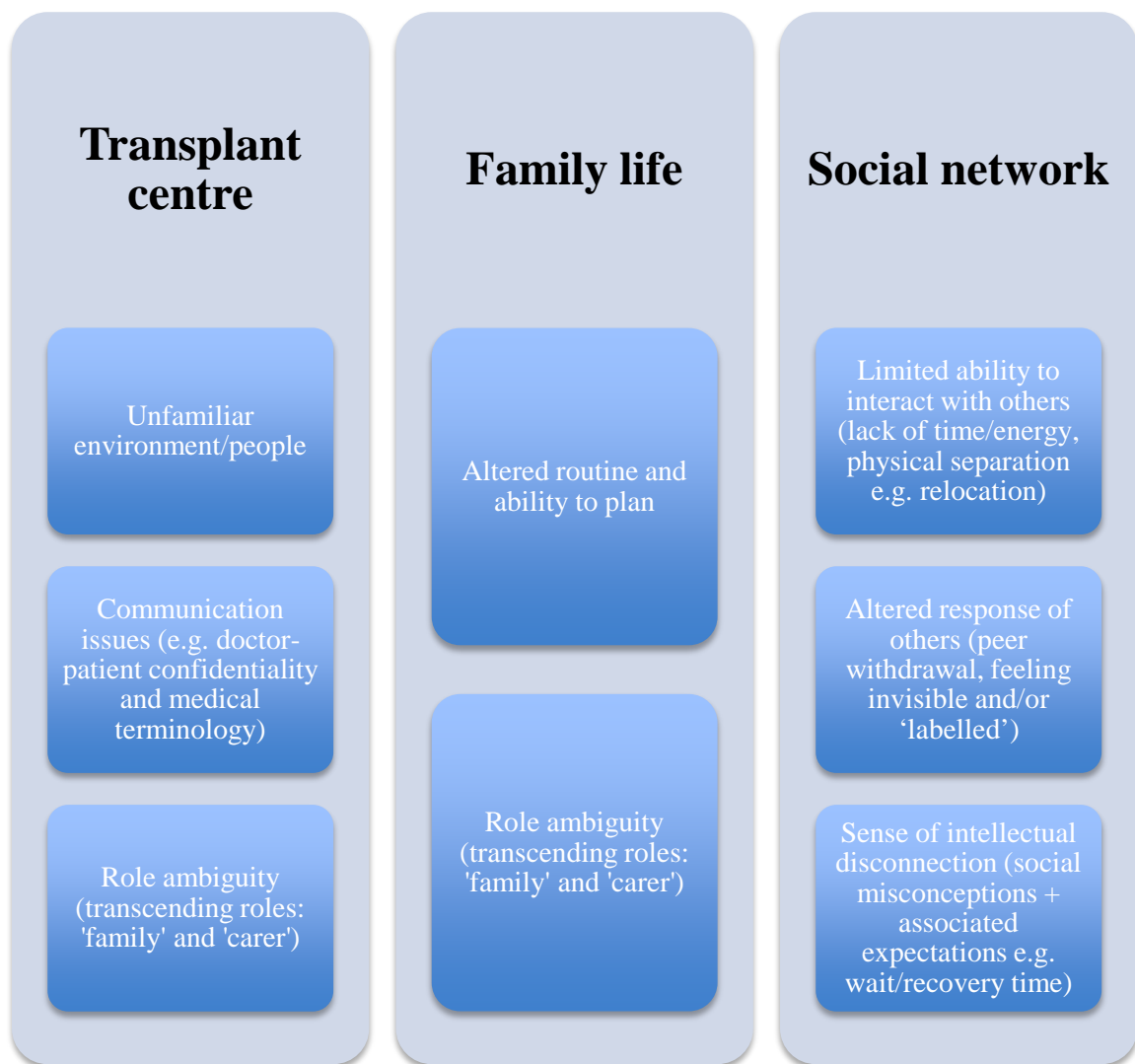


Figure 6: Diagram illustrating the main forms of disruption experienced by family members throughout the transplant trajectory

8.2.1.1 *Clinical encounters*

Participants' accounts revealed that time spent in the transplant centre, a setting alien in appearance, smell, language, and protocols, constituted a significant source of disruption for family members throughout the transplant trajectory. Spending time in the transplant centre was noted to have a particularly disruptive impact on family members' everyday lives and sense of self, affecting the extent to which they were able to fulfil key roles and engage in routine activities. Family members appeared to feel particularly troubled by the uncertainty surrounding their role in the transplant centre, and the disruptive impact of this on their sense of self, pre-transplantation. Accounts showed that some participants experienced role ambiguity in the transplant centre, as the boundaries of their care role became blurred in the presence of the transplant team (cf. Usita *et al.*, 2004; Wright *et al.*, 2017). To manage this role ambiguity, family members appeared keen to establish themselves as 'co-carers' ('co-

workers' according to Twigg, (1989)), partners in their relative's care rather than 'just' relatives (cf. Gibbons *et al.*, 2014).

Establishing oneself as a co-carer proved challenging at times, as this conflicts with the typical expectations of lay-professional relationships in clinical settings (Allen, 2000). Some participants reported that they struggled to assert themselves as a co-carer; they felt overlooked and excluded from clinical conversations between their relative and the transplant team. Haugh and Salyer (2007) have argued that spouses can be made to feel like 'outsiders' in the transplant centre pre-transplant, as though they are interrupting the flow of care. This is supported and expanded by the findings of my research, which demonstrate that communication issues, for example, the protocol surrounding doctor-patient confidentiality, can act as a barrier, preventing family members from feeling able to integrate themselves into the medical world (cf. Morris and Thomas, 2001). Feeling excluded from the care process had implications for some family member's sense of self, as they occupied a liminal position between the roles of 'visiting family' and 'carer'. Turner (1969) defines liminality as being "betwixt and between" two states (p. 95), thus liminal persons are ambiguous individuals who elude clear classification. The duration of this sense of liminality appeared dependent on family members ability to establish themselves as 'co-carers', a process explored in greater detail later in this chapter (see section 8.2.2.1).

Time spent in the transplant centre was acknowledged to have a significant impact on family members' ability to sustain a 'normal' routine. The disruption caused to family routine was particularly prevalent in accounts of life post-transplantation, as this was when individuals typically spent most time at the transplant centre.⁴⁰ Participant accounts demonstrated that family members felt a sense of duty (Vellone *et al.*, 2002; Northfield and Nebauer, 2010), or moral responsibility (Allen, 2000), to be present to provide support to their relative. However, this had a significant impact on their ability to sustain their 'normal' routine, as it limited the time and energy that they felt they had to invest in other areas of their life.

Exposure to certain clinical environments and experiences within the transplant centre were also reported to impact on family member wellbeing. Time spent in the ICU in particular was

⁴⁰ There was an exception to this: family members whose relative was hospitalised for a significant period, or the entirety of, the wait. As this was a small subset of the sample (n=2), I do not feel it is possible to comment on their experience in any great depth here. Research to date appears to have largely overlooked the experience of this group in favour of focusing on families who wait at home for 'the call'.

acknowledged to raise feelings of confusion and fear, exacerbating the stress and anxiety experienced by family members post-transplantation. Reflecting findings of other studies exploring the family experience of ICU, participants often acknowledged that they found it difficult to see their relative in this environment, surrounded by unfamiliar equipment (e.g. Engström and Söderberg, 2004; Urizzi and Corrêa, 2007; McKiernan and McCarthy, 2010). Despite attempting to mentally prepare themselves in advance, participants seemed particularly disturbed by the physical change in their relative, as the familiar became unfamiliar and somewhat frightening (cf. Engström and Söderberg, 2004). While some studies detail organ-recipients' ICU experience (del Barrio et al., 2004; Biancofiore et al., 2005); searches did not yield research on family members' experience of this setting. The knowledge that ICU constituted a stressful and anxiety-inducing experience for the participants of my study is important given that transplant families are recognised to be at significant risk of developing post-traumatic stress disorder (PTSD) as a result of their involvement in the transplantation process (Stukas *et al.*, 1999; Bunzel *et al.*, 2005; Bunzel *et al.*, 2007; Farley *et al.*, 2007).

8.2.1.2 *Family life*

Participant accounts revealed that involvement in the transplantation process had a significant impact on their family life, particularly in terms of roles, routine, and relationships (cf. Mishel and Murdaugh, 1987; Williams, 1991; Mendes and Bousso, 2009; Mendes-Castillo *et al.*, 2012; Rosenberger *et al.*, 2012). Family members reported assuming additional responsibilities, including household chores - for example, cooking, cleaning, gardening and care duties - into their daily routine as their relative's health deteriorated and symptoms, such as breathlessness, extreme fatigue, and disorientation, became debilitating. Consistent with the reports of broader caregiving research, family members appeared to struggle to negotiate the role of 'carer' alongside other household roles (e.g. Barrett et al., 2014; Eifert et al., 2015). Particular elements of the care role, such as the felt need to constantly monitor their relative's health,⁴¹ proved physically and emotionally draining for many participants. The stress induced by balancing care duties with other roles and responsibilities (household/work-related/parental) led to conflict between family members, supporting claims made in other research that illness within the family setting can have a negative effect on family relationships (Young et al., 2002; Barrett et al., 2014; Aasbø et al., 2016; Theed et al., 2017).

⁴¹ The felt need to monitor their ill relative's health appeared rooted in fear that they may overlook or fail to respond quickly enough to deterioration, and thus potentially jeopardise their relative's chance of a transplant (see Chapter 2 for detail).

The similarity between the experience of transplant families and that of families living with chronic illness is somewhat unsurprising, given that a significant proportion of individuals on the transplant waiting list are living with chronic conditions e.g. heart failure, COPD, and cystic fibrosis (see Chapter 2, Section 2.2.1 for an overview of conditions leading to heart/liver/lung transplant). However, my study also revealed a notable difference; while the caregiving experience is often recognised to be uncertain, due to a lack of a clear future and not being able to plan ahead (Gibbons *et al.*, 2014), the sense of uncertainty experienced by transplant families is arguably more acute given the significant ambiguity imbuing each stage of the transplantation process. Participant accounts showed that uncertainty surrounding transplantation can intensify the pressure and stress associated with the carer role, supporting the findings of existing research (e.g. Williams, 1991; Collins *et al.*, 1996; Kurz, 2001b; McCurry and Thomas, 2002; Green *et al.*, 2009; Mendes and Bouso, 2009). Limited certainties and assurances about the transplantation process meant that, as well as living with the usual caregiving concerns, family members also harboured numerous transplant-specific concerns, including the fear that: their relative may become ‘too ill’ for a transplant, they may miss ‘the call’, or a donor may not be found. Fears such as these significantly affected how family members organised their day-to-day life, reinforcing their reluctance to plan ahead and/or visit places with potentially poor access to support/telephone coverage. In this way, the findings of my research concur with US-based transplantation research, which reports that family members can feel that their life is ‘on hold’ during the wait for a transplant (Mishel and Murdaugh, 1987; Buse and Pieper, 1990; Saxe-Braithwaite and Chapman, 1992).

In addition to this, my analysis demonstrated that changes to family life experienced pre-transplantation, particularly a shift in family roles, could affect family member’s sense of self. Emergent roles - principally that of ‘carer’ - increasingly overshadowed, or ‘engulfed’ (Skaff and Pearlin, 1992) roles that had previously constituted key identity markers (e.g. partner/parent/sibling/child). Family members appeared to experience ‘identity discrepancy’ as daily tasks became increasingly misaligned with the expectations associated with their primary identifying role, e.g. partner or child (Montgomery and Kosloski, 2009; 2013). Most participants recounted that their relative’s deterioration was not a linear process, meaning they frequently crisscrossed the role boundaries of ‘family member’ and ‘carer’ during the wait for a transplant. This fluctuation left participants feeling unsure of their sense of self, a finding that is consistent with existing literature which often reports that family members experience ‘loss of self’ during their involvement in the transplantation process (Cater and Taylor, 2017). The uncertainty generated by the oscillation between roles appeared to leave family members

experiencing a sense of liminality, as they bridge a kin- and care-based identity. Gibbons et al. (2014) argue that family members experience liminality when transitioning to the role of informal carer as social roles and relationships change. This liminality, they argue, is finite, subsiding when the caregiver incorporates their relative's disease and/or disability into their lives. As family members providing care in the context of transplantation do not appear to transition permanently to the role of caregiver, but flit between their familial identity and that of caregiver, they likely experience this sense of liminality for longer than family caregivers in other contexts (e.g. cancer, mental illness, multiple sclerosis, physical disability).

Quantitative data on quality of life, hospital readmissions (due to infection/rejection), and death rates among transplant recipients demonstrate that individuals living with a transplant continue to face significant challenges related to their health post-transplantation (Callaghan et al., 2013; Grinyó, 2013; Alba et al., 2016). Given this, it is not surprising that disruption continued to feature as a key theme in family member accounts of family life post-transplantation. Family members reported struggling to maintain a 'normal' life in the first few weeks following their relative's transplant surgery, while their relative recovered in the transplant centre. Individuals who commuted to the transplant centre on a daily basis acknowledged that the time and energy they expended visiting their relative disrupted their ability to adhere to their usual routine and fulfil certain other roles and responsibilities (cf. Healthtalk.org, 2015; Passos *et al.*, 2015). Overall, however, they were better able to maintain a sense of normality than family members who temporarily relocated to be close to the transplant centre.

Though temporarily relocating to be nearer the transplant centre seemed vital for family members' emotional wellbeing (cf. Bellou and Gerogianni, 2007), it came at a cost. As well as being separated from their home comforts and those that would usually provide networks of support, individuals who relocated faced, and had to manage, a greater number of unfamiliar and often challenging people and environments than those who commuted. It was common for these participants to report that they felt stressed and isolated as a result of the move, reflecting the findings of US-based and Brazilian transplantation research (e.g. Mishel and Murdaugh, 1987; Rodrigue *et al.*, 1997; Kurz, 2001b; Stubblefield and Murray, 2002; Mendes and Bousso, 2009; Williams *et al.*, 2012). With the exception of the experience of parents of transplant recipients (e.g. Rodrigue *et al.*, 1997; Stubblefield and Murray, 2002; Mendes and Bousso, 2009), there exists a paucity of research exploring the family experience

of relocating during the transplantation process. As my study demonstrates the impact of temporary relocation experiences of parents and other relatives, including partners, siblings, and a close friend, it offers original insight into this aspect of the family experience of transplantation. My analysis reveals that family members who relocate to support relatives through transplantation can experience role conflict, which generates feelings of guilt and stress (see Chapter 6, Section 6.1.1). While role conflict was apparent within most accounts to some extent, it seemed to be particularly intense for participants who relocated. Individuals often reported struggling to balance the roles of ‘carer’ to their hospitalised relative and ‘parent’ to children at home. Adamson and Donovan (2005) have argued that the guilt resulting from this care dilemma is rooted in the sense of moral duty that humans feel in relation to such roles (p. 45). As ‘parent’ constituted a key identity marker for these individuals, their limited ability to perform this role while staying near the transplant centre appeared to have a detrimental impact upon their psychological wellbeing, resulting in increased stress, low mood, and perceived loss of self. This finding resonates with existing caregiving research, which reports that balancing competing roles can have an adverse effect on informal caregivers, in the form of increased depression, lower life satisfaction, and threatened sense of self (Settles, 2004; Gaunt and Scott, 2014). The role conflict experienced by family members post-transplantation has received little attention to date. A study by Kurz (2002) is a rare exception, reporting that spouses struggle to simultaneously care for their children and partner while they recover from lung transplantation. My study complements and expands upon this work, by highlighting that various family members are at risk of experiencing role conflict post-transplantation, including parents (with multiple children), siblings, and close friends. In addition, my study contributes an alternate viewpoint to research exploring the impact of role conflict on informal carers which traditionally focuses on the incompatibility of paid work and family roles, rather than conflicting family-based roles (e.g. Settles, 2004; Gaunt and Scott, 2014).

Discharge from the transplant centre appeared to have little immediate effect in alleviating the disruption to family life. Despite making physical progress, the transplant recipient often remained too unwell to care for themselves or contribute to family functioning. Thus, family members were often required to continue providing care and/or undertake household roles for some time post-transplantation. While some had anticipated and appeared to feel prepared for this, others had generally resisted thinking ahead to life post-transplantation, fearing their relative might not reach that stage (cf. Mishel and Murdaugh, 1987). For individuals in this

position, the continuation of care and household responsibilities appeared to prompt a shift in their sense of self, as roles they had viewed as fleeting and finite, such as ‘carer’, became more permanent and entwined with their future self. Adjusting to the extension of the carer role proved more challenging for some than others. A subset of individuals seemed to have grown accustomed to fulfilling this role and valued it as a central part of their identity, as it gave them a sense of purpose or gratification that was otherwise missing from their lives (cf. Roth *et al.*, 2015; Litzelman *et al.*, 2017). The newfound significance of the carer role meant that, conversely, these individuals struggled when their relative’s health improved and they were no longer required to provide informal care (see Chapter 6, Section 6.1.2). The consequent transition from the identity of ‘carer’ back to ‘family member’ can be seen as another liminal experience encountered by family members during their involvement in the transplantation process.

Larkin (2007), Corey and McCurry (2017), and Cavaye and Watts (2018) acknowledge that family members can experience feelings of loss, lack of purpose, and even grief, as a result of transitioning to the role of ‘former carer’.⁴² Such feelings were prevalent in the accounts of several family members, particularly mothers who had been providing care for an ill child for a significant period of time. This corresponds with reports in the wider caregiving literature. Bray *et al.* (2014), for example, report that parents experience feelings of loss when their children recover post-surgery, as they become able to manage their condition alone and require less parental care. Transplantation literature has also touched on the disruption experienced by parents when their children regain independence post-transplantation (e.g. Gold *et al.*, 1986; Ullrich *et al.*, 2004; Green *et al.*, 2009; Ordin *et al.*, 2017; Wright *et al.*, 2017). One retrospective questionnaire study from Germany, reported that mothers often experience high stress post-lung transplantation as they no longer feel needed by their child (Ullrich *et al.*, 2004). A recent UK-based qualitative study by Wright *et al.* (2017) supports this, by highlighting the internal conflict that mothers can experience as their children take responsibility for their own care post-transplantation. My research indicates that feelings of loss and grief are not unique to mothers, but can also be felt by partners and siblings, as they become a former carer in the context of transplantation. The detrimental effect of becoming a former carer is rarely acknowledged in transplantation research, as the diminishing need for informal care is routinely framed as a positive outcome, facilitating the re-establishment of family roles and routine (cf. Kurz, 2002). As the vast majority of research on former carers

⁴²The term ‘former carer’ refers to individuals no longer fulfilling the role of ‘caregiver’ due to: 1) the death of the cared for person, 2) institutionalisation of the cared for person (hospital/hospice/long term care), 3) recovery/remission of cared for person, or 4) moving on from the role (young carers) (Larkin, 2007).

focuses on individuals who lose this role following bereavement (Larkin, 2007; Corey and McCurry, 2017; Cavaye and Watts, 2018), my research also provides rare insight into the experience of individuals transitioning to this identity following their relative's recovery.

8.2.1.3 *Social response*

The transplantation process also had a disruptive impact on family members' social relationships. As daily life progressively revolved around care duties and their relative's imminent transplant, participants acknowledged that they felt less able to invest time and energy in maintaining relationships with individuals outside of their family unit, namely: friends, extended family, neighbours, and colleagues. This perceived limited ability to engage in social activities appeared to have a detrimental effect on individual's sense of social belonging over time, leaving them feeling increasingly disconnected from their social world (cf. Mantulak and Nicholas, 2016). The resulting sense of social isolation had a detrimental impact on family member wellbeing. This finding is congruent with the work of Olson and Connor (2015) on informal carers in cancer, who acknowledge that family members suffer when their care role impedes their ability to interact with their social network, as they become unable to access positive emotional energy and affirm their sense of self. Though limitations placed on family members' ability to socialise with others clearly contributed to the sense of social isolation that they felt pre-transplantation, my analysis showed it was not the only, or indeed the most influential, factor at play (cf. Mantulak and Nicholas, 2016).

Family members' ability to sustain social relationships pre-transplantation appeared significantly affected by the way that their social network responded to their relative's condition and imminent transplant. On numerous occasions, participants acknowledged that they felt that others withdrew from them during the wait for a transplant, by limiting communication and/or time spent with them (cf. Young *et al.*, 2001; Agren *et al.*, 2014). Some reasoned that this was because they struggled to be around their ill relative, especially when they began to show significant physical signs of organ failure. Such understanding fits with the concept of social avoidance of illness, the belief that humans are inclined to evade reminders of illness and death in order to keep thoughts of personal vulnerability and mortality at bay (Becker, 1973; Mellor and Shilling, 1993; Waldrop, 2011). Family members of individuals waiting for a liver transplant also attributed social withdrawal to the stigma associated with liver failure, rooted in its link with alcoholism and drug-use (Pierce, 2014; Vaughn-Sandler *et al.*, 2014; Kimbell *et al.*, 2015). Existing literature demonstrates that social withdrawal, and subsequent isolation, is common among family members living with, and

providing care for, individuals with stigmatised conditions, including physical disability, HIV, and mental illness (e.g. Herek *et al.*, 2003; D'Ardenne, 2004; Sartorius, 2007; Overton and Medina, 2008; Golics *et al.*, 2013; Kontomanolis *et al.*, 2017; Theed *et al.*, 2017).

Beyond social avoidance of illness/death and stigma, participants' accounts suggested that social withdrawal could also be influenced by the social view of their relative as different from the norm, someone for whom the future was deeply uncertain. The 'liminal existence' (Standing *et al.*, 2017) of individuals on transplant waiting lists appeared to unsettle others as it conflicted with the future-oriented nature of society, wherein people incessantly look to the future and plan ahead (Mellor and Shilling, 1993). Participant accounts revealed that while some individuals within their social network were willing to accept the uneasiness created by their uncertain future, others were not.

Limited social appreciation of the impact that the transplantation process had on their lives appeared to reinforce the sense of social isolation experienced by family members pre-transplantation. Several participants reported that their conversations with others increasingly centred on their ill relative, leaving them feeling socially invisible and insignificant. Dickson *et al.* (2010) argue that those assuming the role of caregiver can experience this sense of invisibility when their wellbeing is seen as secondary to that of the ill relative. This perception appeared to have a detrimental impact on family members' relationships with others, adversely affecting their willingness to seek support from individuals they had previously felt close to. Increased social focus on their ill relative also appeared to leave some participants feeling 'labelled' as a 'relative and/or carer of someone on the transplant waiting list', rather than an individual in their own right. 'Labelling' refers to a process by which an individual's identity and behaviour is determined or influenced by the way that others define and/or respond to them (Becker, 1963). These findings correspond with the findings of a US-based study by Stubblefield and Murray (2001), which highlights that parents can feel labelled, or set apart, by others following their child's lung transplant. My study demonstrates that family members (not just parents) can feel labelled pre-, as well as post-, transplantation and that this experience can contribute to the sense of social isolation they experience throughout the transplantation process.

My analysis shows that discussing transplantation with others can reinforce feelings of social disconnection among family members, by illuminating the chasm between social understanding of transplantation and the lived reality of the experience. Common misconceptions surrounding transplantation, including the views that: the waiting 'list'

denotes the order that individuals receive donor organs; it is possible to ‘schedule’ transplant operation; and, that transplantation is a ‘cure’; left family members feeling frustrated and alone, as they struggled to find intellectual common ground with those around them. While existing research acknowledges that this sense of misunderstanding can leave family members feeling isolated from their social network post-transplantation (McSweeney *et al.*, 1995; Stubblefield and Murray, 2001; Ågren *et al.*, 2014), this has not been documented pre-transplantation. My study highlights a sense of intellectual disconnection arising from involvement in the transplantation process (see figure 6), which can leave family members feeling increasingly isolated from their established social network pre-transplantation, like a ‘stranger’ among their peers (cf. Exley and Letherby, 2001). This sense of estrangement arguably constitutes another liminal experience for family members involved in the transplantation process, as they can be seen to drift between the social statuses of ‘insider’ and ‘outsider’ in relation to their established social network. The disparity between their experience and knowledge of the transplantation process and that held by their social network means that transplant families likely find it more challenging to obtain good social support than individuals living through other, more widely understood, illness/caregiving experiences (e.g. cancer).

Several of the issues reported regarding social relationships pre-transplantation, remained prevalent in participant’s post-transplant accounts, most notably: limited time and energy to socialise and poor social understanding of the transplantation process. The time and energy that family members had to interact with their social network was felt to be limited in the weeks following the operation, as family members attended the transplant centre to provide care and support in the initial stages of recovery (see Section 8.2.1.1). Participants’ accounts indicated that this perceived social limitation did not necessarily ease following discharge from hospital, because whilst this marked a positive stage in their relative’s trajectory, it did not signify the end of their care needs (see Section 8.2.1.2). Research exploring the social implications of providing informal care post-transplantation is limited. A US-based study by Kurz (2001b) exploring the post-transplantation experience of partners of lung recipients is a rare exception, reporting that partners often feel limited in their ability to connect with their social network as life continues to be dictated by their partner’s care needs. My study expands on these findings by revealing that this experience is not unique to partners, but that other family members feel similarly limited in their ability to engage with their social network as

they provide informal care post-transplantation. Participant accounts suggest that limited time and energy to socialise had a significant, detrimental impact on their ability to access social support post-transplantation, further disrupting their sense of social belonging and isolating them in their caregiving experience.

Participants generally reported feeling well supported by their social network in the initial post-transplant period (up to around two months), however, this typically waned over time. This is somewhat unsurprising, given what is known about how individuals respond after disruptive events:

After the most acute situation of disruption [illness, divorce, bereavement], the people who stepped in to support the wounded return to their own lives and the support transforms into something less intensive [meaning] the wounded [...is] left to deal with the altered situation (Ketokivi et al., 2008, p. 263).

The decline in social interest and support was often attributed to widespread misconceptions of family life post-transplantation. The misconception that transplantation is a 'cure' was felt to be particularly problematic, as participants recognised that it fuelled the erroneous social belief that their relative would soon be enjoying full health. This finding is congruent with the reports of a US-based study by Stubblefield and Murray (2001) and recent Canadian research by Mantulak and Nicholas (2016) which acknowledge that parents can feel socially isolated post-transplantation because of poor social understanding about the challenging reality of caring for a child with a transplant. My study adds to the findings of this research by illuminating that in addition to parents, other family members can feel misunderstood by, and thus consequently unsupported by and isolated from, their social network post-transplantation. Contrary to the hopes of many family members, who believed that they would feel 'normal' and be able to re-establish a sense of social belonging post-transplantation, the continuation of intellectual disconnection worked to reinforce their liminal position between the positions of 'insider' and 'outsider' in relation to their social network for some time post-transplantation.

To address the social disruption and isolation they experienced, several family members established new relationships with other transplant families they met while their relative recovered (see Chapter 7, Section 7.2). Forming relationships with individuals in a similar situation, otherwise known as 'sympathetic others' (Goffman, 1963, p. 32) or 'fellows in fate' (Ketokivi et al., 2008, p. 268), gave family members insight into the 'normality' of their experience, and thus afforded them a sense of social legitimacy in this regard (cf. Ketokivi *et*

al., 2008). This appeared to alleviate the sense of otherness, and subsequent loss of social identity/sense of belonging, that family members typically experienced when interacting with their existing social network. Such behaviour has previously been reported among relatives providing informal care in a range of contexts, including motor neurone disease (Locock and Brown, 2010) and Parkinson's disease (Theed et al., 2017). Reflecting on such support in the context of transplantation, Stubblefield and Murray (2002) acknowledge that while parents of children undergoing transplantation provide vital support to one another in the transplant centre, this sense of support rarely persists post-discharge. This finding is supported by my research which shows that other transplant families appear to constitute a somewhat transient source of support for family members, rooted in a particular place, time, and shared sense of duty to be present and supportive. Returning home post-transplantation appeared to have a negative impact on family member's sense of belonging, and indeed their sense of self, as they again felt isolated from a community of individuals who shared their understanding and experience of transplantation (cf. Stubblefield and Murray, 2002). This is illustrative of another way that family members can experience a sense of liminality during their involvement in the transplantation process, as they fluctuate between feeling part of, and separate from, a community of individuals sharing the experience of supporting a relative through transplantation.

8.2.1.4 *Section summary*

In this section I have outlined the disruption family members can experience throughout the transplantation process, in relation to clinical encounters, family life, and social relationships. I have highlighted that while some elements of disruption are short-term and dissipate as families progress through the process, most are long-term and persist to some extent (or to varying degrees) for some time post-transplantation. This disruption appeared to have a significant effect on family member sense of self, leaving them feeling liminal; caught between the roles of 'family member' and 'carer', and 'insider' and 'outsider' (see figure 7). By demonstrating the disruptive interplay between the transplantation process and family member lifestyle and sense of self over time, a number of these findings support the growing argument that family members can experience biographical disruption as a result of a relative's illness. Literature searches did not identify other research exploring these issues, suggesting that this study provides new insight on the disruption experienced by family members throughout the transplantation trajectory.

8.2.2 Impression management

In this section I explore how family members attempt to limit disruption and regain a sense of control by investing time and energy in managing the way that others perceived, and consequently responded to, them. I examine the extent to which, and what ways, family members sought to manage how others perceived them throughout the transplant trajectory. I then comment on how such behaviour appeared to successfully alleviate the disruption experienced, particularly in relation to their sense of self (see figure 7).

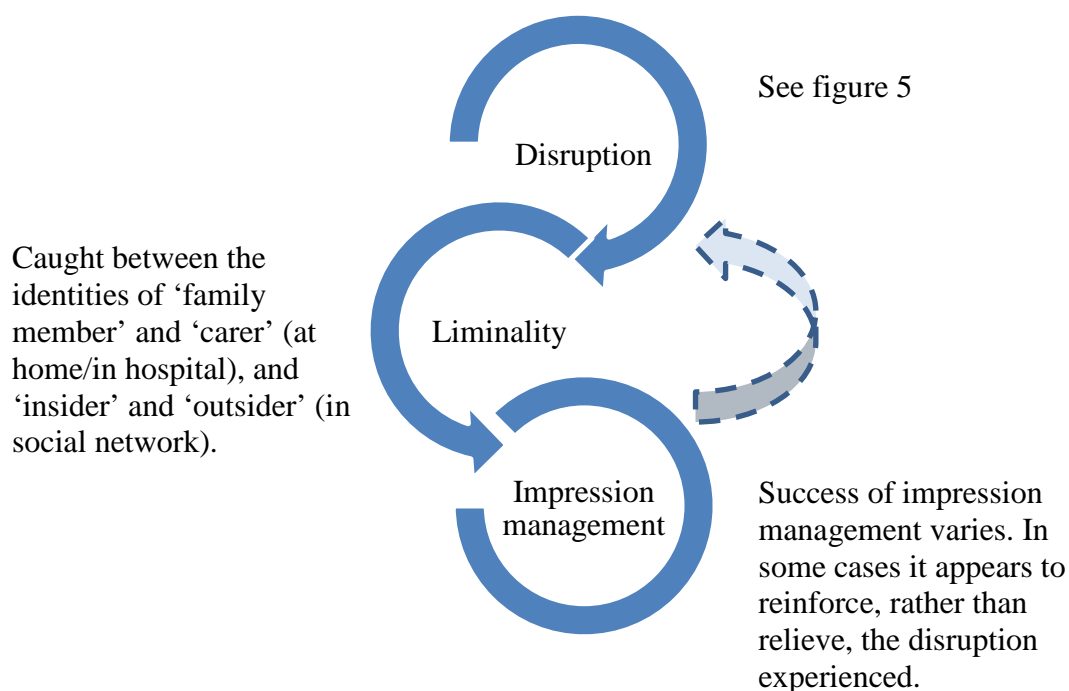


Figure 7: Diagram illustrating the interplay between disruption and impression management

In this section I refer to Goffman's work on presentation of self, most notably the concepts of 'face', meaning "an image of self delineated in terms of approved social attributes" (1955, p. 213), and 'front-stage' image, meaning behaviour that functions "to define the situation for those who observe the performance" (1959, p. 32). Alongside this, I consider the role of emotion work (Hochschild, 1979) (see Chapter 3, Section 3.2.5.4) in impression management, and the implications of this for family member wellbeing and sense of self. Reflecting the previous section, this section of the discussion is comprised of three parts related to the empirical chapters, to facilitate clear communication of the ways that family members

presented themselves in different contexts, namely: the transplant centre (Chapter 5), family life (Chapter 6), and social network (Chapter 7).

8.2.2.1 *Transplant centre*

Participants' accounts showed that they were conscious of, and keen to manage, their front-stage image within the transplant centre from an early stage of the process.

Family members appeared to manage their image in the presence of the transplant team in two key ways: by performing emotion work, and by physically demonstrating their willingness and ability to provide care. Individuals performed emotion work in the transplant centre by concealing negative feelings, such as insecurities about their ability to care and concerns about the future. In addition, they worked to appear engaged and committed to their relative's care, by being visibly present, contributing to conversations, stringently documenting what they were told, and demonstrating their expert knowledge of their relative (medical and personal). My analysis suggests that family members behaved in this way to adhere to social understanding of what it means to be a 'good carer'; that is a responsible and committed individual, who diligently tends to their care-recipient's needs (Pickard, 2010). Establishing themselves as a good carer appeared key to reducing participant's sense of role ambiguity within the transplant centre and to facilitate the negotiation of a collaborative role as 'co-carer'. Allen (2000) argues that it can be extremely difficult for family members to contribute to their relative's care in clinical environments, as their input is often interpreted as criticism by clinical staff. Sensing this, family members often exercised caution when interacting with the transplant team, keen to avoid offending them and to preserve their inclusion in their relative's future care. Arguably, all family members accompanying an ill relative to hospital are likely to feel some pressure to present a good front-stage image to clinical staff, however, this pressure appears particularly intense for transplant families pre-transplantation as they are aware that the transplant team vet their ability to provide good informal care as part of the pre-transplant assessment checks (see Chapter 2, Section 2.3.2 for further detail).

Accounts of life post-transplantation suggest that most family members continued to perform emotion work in the presence of the transplant team, concealing negative feelings and concerns to preserve the good carer image they had endeavoured to portray pre-transplantation. For some, engaging in this emotion work proved more challenging post-transplantation, as they harboured frustrations about not feeling fully-informed about their

relative's condition (see Chapter 5, Section 5.3). Aside from doctor-patient confidentiality (see Section 8.2.1.1), medical terminology was reported to constitute a barrier to feeling informed post-transplantation. Wittenberg-Lyles et al. (2013) argue that the use of medical terminology creates distance between clinical teams and the patient and their family, generating trust issues and decreasing satisfaction. Data collected within my study supports this argument, and thus I suggest that there may be scope to improve family members experience within the transplantation centre by reducing the routine use of medical terminology.

As well as managing their emotions around the transplant team, several participants reported that they felt the need to conceal or project particular emotions around other transplant families, to help bolster their emotional wellbeing. For example, some recalled consciously avoiding overtly positive displays of emotion, such as joy about improvements/the imminent discharge of their relative, as they were conscious that this might exacerbate the grief felt by others. This is illustrative of one way that engaging with sympathetic others can be a 'double-edged sword' (cf. Revenson *et al.*, 1991), as rather than offering relief, such interaction appeared to increase the emotion work that family members felt required to perform, exacerbating the potential for emotional exhaustion (cf. Stubblefield and Murray, 2002).

8.2.2.2 *Family life*

Much of the impression management that participants engaged in occurred behind closed doors with their family. Central to this, it was common for participants to report attempting to conceal, or 'cover' (Goffman, 1963), physical strain and negative feelings (e.g. anxiety/stress) to maintain face around their family. Participants were particularly conscious of covering how they felt in the presence of ill and/or vulnerable relatives, such as young children and elderly parents. Family members appeared keen to conceal the anxiety and distress that they felt about their relative's illness and imminent transplant, as they feared that disclosing these feelings may have ramifications for their relative's psychological wellbeing (cf. Wilkinson and McAndrew, 2008 in the context of informal care and mental health). It is also possible to suggest that repressing their anxiety around others was a form of self-protection, as it meant that they did not have to confront, and subsequently deal with, how they felt (cf. Elias, 1985). As well as repressing negative emotions, family members recounted that they were conscious of concealing the impact of care-related activities from their ill relative. Accounts revealed that this emotion work was influenced by a desire to ease tension in relationships and protect

their ill relative's wellbeing and sense of autonomy. The latter appeared particularly important to family members, as it helped them to sustain a 'normal' relationship and thus limited the identity discrepancy that they experienced (Aasbø *et al.*, 2016) (see Section 8.2.1.2). Moore and Gillespie (2014) warn that efforts to make the care role invisible to others to protect the care-recipient's identity can have a negative effect on caregiver identity. The consequences of this were evident in the data collected during my research, as some participants reported feeling as though their ill relative, and others within the family, underestimated the importance of, and strain resulting from, their care role (cf. Hennings *et al.*, 2013; Moore and Gillespie, 2014). Concealing challenging emotions and downplaying their care role came at a personal cost, both in terms of participant sense of self (as a 'carer') and their wellbeing. My data show that sustaining this emotion work took a toll on participant's physical and psychological health over time (cf. Mac Rae, 1998) (see Chapter 6, Section 6.1.1). Acknowledging this, the findings of my study can be understood to support the assertion that concealing the implications of illness from other family members is a paradox, as it can create more problems than it prevents (Aasbø *et al.*, 2016).

Sustaining emotion work during the wait for a transplant was challenging, and several participants recounted moments where they lost control of their emotions in the presence of their relatives, displaying anxiety, anger, and even resentment. This was particularly prevalent in the accounts of individuals who waited for longer than expected prior to receiving 'the call' and those who received numerous 'false alarms' (see Chapter 2, Section 2.3.4 for further information on 'the call' and 'false alarms'). Family members appeared to feel guilty about failing to control their emotions, or 'losing face' (Goffman, 1955), around their family, particularly the ill relative, as they feared that this could have a harmful effect on their psychological wellbeing. The regret family members felt about expressing negative emotions appeared tied to the sense that they had failed to maintain carer-appropriate feelings, such as tolerance and strength, and thus had not complied with social feeling rules about being a 'good carer' (Olson and Connor, 2015, p. 865). Feeling rules are social rules that dictate the correct behaviour to exhibit (Hochschild, 1979) (see Chapter 3, Section 3.4.1.1 for detail). Lapses in their ability to control their emotions appeared to leave family members questioning others', and their own, confidence in their ability to fulfill the role of 'carer', and thus had a detrimental effect on their sense of self (cf. Mac Rae, 1998).

Post-transplantation, family members continued to manage others' perceptions of them by engaging in emotion work. In the initial post-transplant period, family members continued to downplay the strain that they felt in relation to their household, financial, and care responsibilities, conscious that knowledge of this may adversely affect their relative's recovery or family relationships. Over time, the way in which family members performed emotion work appeared to change, depending on their relative's recovery. Family members of individuals who made a poor recovery, in terms of outcome and timescale, worked to conceal the sense of frustration and disappointment that they felt about the disparity between the post-transplant life they had imagined and that which they were living. The accounts of family members whose relative made a good recovery demonstrated they too continued to manage their emotions around their family. This was particularly the case among individuals who felt an affinity with the carer role, who reported a sense of loss as their requirement to care diminished and they became a former carer (cf. Larkin, 2007; Corey and McCurry, 2017; Cavaye and Watts, 2018) (see Section 8.2.1.2). Though they predominantly worked to conceal the loss that they felt from their family, participant's accounts revealed that they also worked to suppress it in the presence of the transplant team and their wider social circle. The drive to conceal this feeling appeared rooted in the felt pressure to adhere to feeling rules (see above) associated with being a good carer, in this case: that they should feel happy and relieved about the care-recipient's improved health. The tension between the socially expected emotions, of happiness and relief, and their actually experienced emotions, of loss and grief, led these family members to experience 'emotional dissonance' (Hochschild, 1979) (see Chapter 3, Section 3.2.5.4 for detail) as their relative recovered (or did not).

Irrespective of how well their relative recovered, most participants acknowledged that they were reluctant to vocalise the inescapable sense of uncertainty and concern that they felt about their relative's future health (Kurz, 2002; Mantulak and Nicholas, 2016). As well as not vocalising their uncertainty with their relatives, participant accounts showed that they also attempted to repress the uncertainty that they felt within their own minds. It was common for participants to recount willing themselves to focus on the positives, such as the 'extra' time that the transplant had given them together, rather than the eventual failure of the donor organ and subsequent death of their relative. While this approach has been acknowledged within quantitative studies exploring the coping strategies used by transplant families, as 'positive reinterpretation' (Burker et al., 2005), it is largely absent from qualitative research exploring family experience. This finding appears to support Hochschild's (1979) suggestion that individuals do not just perform emotion work on others, but can also use it to reassure oneself.

However, it is possible to reason that family members felt compelled to present a positive face post-transplantation to abide by feeling rules, specifically that transplant recipients and their families should feel happy and grateful that a suitable donor was found and the operation was performed.

8.2.2.3 *Social network*

Family members not only sought to maintain a certain face with those directly involved in the transplantation process, but also in the presence of their wider social network. Several participants reported that they were keen to conceal the challenging reality of their life around their social network, including the pressures of informal caregiving and the uncertainty of the transplantation process, to appear ordinary and thus maintain their ‘normal’ social relationships (cf. Stubblefield and Murray, 2001). Similar efforts to cover the strain of caregiving from others have been reported among family members providing informal care to relatives with chronic conditions, including cancer (Moore and Gillespie, 2014; Knowles et al., 2016). Knowles et al. (2016), for example, report that family members conceal the impact of illness from friends and family to protect the ill relative’s identity as independent and thereby disassociate themselves from the carer identity, which they fear could disrupt their relationships with others. In this study, while transplant families engaged in covering to appear normal and thus maintain social relationships and reduce feelings of social isolation, this desired effect was not always realised. For some, concealing the extent and effect of their caregiving demands from others appeared to reinforce rather than relieve their sense of social isolation, by perpetuating social misconceptions surrounding transplantation and limiting social understanding of their caregiving role (i.e. its prevalence and importance) (see Chapter 7, Section 7.1.1). By acting as a barrier to social comprehension of their caregiving role, this emotion work also appeared to disrupt participants’ sense of self, by undermining their emerging caregiving identity (Moore and Gillespie, 2014).

Family members were also concerned about other people’s perceptions of their ill relative. They were mindful that some within their social network held opinions about who should receive a donor organ, informed by social understanding of, and investment in, organ donation (for example, knowledge of the scarcity of donor organs and ethical issues). Pre-empting this, family members often worked to frame their relative as ‘deserving’ of a transplant, by promoting their ‘high moral status’ through acknowledging their grateful and compliant nature and emphasising that they were blameless for their condition (Charmaz and

Belgrave, 2013). Responding to anticipated social judgement in this way proved emotionally taxing for some family members, and appeared to leave them feeling frustrated and exhausted following interactions with their social network (cf. Olson and Connor, 2015). This was particularly prevalent in the accounts of family members of those awaiting a liver transplant, who were keen to disassociate their relative from problematic conditions, particularly alcoholism. This supports recent claims that anticipated or perceived stigma can significantly influence the way that individuals disclose information to others (Kaushansky *et al.*, 2017). My study is the first to comment on the stigma by association, or ‘courtesy stigma’ (Goffman, 1963), experienced by families involved in the transplantation process.

My research shows that family members continue to manage their front-stage image in social settings for some time post-transplantation. As before surgery, several participants discussed downplaying negative feelings (e.g. discontent, anger, fear, and frustration) or problems around their social network. O'Brien (2017) argues that organ recipients can feel constrained when recounting their experience to others, as:

Sanctioned ways of encountering and speaking about transplantation exist, and the voicing of aspects of transplantation that do not conform to gift-of-life discourse represents a social taboo. (p. 232)

Family members in this study experienced a similar sense of social pressure to: conceal negative elements of their experience; adhere to feeling rules associated with the transplantation process, particularly the belief that organ recipients and their families should be thankful; and, express gratitude toward the donor and the health professionals that ‘saved’ their life. A sense of indebtedness to the transplant team, coupled with the fear that they may be viewed as ‘undeserving’ or ‘ungrateful’ by others, seemed to deter participants from raising issues or verbalising negative feelings related to their experience of transplantation. However, this was not the only motivation for such emotion work. For some participants, attempts to minimise negative feelings and problems experienced post-transplantation appeared driven by a personal desire to disassociate themselves from their transplant experience and re-establish a ‘normal’ life. In this way, participants appeared to use emotion work to shed the labels of ‘carer’ or ‘relative of a transplant recipient’ (see Section 8.3.1.2) and re-establish their identity as a member of the mainstream group (Exley and Letherby, 2001; Knowles *et al.*, 2016). Attempts to re-establish themselves as ‘normal’, though rooted in a desire to feel included, appeared to further isolate some by reminding them of just how different they were as a result their transplantation experience.

8.2.2.4 Section summary

In this section I have outlined how family members consciously ‘manage face’, in the presence of various individuals throughout the transplantation process (see figure 8). I have highlighted the influential role that feeling rules concerning informal caregiving and transplantation play in this. Further, I have demonstrated the centrality of emotion work to impression management, and the potential implications of such behaviour for family member wellbeing and sense of self. In addition, I have outlined that while the aim of impression management was to manage the impact of the disruption experienced, occasionally it appeared to exacerbate this disruption by inadvertently further isolating family members in their experience. This is the first study to explore the emotion work performed by family members throughout the transplant trajectory.

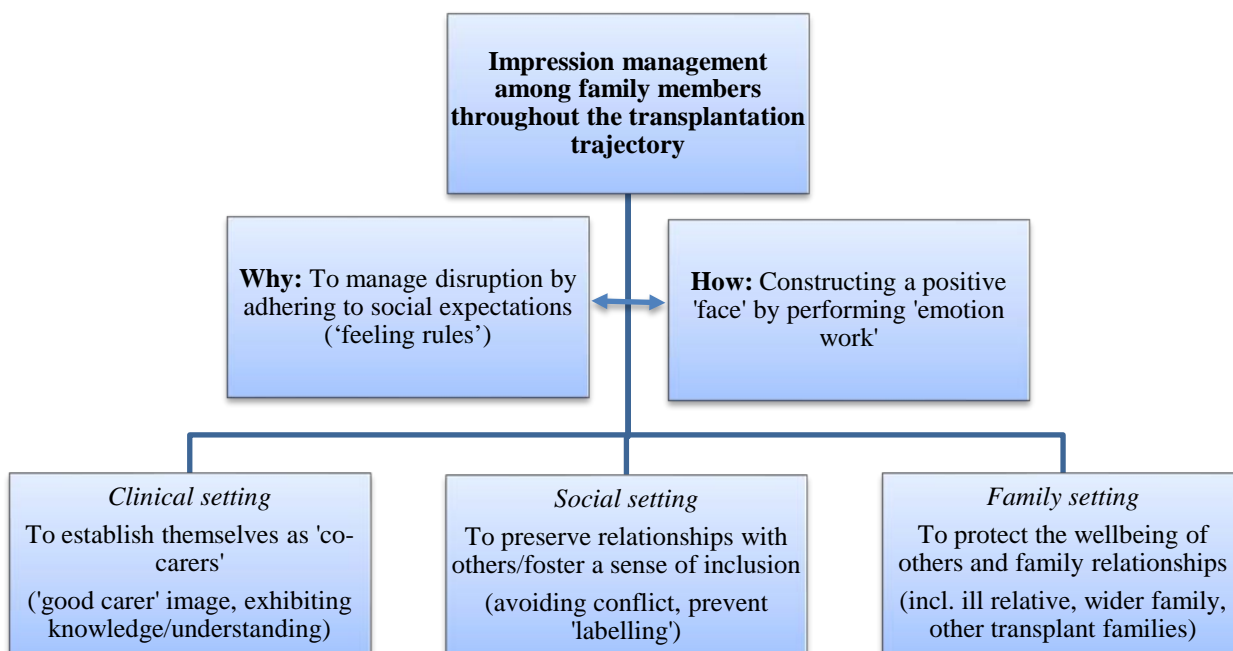


Figure 8: Summary diagram of impression management among family members throughout the transplantation trajectory

8.3 Strengths of this research

This is the first UK-based qualitative study to explore the impact of the transplantation process upon family members of individuals waiting for, or living with, a heart, liver, and/or lung transplant (see Chapter 3 for an overview of the existing research on this topic from other countries). As such it offers vital insights into an under-researched area. By placing the family members at the centre of the enquiry, rather than treating them as a secondary concern, my study gives a voice to this all-too-often overshadowed group of individuals. In doing so, I validate the family experience of transplantation in the UK and permit comparison between this and experiences reported elsewhere, including the USA, Canada, and Brazil. Most participants (n=19) recounted experiences of the same UK-based transplant centre, however, the remaining participants (n=5) discussed five different transplant sites and yet many of their findings overlapped, suggesting that family experience is somewhat consistent regardless of clinical setting. By considering the findings alongside broader literature, my research highlights the ways that providing care for a relative experiencing transplantation both differs from, and is similar to, other care contexts, contributing to the wider social scientific understanding of caring for a relative.

The use of longitudinal and retrospective interviews was a particular strength marking my research out from other work on this topic. Longitudinal interviews provided insight into the 'raw', real-time, emotion experienced by family members during their involvement in the transplantation process, revealing the extent to which participant experience and needs can fluctuate over time (in relation to each 'stage' of the process, see Chapter 2, Section 2.3). The data I collected retrospectively differed, in that it was more reflective rather than descriptive in nature, as participants had had time to process their experience and were able to discuss the longer-term implications of their relative's transplant.

The narrative interview style used meant that the interview was participant-led, allowing them to focus on experiential elements that they deemed most important. This allowed me to remain sensitive to the inherent variation within individual experience, ensuring I avoided making assumptions that may have affected the quality of the data collected. The relaxed, conversation-like style of narrative-style interviews proffered data of a more open and candid nature than I was anticipating. Indeed, several accounts challenged those that are socially expected from those living with, or providing care for, an ill relative, in that participants admitted harbouring negative feelings, such as resentment, toward their relative due to their physical and/or mental limitations.

The analytical approach adopted, underpinned by my interpretative epistemological beliefs, constitutes another strength of my study as consideration was given to the six trustworthiness criteria: 1) credibility, 2) transferability, 3) dependability, 4) conformability, 5) audit trails, 6) reflexivity (Nowell *et al.*, 2017). The iterative approach used during data collection and analysis to determine and refine themes was strengthened by measures used to ensure the credibility of my analysis, such as peer debrief and peer scrutiny (Shenton, 2004). The flexibility of the thematic approach aided the management and examination of the data set, facilitating the identification of similarities and differences in participants' pre- and post-transplant experiences (cf. Nowell *et al.*, 2017). Further, the use of the data management software NVivo facilitated systematic and robust data coding and comparison (Baba and Yusoff, 2011).

8.4 Limitations of this research

The use of convenience, rather than purposive, sampling is perhaps the most notable limitation of my study. This approach meant that several groups within the potential participant population (see tables 5 and 6, Chapter 3, Section 4.3.4.1) are better represented than others, particularly: parents/partners, women, and those above the age of 40. However, this is unsurprising, given the mean age of individuals listed on liver, heart, and/or lung transplant waiting lists (52, 47 and 47 years respectively (NHSBT, 2013a), and that women are more likely to volunteer to participate in qualitative research (Dindia and Allen, 1992; Robinson, 2014). I am aware that the comparatively small number of men, siblings/adult children, and individuals below the age of 40, could be argued to limit the extent to which the findings of my study are deemed representative of the 'family experience'. Further, as only one participant was (or admitted to being) related to someone who required a transplant because of 'risky' behaviour (smoking/alcohol-consumption/drug-use), I am conscious that the findings of my research may not be wholly applicable to this group as they are likely to encounter different social and clinical responses.

The decision to recruit through transplant charities, as opposed to NHS transplant teams, could be viewed as another key limitation of my study. The primary reasoning for this decision was rooted in concerns about recruiting individuals with a range of experiences. As one of the key objectives of this study was to assess how supported family members felt within the transplant centre, the decision was taken not to recruit through the transplant teams for two main reasons. Firstly, I was keen to present myself as independent of the transplant

team, aware that any perceived affiliation may affect participant willingness to disclose negative elements of their experience (see Chapter 4, Section 4.3.4.6). This would have been very challenging to achieve if I was relying on the transplant team to distribute recruitment materials. Secondly, I was aware that transplant teams could, consciously or unconsciously, prevent me from speaking to individuals who may recount a negative experience, damaging the extent to which my research was representative of the family experience. I acknowledge that it is possible to argue that recruiting through transplant teams may have allowed me to achieve a broader sample (inclusive of the underrepresented groups discussed previously), however, this is not a certainty and may have even had a detrimental effect on the data I was able to collect.

It is possible to suggest that my research is also limited by my decision to collect data via narrative-style interviews, rather than using alternative qualitative methods. Employing alternative qualitative approaches, such as observations or ethnographic fieldwork instead of or alongside interviews, might have enabled the acquisition of data not obtainable through interviews. However, I decided not to use such methods as I felt it was inappropriate to shadow or approach family members attending the transplant centre to support their relative through transplant surgery, given the emotionally challenging nature of this scenario. Further, I could see several practical issues that would likely limit the data that I could feasibly collect using this approach, most notably the comparative rarity of heart, liver, and/or lung transplant procedures. In light of these factors, I deemed narrative-style interviews the most appropriate method of data collection, both ethically and practically, as it allowed individuals to engage with the research, in a non-clinical environment, when they felt ready to discuss their experience. Additional benefits of using this approach have previously been discussed at several points throughout this thesis (see Chapter 4, Sections 4.2.3, and 4.3.2.2; Chapter 8, Section 8.3).

The absence of data detailing the perspective of the transplant team could be seen as a further limitation of my study. Collecting data from the transplant team, alongside family members, could have strengthened the findings of my research by providing context (re. the support offered etc.) and/or a potential counter-argument. The decision to focus solely on family members was embedded in my desire to give voice to, and prioritise the views of, individuals who are routinely overlooked in transplantation research in favour of the patient and/or clinical team. As is often the case in transplantation research, I was conscious that collecting and presenting data from the transplant team might detract from, or limit the depth to which I

was able to explore, the family experience. In retrospect, I acknowledge that ascertaining the views of the transplant team could have aided the development of, and clinical engagement with, the recommendations arising from this study, and would suggest that future research consider this approach.

Chapter 9. Conclusion: Recommendations and future research

The overall aim of this research was to explore the extent to which, and in what ways, the transplantation process affects family members of individuals waiting for or living with a heart, liver, and/or lung transplant in the UK. I have achieved this by providing a comparative analysis of pre- and post-transplant accounts, focusing on the impact of the transplantation process on family member roles, relationships, wellbeing, and sense of self. As little is known about the experience of transplant families in the UK, my thesis provides a novel sociological perspective on a frequently overlooked group and reveals similarities between the family experience in the UK and elsewhere. As I have contextualised my findings in relation to broader research on informal caregiving, my thesis also sheds light on the extent to which caring for a relative throughout the transplantation process reflects (or not) other caregiving experiences, such as individuals caring for relatives living with cancer and/or dementia. In this chapter I conclude this thesis by discussing the clinical implications and recommendations of this research, prior to suggesting some areas for future research.

9.1 Implications and recommendations for clinical practice

In this section, I outline some of the key implications of my study for clinical practice, alongside recommendations concerning the delivery of professional support for family members living with, and/or providing care for, a relative awaiting or living with a heart, liver, and/or lung transplant. Some may argue that the role of the transplant team is to treat the transplant patient, thus tending to the needs of the family is a task that lies beyond their remit and responsibility. However, this view overlooks the integral role that family members play in the transplantation process and the extent to which their experience is entwined with that of the patient (cf. Cater and Taylor, 2017). Transplant teams encourage family involvement throughout the transplantation process, prioritising this as one of the key criteria a patient must meet to be considered eligible for a transplant (see Chapter 2, Section 2.3.2), thus it is reasonable to suggest that they should provide support for family members. As well as having a potentially negative affect on patient recovery, overlooking the needs of the family could also create ‘new’ patients, in anxious, depressed, and exhausted (physically and emotionally) family members, thus it is essential that their support needs are assessed and addressed throughout the transplantation process.

The most notable finding of relevance to clinical practice relates to family experience of communicating with the transplant team. Family members reported struggling with the content (re. volume, style, and clarity) and timing of conversations, particularly pre-transplant when they were first learning about the transplantation process. Information delivery was felt to be patient-centred, with the family treated as a secondary concern. While this approach was not felt to be ‘wrong’, it was a source of frustration. It was common for family members to report that they felt the negative elements of the transplantation process were not given enough attention, leaving them feeling unprepared for the issues that they encountered. Though they recognised the need for positivity, they stressed that they would have appreciated more information about what could go wrong, and the long-term negative implications of transplantation. Transplant teams could address these issues by reviewing the way information is distributed to the patient and their family. It is vital that transplant teams are clear and concise in their approach, limiting the volume and complexity of information given at any one time, to prevent families from becoming overwhelmed and/or confused. Transplant teams must also work to strike a balance between encouraging the family to remain positive, and acknowledging the numerous challenges, family- and patient-specific, associated with transplantation. To address the variable information needs of family members, transplant teams could distribute family-specific resource(s) for family members to read at their own pace and return to for reference throughout the process. Transplant teams commonly distribute information to patients in this way; however, it is rare for families to receive a document tailored to their experience.⁴³ This resource should include an overview of their role in the process, what to expect at each stage (including answered FAQs),⁴⁴ support available, and links to clinically approved resources (such as [healthtalk.org](http://www.healthtalk.org)⁴⁵). As well as validating their experience as important, such a resource could facilitate family members to feel better prepared for the issues that they may face in the later stages of the process.

My study has demonstrated that the roles and relationships, central to sustaining family member’s sense of self and wellbeing, are subject to significant change throughout the transplantation process. As has been reported among patients (Bogue Kerr *et al.*, 2017;

⁴³ One notable exception includes a leaflet distributed by Toronto General Hospital to families during lung transplantation (Whytehead *et al.*, 2018).

⁴⁴ Given the lack of resources acknowledging what is involved in the transplantation process, these resources may benefit from the inclusion of a summary diagram similar to Figure 2 – see Chapter 2, Section 2.3

⁴⁵ Healthtalk.org have a page detailing the impact of transplantation on friends and family, see:

<http://www.healthtalk.org/peoples-experiences/organ-donation-transplant/organ-donation/effects-family-and-friends>

Accessing the experience of others through this page could help family members normalise their experience and/or raise awareness about what to expect in the future.

Cormier *et al.*, 2017), transplantation can constitute a liminal experience for family members as they find themselves “betwixt and between” (Turner, 1969) the roles of ‘family member’ and ‘carer’. Family members struggled with a strong sense of role ambiguity while in the transplant centre, as they were unsure of their care responsibilities in the presence of formal carers. Transplant teams could do more to alleviate this sense of uncertainty by clarifying their expectations of family members and/or working to actively include them in their relative’s care while they are hospitalised (cf. Gibbons *et al.*, 2014). This could be improved by altering practice in line with the recommendations made in the ‘Triangle of Care’, a guideline for improving collaboration and partnership between formal and informal carers providing acute care (Worthington and Rooney, 2010). Six key elements required to achieve the Triangle of Care (between formal carer, service user/patient, and informal carer/family), listed below, could be used as a basis for change:

1. Identify carers, and the essential role they play, as soon as possible. Acknowledge and/or seek their views and/or knowledge, and regularly update them on care plans and strategies.
2. Ensure staff are ‘carer aware’ and trained in carer engagement strategies, to encourage awareness of, and respect for, the valuable contribution of carers and their needs.
3. Implement policy and/or practice protocols regarding confidentiality and information sharing.
4. Establish defined post(s) responsible for carers, such as a carers’ lead or ward champion.
5. Provide a carer introduction to the service and staff, with relevant range of information across care pathway (incl. introductory letter with contact details, appointment with a named team member to discuss views and involvement, ward orientation, resource provision, and planning for discharge and aftercare support).
6. Provide access to a range of carer support services (e.g. carer support, carer needs assessment, and/or family work), with regular assessment and auditing to ensure continuance and efficiency.

(Worthington and Rooney, 2010)

While the support provided by transplant teams was felt to reflect these elements to an extent, some areas require further attention. For example, transplant teams would benefit from reviewing the confidentiality and information sharing protocols with family members, as participants felt the current approach was exclusionary. Future service changes should be developed in partnership with family members.

An additional point of note for clinical audiences concerns the propensity for family members to perform emotion work in the presence of their ill relative and health professionals, to 'manage face' (Goffman, 1955). My study reveals such emotion work can have significant personal costs for family members, as it can act as a barrier to support and result in emotional exhaustion. It is important that transplant teams are aware of, and sensitive to, the emotion work performed by family members throughout the transplantation process, as they are best placed to prevent and/or address the negative outcomes of this. To accomplish this, transplant teams could offer confidential one-to-one consultations; an opportunity for family members to ask questions and/or discuss their feelings without fear of jeopardising the way they are perceived by the wider transplant team or upsetting their relative. As family members are keen to project the image of a good carer, and thus are reluctant to seek support or divert attention away from their ill relative, transplant teams must initiate, and encourage family members to engage in, these discussions. This approach could relieve some of the anxiety experienced by family members, by acting to validate their experience as important and of interest to the transplant team (cf. Hasselkus and Murray, 2007).

My study further revealed that the social perceptions and misconceptions of illness, death, and transplantation can leave family members feeling disconnected and isolated from those they would usually turn to in times of need. Transplant teams could do more to acknowledge and address the social ramifications of the transplantation process for family members and the subsequent impact on individuals' felt ability to access social support. This could be achieved by facilitating relationships between transplant families, past and present. My data suggest that, on the whole, family members are keen to establish relationships with other transplant families who have knowledge of, and thus are able to empathise with, their situation. However, given the rarity and complexity of transplantation, they typically struggle to locate and connect with families in a similar situation to their own. Considering their access to, and knowledge of, family members involved in transplantation, transplant teams are arguably best placed to facilitate contact, if both parties desire this. Providing opportunities for transplant families to socialise with one another could potentially work to normalise their experiences, reducing the sense of social isolation and enhancing wellbeing. In facilitating such relationships, it is important for transplant teams to be open with families about the possible negative implications of establishing such relationships, such as exposure to others' emotional issues, to allow them to make an informed decision about whether to engage with this form of support.

The long-term impact of the transplantation process on family members constitutes another clinically relevant finding. Data revealed that family members often continue to feel anxious and stressed for a significant period of time post-transplantation, as they continue to come to terms with their experience and the uncertainty around their relative's health. While organ recipients are assessed and actively supported by the transplant team for the rest of their lives, comparatively little consideration or support is given to the family living with and/or caring for these individuals. It is important that transplant teams remain conscious of family members' ongoing psychological and emotional support needs, and work to actively signpost individuals to appropriate support services, within or independent of the transplant team (GP, social worker, psychologist etc.).

For a concise set of good practice points for clinical consideration and/or dissemination see Appendix 10. In reviewing and implementing these suggested changes, it is important to remain conscious of the limitations of this research, particularly the limited sample characteristics and lack of a counter-narrative from professionals (see Chapter 8, Section 8.4 for further details).

9.2 Future research

My study is the first to provide a sociological analysis of the family experience of the pre- and post- transplantation processes in the UK. While I explore several elements of the family experience, I am aware that some aspects require further attention. I present some key areas for future research below.

- Data from my study suggest that public perception of transplantation could influence social and clinical interaction with family members of individuals requiring, or living with, a transplant as a result of risk-related behaviour (e.g. smoking, alcohol-consumption, and drug-use). More research focusing on this group is needed to determine the extent to which, and in what ways, their experience differs from families of individuals not deemed responsible for their illness, particularly in terms of perceived stigma.
- My research highlights that involvement in the transplantation process can continue to affect family life for some time post-transplantation. Few studies have commented on, or sought to explore, the impact of involvement in the transplantation process on

family members beyond one year post-transplantation. More lengthy longitudinal research is required to improve understanding of the longer-term effects of living with, or providing care for, a relative living with a transplant.

- Accounts collected from participants involved in an ‘unsuccessful’ transplant⁴⁶ (one participant involved in a re-transplantation, two participants bereaved) revealed significant negative ramifications of transplant. Further research on this experience is needed to improve academic and professional understanding of how transplant failure can affect family view of transplantation and relationships with the transplant team, and gain insight into how best to support these individuals.
- The data collected in my study reveal that family members are often involved in, and can feel significantly affected by, the process of negotiating a relationship with the donor/donor family. Research rarely comments on the development, nature, and effect of relationships established between recipient- and donor-families. Further investigation is required to enhance our understanding of how these groups view and interact with one another, to help health professionals improve the support offered to families on either side of the transplantation process.

⁴⁶ An ‘unsuccessful’ transplant refers to cases where the transplant is deemed to have failed (e.g. acute rejection). Depending on the type of transplant and the condition of the recipient, they may be placed back on the waiting list for re-transplantation. However, in most cases the recipient will die.

Chapter 10. References

- Aasbø, G., Solbrække, K.N., Kristvik, E. and Werner, A. (2016) 'Between disruption and continuity: challenges in maintaining the 'biographical we' when caring for a partner with a severe, chronic illness', *Sociology of Health & Illness*, 38(5), pp. 782-796.
- Åberg, A.C., Sidenvall, B., Hepworth, M., O'Reilly, K. and Lithell, H. (2004) 'Continuity of the self in later life: Perceptions of informal caregivers', *Qualitative Health Research*, 14(6), pp. 792-815.
- Adamson, J. and Donovan, J. (2005) 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK', *Social Science & Medicine*, 60(1), pp. 37-48.
- Aghahosseini, S.S., Nayeri, N.D., Shahsavari, H. and Tosi, M.N. (2017) 'Life experiences of hepatitis patients waiting for liver transplantation', *Hepatitis Monthly*, 17(10), pp. 1-9.
- Agren, S., Ivarsson, B. and Ronning, H. (2014) 'The Unsteady Mainstay of the Family: Now Adult Children's Retrospective View on Social Support in Relation to Their Parent's Heart Transplantation', *Nursing research and practice*, 2014, pp. 541241-541241.
- Ågren, S., Ivarsson, B. and Rönning, H. (2014) 'The Unsteady Mainstay of the Family: Now Adult Children's Retrospective View on Social Support in Relation to Their Parent's Heart Transplantation', *Nursing research and practice*, 2014.
- Alba, A.C., Bain, E., Ng, N., Stein, M. and Brien, K.O. (2016) 'Complications after Heart Transplantation: Hope for the Best, but Prepare for the Worst', *International Journal of Transplant Research and Medicine*, 2(2), pp. 1-11.
- Allen, D. (2000) 'Negotiating the role of expert carers on an adult hospital ward', *Sociology of Health & Illness*, 22(2), pp. 149-171.
- Alvesson, M. (2002) *Postmodernism and social research*. Buckingham: Open University.
- Årestedt, L., Persson, C. and Benzein, E. (2014) 'Living as a family in the midst of chronic illness', *Scandinavian Journal of Caring Sciences*, 28(1), pp. 29-37.
- Arksey, H. and O'Malley, L. (2005) 'Scoping studies: towards a methodological framework', *International Journal of Social Research Methodology*, 8(1), pp. 19-32.
- Baba, S. and Yusoff, M. (2011) 'NVivo as a tool for rigor and efficiency in qualitative research', *2nd International Conference on Computer-Aided Qualitative Research Asia*. Macau, 24-25 February.
- Bag, R., Bhimaraj, A. and Garikipati, S. (2014) 'Role of Primary Care Provider in the Referral and Care of Thoracic Organ Transplant Patients', in Kirk, A.D., Knechtle, S.J., Larsen, C.P.,

- Madsen, J.C., Pearson, T.C. and Webber, S.A. (eds.) *Textbook of Organ Transplantation Set*. Sussex: Wiley & Sons.
- Bahn, S. and Weatherill, P. (2013) 'Qualitative social research: a risky business when it comes to collecting 'sensitive' data', *Qualitative Research*, 13(1), pp. 19-35.
- Baines, L.S., Joseph, J.T. and Jindal, R.M. (2002) 'Emotional issues after kidney transplantation: a prospective psychotherapeutic study', *Clinical Transplantation*, 16(6), pp. 455-460.
- Baker, K., Flattery, M., Salyer, J., Haugh, K.H. and Maltby, M. (2010) 'Caregiving for patients requiring left ventricular assistance device support', *Heart Lung*, 39(3), pp. 196-200.
- Banner, N.R., Bonser, R.S., Clark, A.L., Clark, S., Cowburn, P.J., Gardner, R.S., Kalra, P.R., McDonagh, T., Rogers, C.A., Swan, L., Parameshwar, J., Thomas, H.L. and Williams, S.G. (2011) 'UK guidelines for referral and assessment of adults for heart transplantation', *Heart*, 97(18), pp. 1520-1527.
- Barken, R. (2014) 'Caregivers' Interpretations of Time and Biography: The Experiences of Caring for a Spouse with Parkinson's Disease', *Journal of Contemporary Ethnography*, 43(6), pp. 695-719.
- Barrett, P., Hale, B. and Butler, M. (2014) *Family care and social capital transitions in informal care*. Dordrecht: Springer.
- Bastawrous, M. (2013) 'Caregiver burden—A critical discussion', *International Journal of Nursing Studies*, 50(3), pp. 431-441.
- Baumeister, R.F., Bratslavsky, E., Finkenauer, C. and Vohs, K.D. (2001) 'Bad is stronger than good', *Review of general psychology*, 5(4), p. 323.
- Becker, E. (1973) *The Denial of Death*. New York: Free Press Paperbacks.
- Becker, G. (1997) *Disrupted lives: How people create meaning in a chaotic world*. California: University of California Press.
- Becker, H.S. (1963) *Outsiders: Studies in the sociology of deviance*. New York: Free Press.
- Bell, A.J. (2005) "'Oh yes, I remember it well!" Reflections on Using the Life-Grid in Qualitative Interviews with Couples', *Qualitative Sociology Review*, 1(1), pp. 51-67.
- Bell, S.L., Tyrrell, J. and Phoenix, C. (2016) 'Ménière's disease and biographical disruption: Where family transitions collide', *Social Science & Medicine*, 166, pp. 177-185.
- Bellou, P. and Gerogianni, K. (2007) 'The contribution of family in the care of patient in the hospital', *Health Science Journal*, (3), pp. 1-6.
- Benning, C.R. and Smith, A. (1994) 'Psychosocial needs of family members of liver transplant patients', *Clinical Nurse Specialist*, 8(5), pp. 280-288.

- Biancofiore, G., Bindi, M.L., Romanelli, A.M., Urbani, L., Mosca, F. and Filipponi, F. (2005) 'Stress-inducing factors in ICUs: What liver transplant recipients experience and what caregivers perceive', *Liver Transplantation*, 11(8), pp. 967-972.
- Birks, M., Chapman, Y. and Francis, K. (2008) 'Memoing in qualitative research probing data and processes', *Journal of Research in Nursing*, 13(1), pp. 68-75.
- Blumer, H. (1969) *Symbolic interactionism: Perspective and method*. Englewood Cliffs: Prentice-Hall, Inc.
- Boden, Z.V.R., Gibson, S., Owen, G.J. and Benson, O. (2016) 'Feelings and Intersubjectivity in Qualitative Suicide Research', *Qualitative Health Research*, 26(8), pp. 1078-1090.
- Bogue Kerr, S., Soulière, M. and Bell, L. (2017) 'The Transliminal Self: The Ebb and Flow of the Kidney Transplant Experience', *Qualitative Health Research*, 28(4), pp. 561-571.
- Bohachick, P., Reeder, S., Taylor, M.V. and Anton, B.B. (2001) 'Psychosocial impact of heart transplantation on spouses', *Clinical Nursing Research*, 10(1), pp. 6-25.
- Bolton, S. (2001) 'Changing faces: nurses as emotional jugglers', *Sociology of Health & Illness*, 23(1), pp. 85-100.
- Bolton, S.C. (2000) 'Who cares? Offering emotion work as a 'gift' in the nursing labour process', *Journal of Advanced Nursing*, 32(3), pp. 580-586.
- Bone, D. (2002) 'Dilemmas of emotion work in nursing under market-driven health care', *International Journal of Public Sector Management*, 15(2), pp. 140-150.
- Botha, P., Fisher, A.J. and Dark, J.H. (2006) 'Marginal lung donors: a diminishing margin of safety?', *Transplantation*, 82(10), pp. 1273-1279.
- Bowker, L., Price, J. and Smith, S. (2012) 'Renal medicine', in Bowker, L., Price, J. and Smith, S. (eds.) *Oxford Handbook of Geriatric Medicine*. 2 edn. Oxford University Press.
- Bowlby, S. (2012) 'Recognising the time—space dimensions of care: Caringscapes and carescapes', *Environment and Planning A*, 44(9), pp. 2101-2118.
- Bowling, A. (2002) *Research methods in health*. 2nd edn. Buckingham: Open University Press.
- Boyatzis, R.E. (1998) *Transforming qualitative information: Thematic analysis and code development*. London: Sage.
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77-101.
- Bray, L., Kirk, S. and Callery, P. (2014) 'Developing biographies: the experiences of children, young people and their parents of living with a long - term condition', *Sociology of Health & Illness*, 36(6), pp. 823-839.

- Breen, L.J. and O'Connor, M. (2011) 'Family and social networks after bereavement: Experiences of support, change and isolation', *Journal of Family Therapy*, 33(1), pp. 98-120.
- British Liver Trust (2017a) *Liver Transplantation*. Available at: <https://www.britishlivertrust.org.uk/liver-information/liver-transplantation/> (Accessed: 02.04.2017).
- British Liver Trust (2017b) *When will I have my transplant?* Available at: <http://www.britishlivertrust.org.uk/liver-information/liver-transplantation/when-will-i-have-my-transplant/> (Accessed: 27.02.2017).
- Bryman, A. (1984) 'The debate about quantitative and qualitative research: a question of method or epistemology?', *British Journal of Sociology*, 35(1), pp. 75-92.
- Bull, D.A., Reid, B.B., Selzman, C.H., Mesley, R., Drakos, S., Clayson, S., Stoddard, G., Gilbert, E., Stehlik, J. and Bader, F. (2010) 'The impact of bridge-to-transplant ventricular assist device support on survival after cardiac transplantation', *The Journal of Thoracic and Cardiovascular Surgery*, 140(1), pp. 169-173.
- Bunzel, B., Laederach-Hofmann, K., Wieselthaler, G.M., Roethy, W. and Drees, G. (2005) 'Posttraumatic stress disorder after implantation of a mechanical assist device followed by heart transplantation: evaluation of patients and partners', *Transplantation Proceedings*, 37(2), pp. 1365-1368.
- Bunzel, B., Laederach-Hofmann, K., Wieselthaler, G.M., Roethy, W. and Wolner, E. (2007) 'Mechanical circulatory support as a bridge to heart transplantation: What remains? Long-term emotional sequelae in patients and spouses', *Journal of Heart and Lung Transplantation*, 26(4), pp. 384-389.
- Bunzel, B., Laederach - Hofmann, K. and Schubert, M.T. (1999) 'Patients benefit - partners suffer? The impact of heart transplantation on the partner relationship.', *Transplant International*, 12(1), pp. 33-41.
- Burker, E.J., Evon, D., Loiselle, M.M., Finkel, J. and Mill, M. (2005) 'Planning helps, behavioral disengagement does not: coping and depression in the spouses of heart transplant candidates', *Clinical Transplantation*, 19(5), pp. 653-658.
- Burr, V. (2004) 'Social constructionism' 2nd ed.. Hoboken: Taylor and Francis.
- Burra, P. and De Bona, M. (2007) 'Quality of life following organ transplantation', *Transplant International*, 20(5), pp. 397-409.
- Bury, M. (1982) 'Chronic illness as biographical disruption', *Sociology of Health & Illness*, 4(2), pp. 167-182.
- Buse, S.M. and Pieper, B. (1990) 'Impact of cardiac transplantation on the spouse's life', *Heart & Lung: The Journal of Acute and Critical Care*, 19(6), pp. 641-648.

- Byrne, B. (2004) 'Qualitative interviewing', in Seale, C. (ed.) *Researching Society and Culture*. 2nd edn. London: Sage.
- Callaghan, C.J., Charman, S.C., Muiesan, P., Powell, J.J., Gimson, A.E. and van der Meulen, J.H. (2013) 'Outcomes of transplantation of livers from donation after circulatory death donors in the UK: a cohort study', *BMJ open*, 3(9), p. e003287.
- Canning, R.D., Dew, M.A. and Davidson, S. (1996) 'Psychological distress among caregivers to heart transplant recipients', *Social Science and Medicine*, 42(4), pp. 599-608.
- Cardiomyopathy UK (2017) *Support for Carers: Support for those caring for someone with cardiomyopathy*. Available at: <https://www.cardiomyopathy.org/downloads/information-section/factsheets-2016-onwards/support-for-carers-april-2017.pdf>.
- Carel, H., Kidd, I.J. and Pettigrew, R. (2016) 'Illness as transformative experience', *The Lancet*, 388(10050), pp. 1152-1153.
- Carter, M.J. and Fuller, C. (2016) 'Symbols, meaning, and action: The past, present, and future of symbolic interactionism', *Current Sociology Review*, 64(6), pp. 931-961.
- Casida, J. (2005) 'The lived experience of spouses of patients with a left ventricular assist device before heart transplantation', *American Journal of Critical Care*, 14(2), pp. 145-151.
- Cater, R. and Taylor, J. (2017) 'The experiences of heart transplant recipients' spouses during the pretransplant waiting period: integrative review', *Journal of Clinical Nursing*, 26(19-20), pp. 2865-2877.
- Cavaye, J. and Watts, J.H. (2018) 'Former carers: issues from the literature', *Families, Relationships and Societies*, 7(1), pp. 141-157.
- Chamberlayne, P. and King, A. (1997) 'The biographical challenge of caring', *Sociology of Health & Illness*, 19(5), pp. 601-621.
- Chapple, A., Ziebland, S. and McPherson, A. (2004) 'Stigma, shame, and blame experienced by patients with lung cancer: qualitative study', *BMJ*, 328(7454), p. 1470.
- Charmaz, K. (2008) 'Constructionism and the Grounded Theory Method', in Holstein, J.A. and Gubrium, J.F. (eds.) *Handbook of Constructionist Research*. New York: The Guilford Press, pp. 397-412.
- Charmaz, K. and Belgrave, L.L. (2013) 'Modern symbolic interaction theory and health', in *Medical sociology on the move*. Birmingham, USA: Springer, pp. 11-39.
- Chase, S.E. (2005) 'Narrative Inquiry: Multiple lenses, approaches and voices', in Denzin, K.N. and Lincoln, Y.S. (eds.) *The Sage Handbook of Qualitative Research*. 3rd edn. California: Sage, pp. 651-679.
- Chataika, T. (2005) 'Narrative Research: What's in a Story?', *8th Nordic Network for Disability Research*. Oslo. Available at:

http://www.academia.edu/1671034/Narrative_Research_Whats_in_a_story (Accessed: 22.05.18).

Chen, P., Wang, W., Yan, L., Yang, J., Wen, T., Li, B., Zhao, J. and Xu, M. (2015) 'Risk factors for first-year hospital readmission after liver transplantation', *European Journal of Gastroenterology & Hepatology*, 27(5), pp. 600-606.

Cheung, J. and Hocking, P. (2004) 'Caring as worrying: The experience of spousal carers', *Journal of Advanced Nursing*, 47(5), pp. 475-482.

Claar, R.L., Parekh, P.I., Palmer, S.M., LaCaille, R.A., Davis, R.D., Rowe, S.K., Babyak, M.A. and Blumenthal, J.A. (2005) 'Emotional distress and quality of life in caregivers of patients awaiting lung transplant', *Journal of Psychosomatic Research*, 59(1), pp. 1-6.

Cohen, M., Katz, D. and Baruch, Y. (2007) 'Stress among the family caregivers of liver transplant recipients', *Progress in Transplantation*, 17(1), pp. 48-53.

Collins, E.G., White-Williams, C. and Jalowiec, A. (1996) 'Spouse stressors while awaiting heart transplantation', *Heart & Lung: The Journal of Acute and Critical Care*, 25(1), pp. 4-13.

Collins, E.G., White-Williams, C. and Jalowiec, A. (2000) 'Spouse quality of life before and 1 year after heart transplantation', *Critical care nursing clinics of North America*, 12(1), pp. 103-110.

Colombo, D. and Ammirati, E. (2011) 'Cyclosporine in transplantation—a history of converging timelines', *Journal of Biological Regulators and Homeostatic Agents*, 25(4), pp. 493-504.

Cook, R.I. (2006) 'Hobson's Choices: matching and mismatching in transplantation work processes', in Walloo, K., Livingston, J. and Guarmaccia, P. (eds.) *A Death Retold: Jesica Santillian, the Bungled Transplant, and Paradoxes of Medical Citizenship*. University of North Carolina Press, pp. 46-69.

Cooley, C.H. (1902) *Human nature and the social order*. New York: Scibner.

Cooper, D.K., Miller, L.W. and Patterson, G.A. (1997) *The transplantation and replacement of thoracic organs: the present status of biological and mechanical replacement of the heart and lungs*. Lancaster: Kluwer Academic Publishers.

Corbin, J. and Morse, J.M. (2003) 'The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics', *Qualitative Inquiry*, 9(3), pp. 335-354.

Corbin, J. and Strauss, A. (1985) 'Managing chronic illness at home: three lines of work', *Qualitative Sociology*, 8(3), pp. 224-247.

Corey, K.L. and McCurry, M.K. (2017) 'When caregiving ends: The experiences of former family caregivers of people with dementia', *The Gerontologist*, pp. e87-e96.

- Cormier, N.R., Gallo - Cruz, S.R. and Beard, R.L. (2017) 'Navigating the new, transplanted self: how recipients manage the cognitive risks of organ transplantation', *Sociology of Health & Illness*, 39(8), pp. 1496-1513.
- Corris, P. (2011) 'Long-term management and outcomes', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 155-163.
- Cotterill, P. and Letherby, G. (1994) 'The "Person" in the Researcher', in Burgess, R.G. (ed.) *Studies in Qualitative Methodology*. Greenwich: JAI Press, pp. 107-136.
- Crooks, V.A., Kingsbury, P., Snyder, J. and Johnston, R. (2010) 'What is known about the patient's experience of medical tourism? A scoping review', *BMC Health Services Research*, 10(1), p. 266.
- Crowley-Matoka, M. (2005) 'Desperately seeking "normal": the promise and perils of living with kidney transplantation', *Social Science & Medicine*, 61(4), pp. 821-831.
- D'Ardenne, P. (2004) 'The couple sharing long-term illness', *Sexual and Relationship Therapy*, 19(3), pp. 291-308.
- Date, H. (2011) 'Living donor lobar lung transplantation', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 128-132.
- del Barrio, M., Lacunza, M.M., Armendariz, A.C., Margall, M.A. and Asiain, M.C. (2004) 'Liver transplant patients: their experience in the intensive care unit. A phenomenological study', *Journal of clinical nursing*, 13(8), pp. 967-976.
- Denny, B., Beyerle, K., Kienhuis, M., Cora, A., Gavidia-Payne, S. and Hardikar, W. (2012) 'New insights into family functioning and quality of life after pediatric liver transplantation', *Pediatric Transplantation*, 16(7), pp. 711-715.
- Denzin, N.K. (2004) 'Symbolic Interactionism', in Flick, U., Kardoff, E.V. and Steinke, I. (eds.) *A Companion to Qualitative Research*. London: Sage, pp. 81-87.
- Devlin, J. and O'Grady, J. (1999) 'Indications for referral and assessment in adult liver transplantation: a clinical guideline', *Gut*, 45(suppl 6), pp. VI1-VI22.
- Dew, M.A., Goycoolea, J.M., Stukas, A.A., Switzer, G.E., Simmons, R.G., Roth, L.H. and DiMartini, A. (1998) 'Temporal profiles of physical health in family members of heart transplant recipients: Predictors of health change during caregiving', *Health Psychology*, 17(2), pp. 138-151.
- Dew, M.A., Myaskovsky, L., Dimartini, A.F., Switzer, G.E., Schulberg, H.C. and Kormos, R.L. (2004) 'Onset, timing and risk for depression and anxiety in family caregivers to heart transplant recipients', *Psychological Medicine*, 34(6), pp. 1065-1082.

Dew, M.A., Switzer, G.E., Goycoolea, J.M., Allen, A.S., DiMartini, A., Kormos, R.L. and Griffith, B.P. (1997) 'Does transplantation produce quality of life benefits?: A Quantitative Analysis of the Literature', *Transplantation*, 64(9), pp. 1261-1273.

Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P. (2006) 'Blurring boundaries in qualitative health research on sensitive topics', *Qualitative Health Research*, 16(6), pp. 853-871.

Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P. (2007) 'Doing sensitive research: what challenges do qualitative researchers face?', *Qualitative Research*, 7(3), pp. 327-353.

Dickson, A., O'Brien, G., Ward, R., Allan, D. and O'Carroll, R. (2010) 'The impact of assuming the primary caregiver role following traumatic spinal cord injury: an interpretative phenomenological analysis of the spouse's experience', *Psychology and Health*, 25(9), pp. 1101-1120.

Dindia, K. and Allen, M. (1992) 'Sex differences in self-disclosure: A meta-analysis', *Psychological Bulletin*, 112(1), pp. 106-124.

Dunning, J. and Calne, R. (2011) 'Historical Perspectives', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 1-8.

Edwards, R. and Holland, J. (2013) *What is Qualitative Interviewing?* London: Bloosbury.

Eifert, E.K., Adams, R., Dudley, W. and Perko, M. (2015) 'Family Caregiver Identity: A Literature Review', *American Journal of Health Education*, 46(6), pp. 357-367.

Eisikovits, Z. and Koren, C. (2010) 'Approaches to and outcomes of dyadic interview analysis', *Qualitative Health Research*, 20(12), pp. 1642-55.

Elias, N. (1985) *The Loneliness of the Dying*. Oxford: Basil Blackwell.

Engström, Å. and Söderberg, S. (2004) 'The experiences of partners of critically ill persons in an intensive care unit', *Intensive and Critical Care Nursing*, 20(5), pp. 299-308.

Erickson, R.J. (1993) 'Reconceptualizing family work: The effect of emotion work on perceptions of marital quality', *Journal of Marriage and the Family*, pp. 888-900.

Erickson, R.J. (2005) 'Why emotion work matters: Sex, gender, and the division of household labor', *Journal of Marriage and Family*, 67(2), pp. 337-351.

Eriksson, M. and Svedlund, M. (2006) 'The intruder': Spouses' narratives about life with a chronically ill partner', *Journal of Clinical Nursing*, 15(3), pp. 324-333.

Exley, C. (2004) 'Emotional fact', in Hallowell, N., Lawton, J. and Gregory, S. (eds.) *Reflections on Research: The realities of doing research in the social sciences*. UK: McGraw-Hill Education.

- Exley, C. and Letherby, G. (2001) 'Managing a disrupted lifecourse: issues of identity and emotion work', *Health*, 5(1), pp. 112-132.
- Farah, M. and Gill, J.S. (2014) 'Artificial organs and assist devices', in Kirk, A.D., Knechtle, S.J., Larsen, C.P., Madsen, J.C., Pearson, T.C. and Webber, S.A. (eds.) *Textbook of Organ Transplantation Set*. John Wiley & Sons.
- Farley, L.M., DeMaso, D.R., D'Angelo, E., Kinnamon, C., Bastardi, H., Hill, C.E., Blume, E.D. and Logan, D.E. (2007) 'Parenting Stress and Parental Post-traumatic Stress Disorder in Families After Pediatric Heart Transplantation', *Journal of Heart and Lung Transplantation*, 26(2), pp. 120-126.
- Festle, M. (2012) *Second wind: oral histories of lung transplant survivors*. Springer.
- Fisher, A.J. (2007) 'Selecting patients suitable for lung transplantation: the art of balancing risks', *Expert review of respiratory medicine*, 1(3), pp. 299-301.
- Fisher, A.J., Andreasson, A., Chrysos, A., Lally, J., Mamasoula, C., Exley, C., Wilkinson, J., Qian, J., Watson, G. and Lewington, O. (2016) 'An observational study of Donor Ex Vivo Lung Perfusion in UK lung transplantation: DEVELOP-UK', *Health Technology Assessment*, 20(85), pp. 1-276.
- Florman, S. and Miller, C.M. (2006) 'Live donor liver transplantation', *Liver transplantation*, 12(4), pp. 499-510.
- Foster, C. (2004) 'Loosening the bond', in Hallowell, N., Lawton, J. and Gregory, S. (eds.) *Reflections on Research: The realities of doing research in the social sciences*. UK: McGraw-Hill Education.
- Fulbrook, P., Leisfield, T. and Wiggins, K. (2013) 'Children's conceptions of their parent's lung transplant', *Journal of Child Health Care*, 17(1), pp. 6-16.
- Funk, L.M. and Stajduhar, K.I. (2009) 'Interviewing family caregivers: Implications of the caregiving context for the research interview', *Qualitative Health Research*, 19(6), pp. 859-867.
- Gaunt, R. and Scott, J. (2014) 'Parents' involvement in childcare: Do parental and work identities matter?', *Psychology of Women Quarterly*, 38(4), pp. 475-489.
- Gelson, W. and Alexander, G.J.M. (2011) 'Long-term management and outcomes', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 212-219.
- George, L.K. and Gwyther, L.P. (1986) 'Caregiver well-being: A multidimensional examination of family caregivers of demented adults', *The Gerontologist*, 26(3), pp. 253-259.

- Gibbons, S.W., Ross, A. and Bevans, M. (2014) 'Liminality as a Conceptual Frame for Understanding the Family Caregiving Rite of Passage: An Integrative Review', *Research in nursing & health*, 37(5), pp. 423-436.
- Global Observatory on Donation and Transplantation (2015) *WHO-ONT*. Available at: <http://www.transplant-observatory.org/> (Accessed: 24.02.2017).
- Goffman, E. (1955) 'On face-work: An analysis of ritual elements in social interaction', *Psychiatry*, 18(3), pp. 213-231.
- Goffman, E. (1959) *Presentation of Self in Everyday Life*. New York: Doubleday Anchor Books.
- Goffman, E. (1963) *Stigma: Notes on a spoiled identity*. New York: Simon & Schuster Inc.
- Gold, L.M., Kirkpatrick, B.S., Fricker, F.J. and Zitelli, B.J. (1986) 'Psychosocial issues in pediatric organ transplantation: the parents' perspective', *Pediatrics*, 77(5), pp. 738-44.
- Golics, C.J., Basra, M.K.A., Salek, M.S. and Finlay, A.Y. (2013) 'The impact of patients' chronic disease on family quality of life: an experience from 26 specialties', *International Journal of General Medicine*, 6, pp. 787-798.
- Gordon, P.A. and Perrone, K.M. (2004) 'When spouses become caregivers: Counseling implications for younger couples', *Journal of Rehabilitation*, 70(2), pp. 27-32.
- Green, A., Meaux, J., Huett, A. and Ainley, K. (2009) 'Constantly responsible, constantly worried, constantly blessed: parenting after pediatric heart transplant', *Progress in Transplantation*, 19(2), pp. 122-127.
- Green, J. (1999) 'Qualitative methods', *Community Eye Health*, 12(31), pp. 46-47.
- Green, J. and Thorogood, N. (2004) *Qualitative methods for health research*. London: Sage.
- Green, J. and Thorogood, N. (2009) *Qualitative methods for health research*. London: Sage Publications.
- Gregory, S. (2005) 'Living with chronic illness in the family setting', *Sociology of Health & Illness*, 27(3), pp. 372-392.
- Grinyó, J.M. (2013) 'Why Is Organ Transplantation Clinically Important?', *Cold Spring Harbor Perspectives in Medicine*, 3(6), pp. 1-10.
- Gutermann, L., Decottignies, A., Sharif, K., Sinclair, A., Rieutord, A. and Terry, D. (2014) 'Parents and carers of patients who had liver transplants: opinions and experiences of medication issues', *European Journal of Hospital Pharmacy*, 21(6), pp. 339-343.
- Hamann, H.A., Ostroff, J.S., Marks, E.G., Gerber, D.E., Schiller, J.H. and Craddock Lee, S.J. (2014) 'Stigma among patients with lung cancer: A patient-reported measurement model', *Psycho-oncology*, 23(1), pp. 81-92.

- Hasselkus, B.R. and Murray, B.J. (2007) 'Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia', *American Journal of Occupational Therapy*, 61(1), pp. 9-20.
- Haugh, K.H. and Salyer, J. (2007) 'Needs of patients and families during the wait for a donor heart', *Heart & Lung: The Journal of Acute and Critical Care*, 36(5), pp. 319-329.
- Healthtalk.org (2015) *Intensive care: experiences of family & friends*. Available at: <http://www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-experiences-family-friends/emotional-impact-relatives-friends-icu> (Accessed: 22.05.18).
- healthtalk.org (2017) *Organ Donation: Effects on family and friends*. Available at: <http://www.healthtalk.org/peoples-experiences/organ-donation-transplant/organ-donation/effects-family-and-friends> (Accessed: 13.06.17).
- Heinrich, T.W. and Marcangelo, M. (2009) 'Psychiatric issues in solid organ transplantation', *Harvard Review of Psychiatry*, 17(6), pp. 398-406.
- Hennings, J., Froggatt, K. and Payne, S. (2013) 'Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study', *Palliative Medicine*, 27(7), pp. 683-691.
- Herek, G.M., Capitano, J.P. and Widaman, K.F. (2003) 'Stigma, social risk, and health policy: public attitudes toward HIV surveillance policies and the social construction of illness', *Health Psychology*, 22(5), pp. 533-540.
- Higgins, S.S. (2001) 'Parental role in decision making about pediatric cardiac transplantation: Familial and ethical considerations', *Journal of Pediatric Nursing*, 16(5), pp. 332-337.
- Hiratsuka, K., Nakamura, N. and Sato, N. (2017) 'Maternal coping with the prospect of liver transplant among their school - age children', *International journal of nursing practice*, 23, p. e12544.
- Hirschfield, G.M., Gibbs, P. and Griffiths, W.J.H. (2009) 'Adult liver transplantation: what non-specialists need to know', *BMJ*, 338.
- Hochschild, A.R. (1979) 'Emotion work, feeling rules, and social structure', *American Journal of Sociology*, 85(3), pp. 551-575.
- Hochschild, A.R. (1983) *The Managed Heart*. California: University of California Press.
- Holt, A. (2010) 'Using the telephone for narrative interviewing: a research note', *Qualitative Research*, 10(1), pp. 113-121.
- Holtzman, S., Abbey, S.E., Singer, L.G., Ross, H.J. and Stewart, D.E. (2011) 'Both patient and caregiver gender impact depressive symptoms among organ transplant caregivers: Who is at risk and why?', *Journal of Health Psychology*, 16(5), pp. 843-856.

- Hopf, C. (2004) 'Qualitative Interviews: An Overview', in Flick, U., Von Kardoff, E. and Steinke, I. (eds.) *A Companion to Qualitative Research*. London: Sage, pp. 203-208.
- Hudson, N., Culley, L., Law, C., Mitchell, H., Denny, E. and Raine-Fenning, N. (2016) 'We needed to change the mission statement of the marriage': biographical disruptions, appraisals and revisions among couples living with endometriosis', *Sociology of Health & Illness*, 38(5), pp. 721-735.
- Hughes, N., Locock, L. and Ziebland, S. (2013) 'Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis', *Social Science & Medicine*, 96(0), pp. 78-85.
- Hunt, C.K. (2003) 'Concepts in Caregiver Research', *Journal of Nursing Scholarship*, 35(1), pp. 27-32.
- Ivarsson, B., Ekmehag, B. and Sjöberg, T. (2014a) 'Relative's experiences before and after a heart or lung transplantation', *Heart and Lung: The Journal of Acute and Critical Care*, 43(3), pp. 198-203.
- Ivarsson, B., Ekmehag, B. and Sjöberg, T. (2014b) 'Waiting for a heart or lung transplant: Relatives' experience of information and support', *Intensive and Critical Care Nursing*, 30(4), pp. 188-195.
- James, N. (1992) 'Care = organisation+ physical labour+ emotional labour', *Sociology of Health & Illness*, 14(4), pp. 488-509.
- Jarvie, I. (1983) 'Rationality and Relativism', *The British Journal of Sociology*, 34(1), pp. 44-60.
- Johnson, B. and Clarke, J.M. (2003) 'Collecting sensitive data: The impact on researchers', *Qualitative Health Research*, 13(3), pp. 421-434.
- Johnson, K.A. (1990) 'Medical technology and public meaning: the case of viable organ transplantation.', in Shanteau, J. and Harris, R.J. (eds.) *Organ donation and transplantation: Psychological and behavioural factors*. Washington DC: American Psychological Association, pp. 168-78.
- Jones, R.K. (2000) 'The unsolicited diary as a qualitative research tool for advanced research capacity in the field of health and illness', *Qualitative Health Research*, 10(4), pp. 555-567.
- Jordan, J., Price, J. and Prior, L. (2015) 'Disorder and disconnection: parent experiences of liminality when caring for their dying child', *Sociology of health & illness*, 37(6), pp. 839-855.
- Kaller, T., Petersen, I., Petermann, F., Fischer, L., Grabhorn, E. and Schulz, K.H. (2014) 'Family strain and its relation to psychosocial dysfunction in children and adolescents after liver transplantation', *Pediatric Transplantation*, 18(8), pp. 851-9.

- Kalra, G. and Desousa, A. (2011) 'Psychiatric aspects of organ transplantation', *International Journal of Organ Transplantation Medicine*, 2(1), pp. 9-19.
- Karner, T.X. and Bobbitt - Zeher, D. (2005) 'Losing selves: Dementia care as disruption and transformation', *Symbolic Interaction*, 28(4), pp. 549-570.
- Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S. and Iverson, E. (2017) 'Living a secret: Disclosure among adolescents and young adults with chronic illnesses', *Chronic Illness*, 13(1), pp. 49-61.
- Ketokivi, K., Widmer, E. and Jallinoja, R. (2008) 'Biographical disruption, the wounded self and the reconfiguration of significant others', *Beyond the Nuclear Family: Families in a Configurational Perspective*. Bern: Peter Lang, pp. 255-77.
- Khaghani, A., Birks, E.J., Anyanwu, A.C. and Banner, N.R. (2004) 'Heart transplantation from live donors: "Domino procedure"', *The Journal of Heart and Lung Transplantation*, 23(9), pp. S257-S259.
- Kimbell, B., Boyd, K., Kendall, M., Iredale, J. and Murray, S.A. (2015) 'Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study', *BMJ open*, 5(11), p. e009241.
- Kinman, G. and Leggetter, S. (2016) *Healthcare*. Multidisciplinary Digital Publishing Institute.
- Knafl, K.A. and Gilliss, C.L. (2002) 'Families and Chronic Illness: A Synthesis of Current Research', *Journal of Family Nursing*, 8(3), pp. 178-198.
- Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N. and Sanders, C. (2016) 'Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions', *Health & Social Care in the Community*, 24(2), pp. 203-213.
- Kontomanolis, E.N., Michalopoulos, S., Gkadaris, G. and Fasoulakis, Z. (2017) 'The social stigma of HIV–AIDS: society's role', *HIV/AIDS (Auckland, NZ)*, 9, p. 111.
- Krueger, T., Cypel, M. and Kashavjee, S. (2015) 'Ex vivo lung perfusion', in Vigneswaran, W., Garrity, E. and Odell, J. (eds.) *Lung Transplantation: Principles and Practice*. Florida: CRC Press.
- Kurz, J.M. (2001a) 'Desire for control, coping, and quality of life in heart and lung transplant candidates, recipients, and spouses: a pilot study', *Progress in Transplantation*, 11(3), pp. 224-230.
- Kurz, J.M. (2001b) 'Experiences of well spouses after lung transplantation', *Journal of Advanced Nursing*, 34(4), pp. 493-500.
- Kurz, J.M. (2002) 'Vulnerability of Well Spouses Involved in Lung Transplantation', *Journal of Family Nursing*, 8(4), pp. 353-370.

- Kurz, J.M. and Cavanaugh, J.C. (2001) 'A qualitative study of stress and coping strategies used by well spouses of lung transplant candidates', *Families, Systems and Health*, 19(2), pp. 181-197.
- Kuyper, M.B. and Wester, F. (1998) 'In the shadow: the impact of chronic illness on the patient's partner', *Qualitative Health Research*, 8(2), pp. 237-253.
- Ladin, K., Daniels, A., Osani, M. and Bannuru, R.R. (2018) 'Is social support associated with post-transplant medication adherence and outcomes? A systematic review and meta-analysis', *Transplantation Reviews*, 32(1), pp. 16-28.
- Ladin, K. and Hanto, D. (2010) 'Understanding disparities in transplantation: do social networks provide the missing clue?', *American Journal of Transplantation*, 10(3), pp. 472-476.
- Larkin, M. (2007) 'Group support during caring and post-caring', *Groupwork*, 17(2), pp. 28-50.
- Larossa, R., Bennett, L.A. and Gelles, R.J. (1981) 'Ethical dilemmas in qualitative family research', *Journal of Marriage and the Family*, pp. 303-313.
- LaValley, S. (2017) 'Life course stage and social support for end-of-life caregivers', *Innovation in Aging*, 1(suppl_1), pp. 248-248.
- Lawn, S., Walsh, J., Barbara, A., Springgay, M. and Sutton, P. (2013) 'The bond we share: Experiences of caring for a person with mental and physical health conditions', in *Mental Disorders: Theoretical and Empirical Perspectives*. InTech.
- Leech, N.L. and Onwuegbuzie, A.J. (2008) 'Debriefing', in Given, L.M. (ed.) *The Sage Encyclopedia of Qualitative Research Methods*. California: Sage publications, pp. 199-201.
- Leeds Teaching Hospitals (2016) 'Booklet 1 - Is Kidney Transplantation for you? Information for patients' 3rd NHS. Available at: <http://flipbooks.leedsth.nhs.uk/LN002167P/LN002167.pdf> (Accessed: 20.06.18).
- Lefaiver, C.A., Keough, V.A., Letizia, M. and Lanuza, D.M. (2009) 'Quality of life in caregivers providing care for lung transplant candidates', *Progress in Transplantation*, 19(2), pp. 142-152.
- Lewis, J., Ritchie, J., Ormston, R. and Morrell, G. (2014) 'Generalising from qualitative research', in Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (eds.) *Qualitative Research Practice*. 2nd edn. London: Sage, pp. 348-366.
- Liamputtong, P. (2006) *Researching the Vulnerable: A guide to sensitive research methods*. London: Sage.
- Lingard, L., Albert, M. and Levinson, W. (2008) 'Grounded theory, mixed methods, and action research', *BMJ*, 337, pp. 459-461.

- Litzelman, K., Tesauro, G. and Ferrer, R. (2017) 'Internal resources among informal caregivers: trajectories and associations with well-being', *Quality of Life Research*, 26(12), pp. 3239-3250.
- LoBiondo-Wood, G., Bernier-Henn, M. and Williams, L. (1992) 'Impact of the child's liver transplant on the family: maternal perspective', *Pediatric Nursing*, 18(5), pp. 461-6.
- LoBiondo-Wood, G., Williams, L., Kouzekanani, K. and McGhee, C. (2000) 'Family adaptation to a child's transplant: pretransplant phase', *Progress in Transplantation*, 10(2), pp. 81-7.
- LoBiondo-Wood, G., Williams, L. and McGhee, C. (2004) 'Liver Transplantation in Children: Maternal and Family Stress, Coping, and Adaptation', *Journal for Specialists in Pediatric Nursing*, 9(2), pp. 59-66.
- Locock, L. and Brown, J.B. (2010) '“All in the same boat”? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND)', *Social Science & Medicine*, 71(8), pp. 1498-1505.
- Lopez, S.H. (2006) 'Emotional labor and organized emotional care: Conceptualizing nursing home care work', *Work and Occupations*, 33(2), pp. 133-160.
- Lu, C.-J. and Shulman, S.W. (2008) 'Rigor and flexibility in computer-based qualitative research: Introducing the Coding Analysis Toolkit', *International Journal of Multiple Research Approaches*, 2(1), pp. 105-117.
- Lung Institute (2016) *Lung Transplant Survival Rates*. Available at: <https://lunginstitute.com/blog/lung-transplant-survival-rates-for-one-month-one-year-and-three-years/> (Accessed: 10.03.17).
- Mac Rae, H. (1998) 'Managing feelings caregiving as emotion work', *Research on Aging*, 20(1), pp. 137-160.
- MacDonald, K. (2006) 'Living in limbo--patients with cystic fibrosis waiting for transplant', *British Journal of Nursing*, 15(10), pp. 566-572.
- MacGowan, G.A., Crossland, D.S., Hasan, A. and Schueler, S. (2015) 'Considerations for patients awaiting heart transplantation—Insights from the UK experience', *Journal of Thoracic Disease*, 7(3), p. 527.
- Machuca, T.N. and Cypel, M. (2014) 'Ex vivo lung perfusion', *Journal of Thoracic Disease*, 6(8), pp. 1054-1062.
- Maggio, L. (2015) *Explore the Relationship Among Lung Cancer Stigma, Social Support, and Psychological Distress*. University of Kentucky [Online]. Available at: https://uknowledge.uky.edu/cgi/viewcontent.cgi?article=1021&context=nursing_etds (Accessed: 20.08.2018).

- Mair, F.S. and May, C.R. (2014) 'Thinking about the burden of treatment', *British Medical Journal*, 349(g6680), p. 7.
- Malik, P., Kohl, C., Holzner, B., Kemmler, G., Graziadei, I., Vogel, W. and Sperner-Unterweger, B. (2014) 'Distress in primary caregivers and patients listed for liver transplantation', *Psychiatry Research*, 215(1), pp. 159-162.
- Manara, A.R., Murphy, P.G. and O'Callaghan, G. (2012) 'Donation after circulatory death', *British Journal of Anaesthesia*, 108(suppl 1), pp. i108-i121.
- Mann, S. and Cowburn, J. (2005) 'Emotional labour and stress within mental health nursing', *Journal of Psychiatric and Mental Health Nursing*, 12(2), pp. 154-162.
- Mantulak, A. and Nicholas, D.B. (2016) "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', *Social Work in Health Care*, 55(8), pp. 580-594.
- Marshall, M.N. (1996) 'Sampling for qualitative research', *Family Practice*, 13(6), pp. 522-526.
- Martin, S.C., Stone, A.M., Scott, A.M. and Brashers, D.E. (2010) 'Medical, Personal, and Social Forms of Uncertainty Across the Transplantation Trajectory', *Qualitative Health Research*, 20(2), pp. 182-196.
- Mary, A. and Ward, K.D. (2015) 'Association between quality of life and depression among heart transplant recipients and family caregivers', *Cardiovascular Surgery*, 3(2), pp. 35-42.
- Mason, J. (2002) *Qualitative Researching*. 2nd edn. London: Sage.
- Mays, N. and Pope, C. (1995) 'Rigour and qualitative research', *British Medical Journal*, 311(6997), pp. 109-112.
- McCosker, H., Barnard, A. and Gerber, R. (2001) 'Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants', *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 2(1), pp. 1-14.
- McCurry, A.H. and Thomas, S.P. (2002) 'Spouses' Experiences in Heart Transplantation', *Western Journal of Nursing Research*, 24(2), pp. 180-194.
- McKiernan, M. and McCarthy, G. (2010) 'Family members' lived experience in the intensive care unit: a phenomenological study', *Intensive and Critical Care Nursing*, 26(5), pp. 254-261.
- McSweeney, J.C., Innerarity, S.A., Clark, A.P., Richards, R., Mitchell, M.B. and Tyler, D.O. (1995) 'What about me? Spouses' quality of life after heart transplantation', *Journal of Transplant Coordination*, 5(2), pp. 59-64.
- Mead, G.H. (1934) *Mind, self and society*. Chicago University of Chicago Press.
- Mehra, M.R., Canter, C.E., Hannan, M.M., Semigran, M.J., Uber, P.A., Baran, D.A., Danziger-Isakov, L., Kirklin, J.K., Kirk, R. and Kushwaha, S.S. (2016) 'The 2016

- International Society for Heart Lung Transplantation listing criteria for heart transplantation: a 10-year update', *Journal of Heart and Lung Transplantation*, 35(1), pp. 1-23.
- Mellor, P.A. and Shilling, C. (1993) 'Modernity, self-identity and the sequestration of death', *Sociology*, 27(3), pp. 411-431.
- Meltzer, L.J. and Rodrigue, J.R. (2001) 'Psychological distress in caregivers of liver and lung transplant candidates', *Journal of Clinical Psychology in Medical Settings*, 8(3), pp. 173-180.
- Mendes-Castillo, A.M.C., Bousso, R.S., de Faria Ichikawa, C.R. and Silva, L.R. (2014) 'The use of the Family Management Style Framework to evaluate the family management of liver transplantation in adolescence', *Revista Da Escola De Enfermagem Da Usp*, 48(3), pp. 430-437.
- Mendes-Castillo, A.M.C., Bousso, R.S., Santos, M.R.d. and Damião, E.B.C. (2012) 'Family management styles: a possibility of evaluation in pediatric liver transplant', *Acta Paulista de Enfermagem*, 25(6), pp. 867-872.
- Mendes-Castillo, A.M.C., Bousso, R.S. and Sloand, E. (2017) 'The Family Management Styles Framework as A Tool for Tailoring Interventions for Pediatric Transplant Recipients and Their Families: A Case Study', *Comprehensive Child and Adolescent Nursing-Building Evidence for Practice*, 40(1), pp. 39-52.
- Mendes, A.M.C. and Bousso, R.S. (2009) 'Not being able to live like before: the family dynamics during the experience of pediatric liver transplantation', *Revista latino-americana de enfermagem*, 17(1), pp. 74-80.
- Minichiello, V., Aroni, R., Timewell, E. and Alexander, L. (1990) *Interviewing: Researching People*. Melbourne: Longman Cheshire.
- Mishel, M.H. and Murdaugh, C.L. (1987) 'Family adjustment to heart transplantation: redesigning the dream', *Nursing Research*, 36(6), pp. 332-338.
- Mishler, E.G. (1986) 'Research interviewing: Context and Narrative', in *Standard Practice*. Cambridge: Harvard University Press, pp. 155-168.
- Miyazaki, E.T., Santos, R.D., Miyazaki, M.C., Domingos, N.M., Felicio, H.C., Rocha, M.F., Arroyo Jr, P.C., Duca, W.J., Silva, R.F. and Silva, R.C.M.A. (2010) 'Patients on the waiting list for liver transplantation: Caregiver burden and stress', *Liver Transplantation*, 16(10), pp. 1164-1168.
- Monaghan, L.F. and Gabe, J. (2015) 'Chronic illness as biographical contingency? Young people's experiences of asthma', *Sociology of Health & Illness*, 37(8), pp. 1236-1253.
- Montgomery, R.J.V. and Kosloski, K. (2009) 'Caregiving as a process of changing identity: Implications for caregiver support', *Generations*, 33(1), pp. 47-52.

Montgomery, R.J.V. and Kosloski, K.D. (2013) 'Pathways to a caregiver identity and implications for support services', in *Caregiving Across the Lifespan*. New York: Springer, pp. 131-156.

Moore, H. and Gillespie, A. (2014) 'The caregiving bind: Concealing the demands of informal care can undermine the caregiving identity', *Social Science & Medicine*, 116, pp. 102-109.

Morgan, D.L., Ataie, J., Carder, P. and Hoffman, K. (2013) 'Introducing dyadic interviews as a method for collecting qualitative data', *Qualitative Health Research*, 23(9), pp. 1276-1284.

Morris, S.M. and Thomas, C. (2001) 'The carer's place in the cancer situation: where does the carer stand in the medical setting?', *European Journal of Cancer Care*, 10(2), pp. 87-95.

Musselwhite, K., Cuff, L., McGregor, L. and King, K. (2007) 'The telephone interview is an effective method of data collection in clinical nursing research: A discussion paper', *International Journal Of Nursing Studies*, 44(6), pp. 1064-1070.

Myaskovsky, L., Amanda Dew, M., Switzer, G.E., McNulty, M.L., DiMartini, A.F. and McCurry, K.R. (2005) 'Quality of life and coping strategies among lung transplant candidates and their family caregivers', *Social Science & Medicine*, 60(10), pp. 2321-2332.

Myaskovsky, L., Posluszny, D.M., Schulz, R., Dimartini, A.F., Switzer, G.E., Dabbs, A.D., McNulty, M.L., Kormos, R.L., Toyoda, Y. and Dew, M.A. (2012) 'Predictors and Outcomes of Health - Related Quality of Life in Caregivers of Cardiothoracic Transplant Recipients', *American Journal of Transplantation*, 12(12), pp. 3387-3397.

Nelson, J. (2017) 'Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research', *Qualitative Research*, 17(5), pp. 554-570.

NHS (2016a) *Heart transplant waiting list*. Available at: <http://www.nhs.uk/Conditions/heart-transplant/Pages/Waiting-list.aspx> (Accessed: 27.02.2016).

NHS (2016b) *Liver transplant*. Available at: <http://www.nhs.uk/conditions/Liver-transplant/Pages/Introduction.aspx> (Accessed: 21.09.16).

NHS (2016c) *Recovering from a lung transplant*. Available at: <http://www.nhs.uk/Conditions/Lung-transplant/Pages/Recovery.aspx> (Accessed: 25.04.2017).

NHS (2017a) *Heart-lung transplant*. Available at: <http://www.nhs.uk/conditions/heart-lung-transplant/Pages/Introduction.aspx> (Accessed: 02.04.2017).

NHS (2017b) *Heart transplant*. Available at: <http://www.nhs.uk/conditions/heart-transplant/Pages/Introduction.aspx> (Accessed: 13.06.17).

NHS (2017c) *How a liver transplant is performed*. Available at: <http://www.nhs.uk/Conditions/Liver-transplant/Pages/How-is-it-performed.aspx> (Accessed: 25.04.2017).

NHS (2017d) *Liver transplant - How it's performed*. Available at: <http://www.nhs.uk/Conditions/Liver-transplant/Pages/How-is-it-performed.aspx> (Accessed: 13.06.17).

NHS (2017e) *Liver transplant - Living with*. Available at: <http://www.nhs.uk/Conditions/Liver-transplant/Pages/Recovery.aspx> (Accessed: 13.06.17).

NHS (2017f) *Lung Transplant*. Available at: <http://www.nhs.uk/Conditions/Lung-transplant/Pages/Introduction.aspx> (Accessed: 13.06.17).

NHS (2017g) 'Organ Donation and Transplantation Activity Report 2016/17'.

NHS (2017h) *Preparing for lung transplant*. Available at: <http://www.nhs.uk/Conditions/Lung-transplant/Pages/Preparation.aspx>.

NHS (2017i) *Risks of lung transplant*. Available at: <http://www.nhs.uk/Conditions/Lung-transplant/Pages/Risks.aspx> (Accessed: 13.06.17).

NHS (2017j) *What happens during heart transplant*. Available at: <http://www.nhs.uk/Conditions/heart-transplant/Pages/Surgery.aspx> (Accessed: 13.06.17).

NHS (2018a) *Liver transplant: Waiting list*. Available at: <https://www.nhs.uk/conditions/liver-transplant/waiting-list/>.

NHS (2018b) *Organ Donation and Transplantation: Activity report 2017/18*. [Online]. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1848/transplant-activity-report-2017-2018.pdf> (Accessed: 13.07.2018).

NHS Choices (2015) *History of Donation*. Available at: <http://www.nhs.uk/Tools/Documents/transplant.htm> (Accessed: 24.02.2017).

NHSBT (2012a) *Guidelines for Referral for Liver Transplant Assessment*. Available at: http://www.odt.nhs.uk/pdf/advisory_group_papers/LAG/referral_for_transplantation.pdf.

NHSBT (2012b) *Provisional offering of hearts and lungs: organs unsuitable for offering*. [Online]. Available at: http://www.odt.nhs.uk/pdf/advisory_group_papers/CTAG/audit_of_organ_unsuitable_for_offering_february_2012.pdf (Accessed: 25.04.2017).

NHSBT (2013a) *Patient survival from time of listing for transplant*. [Online]. Available at: http://www.odt.nhs.uk/pdf/patient_survival_from_time_of_listing_for_transplant.pdf (Accessed: 09.12.14).

NHSBT (2013b) *Taking Organ Transplantation to 2020: A UK strategy*. [Online]. Available at: http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf.

NHSBT (2015a) *Heart Transplantation: Selection Criteria and Recipient Registration*. [Online]. Available at: http://www.odt.nhs.uk/pdf/heart_selection_policy.pdf.

NHSBT (2015b) *Organ Donation and Transplantation: Activity Report 2014/15*. [Online]. Available at: http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/activity_report_2014_15.pdf (Accessed: 27.02.2017).

NHSBT (2016a) *Cardiothoracic Activity*. [Online]. Available at: http://www.odt.nhs.uk/pdf/activity-report/cardiothoracic_activity.pdf (Accessed: 21.09.16).

NHSBT (2016b) *Liver Activity*. [Online]. Available at: http://www.odt.nhs.uk/pdf/activity-report/liver_activity.pdf (Accessed: 21.09.16).

NHSBT (2017a) *Heart Transplantation: Selection Criteria and Recipient Registration*. [Online]. Available at: http://www.odt.nhs.uk/pdf/heart_selection_policy.pdf.

NHSBT (2017b) *Introduction to Patient Selection and Organ Allocations Policies*. [Online]. Available at: https://nhsbtde.blob.core.windows.net/umbraco-assets-corp/4955/introduction_to_selection_and_allocation_policies.pdf (Accessed: 19.03.2018).

NHSBT (2017c) *Liver Transplantation: Selection Criteria and Recipient Registration*. [Online]. Available at: http://odt.nhs.uk/pdf/heart_selection_policy.pdf (Accessed: 17.07.2018).

NHSBT (2017d) *Lung Candidate Selection Criteria*. [Online]. Available at: http://www.odt.nhs.uk/pdf/lung_selection_policy.pdf.

NHSBT (2017e) *Organ Donation and Transplantation*. Available at: <http://www.nhsbt.nhs.uk/what-we-do/organ-donation-transplantation/> (Accessed: 13.06.2017).

NHSBT (2017f) *Patient Registration*. Available at: <http://www.odt.nhs.uk/transplantation/recipient-coordination/patient-registration/> (Accessed: 13.06.17).

NHSBT (2017g) *UK Transplant Registry: Other reports*. Available at: <http://www.odt.nhs.uk/uk-transplant-registry/other-reports/> (Accessed: 26.04.17).

NHSBT (2018) *Organ donation and Transplantation - Activity figures for the UK as at 6 April 2018*. Available at: https://nhsbtde.blob.core.windows.net/umbraco-assets/1343/annual_stats.pdf (Accessed: 22.05.18).

Northfield, S. and Nebauer, M. (2010) 'The Caregiving Journey for Family Members of Relatives With Cancer', *Clinical Journal of Oncology Nursing*, 14(5), pp. 567-577.

Novick, G. (2008) 'Is there a bias against telephone interviews in qualitative research?', *Research in Nursing & Health*, 31(4), pp. 391-398.

Nowell, L.S., Norris, J.M., White, D.E. and Moules, N.J. (2017) 'Thematic analysis: Striving to meet the trustworthiness criteria', *International Journal of Qualitative Methods*, 16(1), pp. 1-13.

- O'Brien, G. (2017) 'Gift-of-life? The Psychosocial Experiences of Heart, Liver and Kidney Recipients. ', in Shaw, R.M. (ed.) *Bioethics Beyond Altruism*. Cham: Palgrave Macmillan, pp. 215-237.
- O'Reilly, M. and Parker, N. (2012) 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research', *Qualitative Research*, 13(2), pp. 190-197.
- Ohler, L. (1998) 'In sickness and in health: Testing the vow after transplantation', *Journal of Transplant Coordination*, 8(4), p. 198.
- Olson, R.E. (2011) 'Managing hope, denial or temporal anomie? Informal cancer carers' accounts of spouses' cancer diagnoses', *Social Science & Medicine*, 73(6), pp. 904-911.
- Olson, R.E. (2015) *Towards a Sociology of Cancer Caregiving: Time to Feel*. New York: Routledge.
- Olson, R.E. and Connor, J. (2015) 'When they don't die: Prognosis ambiguity, role conflict and emotion work in cancer caregiving', *Journal of Sociology*, 51(4), pp. 857-871.
- Oltmann, S. (2016) 'Qualitative interviews: a methodological discussion of the interviewer and respondent contexts', *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 17(2).
- Ordin, Y.S., Karayurt, O., Unek, T. and Astarcioglu, I. (2017) 'Pediatric liver transplant patients' transition to adulthood: Patient and parent experiences', *Nursing & Health Sciences*, 19(3), pp. 393-399.
- Orzeck, P. and Silverman, M. (2008) 'Recognizing post - caregiving as part of the caregiving career: implications for practice', *Journal of Social Work Practice*, 22(2), pp. 211-220.
- Overton, S.L. and Medina, S.L. (2008) 'The stigma of mental illness', *Journal of Counseling & Development*, 86(2), pp. 143-151.
- Parmar, J.S. (2011) 'Recipient Selection', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 122-127.
- Parsons, T. (1951) 'Illness and the role of the physician: A sociological perspective', *American Journal of Orthopsychiatry*, 21(3), pp. 452-460.
- Parthasarathy, H.K. and Lewis, C.J. (2011) 'Long-term management and outcomes', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 102-111.
- Passos, S.d.S.S., Pereira, Á. and Nitschke, R.G. (2015) 'Routine of the family companion during hospitalization of a family member', *Acta Paulista de Enfermagem*, 28(6), pp. 539-545.

Patel, M.S., Mohebbali, J., Shah, J.A., Markmann, J.F. and Vagefi, P.A. (2016) 'Readmission following liver transplantation: an unwanted occurrence but an opportunity to act', *HPB*, 18(11), pp. 936-942.

Payne, S., Smith, P. and Dean, S. (1999) 'Identifying the concerns of informal carers in palliative care', *Palliative medicine*, 13(1), pp. 37-44.

Pearlin, L.I. and Aneshensel, C.S. (1994) 'Caregiving: The unexpected career', *Social Justice Research*, 7(4), pp. 373-390.

Pérez-San-Gregorio, M., Martín-Rodríguez, A., Borda-Mas, M., Avargues-Navarro, M., Pérez-Bernal, J. and Gómez-Bravo, M. (2018) 'Family Caregivers of Liver Transplant Recipients: Coping Strategies Associated With Different Levels of Post-traumatic Growth', *Transplantation proceedings*, 50(2), pp. 646-649.

Pickard, S. (2010) 'The 'Good Carer': Moral Practices in Late Modernity', *Sociology*, 44(3), pp. 471-487.

Pierce, B.A. (2014) *Waiting for a Liver Transplant: An Exploration of the Lived Experience of Patients and Caregivers in Atlantic Canada*. Unpublished PhD thesis. Dalhousie University.

Plank, A., Mazzoni, V. and Cavada, L. (2011) 'Becoming a caregiver: new family carers' experience during the transition from hospital to home', *Journal of Clinical Nursing*, 21(13-14), pp. 2072-2082.

Polkinghorne, D.E. (2005) 'Language and meaning: Data collection in qualitative research', *Journal of Counseling Psychology*, 52(2), pp. 137-145.

Pope, C., Ziebland, S. and Mays, N. (2000) 'Qualitative research in health care. Analysing qualitative data', *British Medical Journal*, 320(7227), pp. 114-116.

Potlolla, V., Patten, R.D., DeNofrio, D., Konstam, M.A. and R., K. (2009) 'The Effects of Ventricular Assist Devices on Post-Transplant Mortality', *Journal of the American College of Cardiology*, 53(3), pp. 264-271.

Queen Elizabeth Hospital Birmingham (2017) 'Liver Transplantation: What does it mean to me and my family?' National Health Service. Available at: <http://www.uhb.nhs.uk/Downloads/pdf/PiLiverTransplantation.pdf> (Accessed: 13.06.17).

Quick, C.R.G., Reed, J.B., Harper, S.J.F., Saeb-Parsy, K. and Deakin, P.J. (2014) *Essential Surgery: Problems, Diagnosis and Management*. New York: Elsevier Health Sciences.

Rainer, J.P., Thompson, C.H. and Lambros, H. (2010) 'Psychological and psychosocial aspects of the solid organ transplant experience—A practice review', *Psychotherapy: Theory, Research, Practice, Training*, 47(3), p. 403.

- Revenson, T.A., Schiaffino, K.M., Majerovitz, S.D. and Gibofsky, A. (1991) 'Social support as a double-edged sword: The relation of positive and problematic support to depression among rheumatoid arthritis patients', *Social science & medicine*, 33(7), pp. 807-813.
- Ritchie, J., Lewis, J., Elam, G., Tennent, R. and Rahim, N. (2014) 'Designing and selecting samples', in Ritchie, J. and Lewis, J. (eds.) *Qualitative Research Practice: A guide for social science students and researchers*. London: Sage.
- Roberts, K. and Clarke, C. (2009) 'Future disorientation following gynaecological cancer: Women's conceptualisation of risk after a life threatening illness', *Health, Risk & Society*, 11(4), pp. 353-366.
- Robinson, O.C. (2014) 'Sampling in interview-based qualitative research: A theoretical and practical guide', *Qualitative Research in Psychology*, 11(1), pp. 25-41.
- Rodrigue, J.R. and Baz, M.A. (2007) 'Waiting for lung transplantation: quality of life, mood, caregiving strain and benefit, and social intimacy of spouses', *Clinical Transplantation*, 21(6), pp. 722-727.
- Rodrigue, J.R., Dimitri, N., Reed, A., Antonellis, T., Hanto, D.W. and Curry, M. (2011) 'Quality of life and psychosocial functioning of spouse/partner caregivers before and after liver transplantation', *Clinical Transplantation*, 25(2), pp. 239-247.
- Rodrigue, J.R., MacNaughton, K., Hoffmann III, R.G., Graham-Pole, J., Andres, J.M., Novak, D.A. and Fennell, R.S. (1997) 'Transplantation in children: A longitudinal assessment of mothers' stress, coping, and perceptions of family functioning', *Psychosomatics*, 38(5), pp. 478-486.
- Rolland, J.S. (1994) 'In Sickness and in Health: the impact of illness on couples' relationships', *Journal of Marital and Family Therapy*, 20(4), pp. 327-347.
- Rosenberger, E.M., Dew, M.A., DiMartini, A.F., DeVito Dabbs, A.J. and Yusen, R.D. (2012) 'Psychosocial Issues Facing Lung Transplant Candidates, Recipients and Family Caregivers', *Thoracic Surgery Clinics*, 22(4), pp. 517-529.
- Roth, D.L., Fredman, L. and Haley, W.E. (2015) 'Informal caregiving and its impact on health: A reappraisal from population-based studies', *The Gerontologist*, 55(2), pp. 309-319.
- Sá, A.S., Ziviani, L.C., Galvão, C.M. and Mendes, K.D.S. (2016) 'Information needs of family caregivers regarding liver transplant candidates', *Revista Gaúcha de Enfermagem*, 37(1), pp. 1-8.
- Sadala, M.L.A., Stolf, N.G., Bocchi, E.A. and Bicudo, M.A.V. (2013) 'Caring for heart transplant recipients: The lived experience of primary caregivers', *Heart and Lung: Journal of Acute and Critical Care*, 42(2), pp. 120-125.

- Sahin, Y., Virit, O. and Demir, B. (2016) 'Despression and anxiety in parents of children who are candidates for liver transplantation', *Arquivos de gastroenterologia*, 53(1), pp. 25-30.
- Saldaña, J. (2009) *The coding manual for qualitative researchers*. London: Sage.
- Sartorius, N. (2007) 'Stigmatized illnesses and health care', *Croatian Medical Journal*, 48(3), pp. 396-7.
- Saunders, B., Kitzinger, J. and Kitzinger, C. (2015) 'Anonymising interview data: challenges and compromise in practice', *Qualitative Research*, 15(5), pp. 616-632.
- Savulescu, J., Foddy, B. and Rogers, J. (2006) 'What should we say?', *Journal of Medical Ethics*, 32(1), pp. 7-12.
- Saxe-Braithwaite, M.E. and Chapman, J.C. (1992) 'Life on hold: the experience of the support person involved in a lung transplant program', *Canadian Journal of Nursing Research Archive*, 24(3).
- Schwandt, T.A. (2000) 'Three epistemological stances for qualitative inquiry', *Handbook of Qualitative Research*, 2(2), pp. 189-213.
- Scottish Health Council (2015) *Commissioning Transplantation to 2020: Gathering views from people about transplant services*. [Online]. Available at: <http://www.nsd.scot.nhs.uk/publications/ServiceReviews/CTT2020%20final%20report.pdf> (Accessed: 17.07.18).
- Seale, C. and Silverman, D. (1997) 'Ensuring rigour in qualitative research', *The European Journal of Public Health*, 7(4), pp. 379-384.
- Settles, I.H. (2004) 'When multiple identities interfere: The role of identity centrality', *Personality and Social Psychology Bulletin*, 30(4), pp. 487-500.
- Sharp, L.A. (1995) 'Organ transplantation as a transformative experience: anthropological insights into the restructuring of the self', *Medical Anthropology Quarterly*, 9(3), pp. 357-389.
- Shenton, A.K. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects', *Education for information*, 22(2), pp. 63-75.
- Simpson, C. and Acton, G. (2013) 'Emotion work in family caregiving for persons with dementia', *Issues in Mental Health Nursing*, 34(1), pp. 52-8.
- Skaff, M.M. and Pearlin, L.I. (1992) 'Caregiving: Role engulfment and the loss of self', *The Gerontologist*, 32(5), pp. 656-664.
- Skaff, M.M., Pearlin, L.I. and Mullan, J.T. (1996) 'Transitions in the caregiving career: effects on sense of mastery', *Psychology and Aging*, 11(2), pp. 247-57.
- Squire, C. (2008) 'Experience-centered and culturally-orientated approaches to narrative', in Andrews, M., Squire, C. and Tamboukou, M. (eds.) *Doing Narrative Research*. Sage, pp. 41-63.

- St John, W. and Johnson, P. (2000) 'The pros and cons of data analysis software for qualitative research', *Journal of Nursing Scholarship*, 32(4), pp. 393-397.
- Standing, H.C., Rapley, T., MacGowan, G.A. and Exley, C. (2017) '‘Being’ a ventricular assist device recipient: A liminal existence', *Social Science & Medicine*, 190, pp. 141-148.
- Stanford, D.A., Lee, J.M., Chandok, N. and McAlister, V. (2014) 'A queuing model to address waiting time inconsistency in solid-organ transplantation', *Operations Research for Health Care*, 3(1), pp. 40-45.
- Stone, A.M., Scott, A.M., Martin, S.C. and Brashers, D.E. (2013) 'Using Information to Manage Uncertainty During Organ Transplantation', *Qualitative Communication Research*, 2(1), pp. 42-60.
- Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research*. California: Sage.
- Stubblefield, C. and Murray, R.L. (1999) 'Parents call for concerned and collaborative care', *Western Journal of Nursing Research*, 21(3), pp. 356-371.
- Stubblefield, C. and Murray, R.L. (2001) 'Pediatric lung transplantation: families’ need for understanding', *Qualitative Health Research*, 11(1), pp. 58-68.
- Stubblefield, C. and Murray, R.L. (2002) 'Waiting for lung transplantation: family experiences of relocation', *Pediatric Nursing*, 28(5), pp. 501-504.
- Stukas, A.A., Dew, M.A., Switzer, G.E., Dimartini, A., Kormos, R.L. and Griffith, B.P. (1999) 'PTSD in heart transplant recipients and their primary family caregivers', *Psychosomatics*, 40(3), pp. 212-221.
- Sturges, J.E. and Hanrahan, K.J. (2004) 'Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note', *Qualitative Research*, 4(1), pp. 107-118.
- Suddaby, E.C., Flattery, M.P. and Luna, M. (1997) 'Stress and coping among parents of children awaiting cardiac transplantation', *Journal of transplant coordination*, 7(1), pp. 36-40.
- Suri, H. (2011) 'Purposeful sampling in qualitative research synthesis', *Qualitative Research Journal*, 11(2), pp. 63-75.
- Tabler, J.B. and Frierson, R.L. (1990) 'Sexual concerns after heart transplantation', *Journal of Heart Transplantation*, 9(4), pp. 397-403.
- Taylor, F., Gutteridge, R. and Willis, C. (2016) 'Peer support for CKD patients and carers: overcoming barriers and facilitating access', *Health Expectations*, 19(3), pp. 617-630.
- Theed, R., Eccles, F. and Simpson, J. (2017) 'Experiences of caring for a family member with Parkinson's disease: a meta-synthesis', *Aging & Mental Health*, 21(10), pp. 1007-1016.
- Thomas, C., Morris, S.M. and Harman, J.C. (2002) 'Companions through cancer: the care given by informal carers in cancer contexts', *Social Science & Medicine*, 54(4), pp. 529-544.

- Tong, A., Chapman, J., Israni, A., Gordon, E. and Craig, J. (2013) 'Qualitative research in organ transplantation: recent contributions to clinical care and policy', *American Journal of Transplantation*, 13(6), pp. 1390-1399.
- Torgé, C.J. (2013) 'Using conjoint interviews with couples that have been living with disabilities and illnesses for a long time—implications and insights', *Qualitative Studies*, 4(2), pp. 100-113.
- Turner, V. (1969) 'Liminality and communitas', in *The Ritual Process: Structure and Anti-structure*. Chicago: Aldine Publishing, pp. 94-130.
- Twigg, J. (1989) 'Models of carers: how do social care agencies conceptualise their relationship with informal carers?', *Journal of Social Policy*, 18(01), pp. 53-66.
- Ullrich, G., Jansch, H., Schmidt, S., Struber, M. and Niedermeyer, J. (2004) 'The experience of the support person involved in a lung transplant programme: results of a pilot study', *European Journal of Medical Research*, 9(12), pp. 555-652.
- Ullrich, G., Jansch, H., Schmidt, S., Struber, M. and Niedermeyer, J. (2005) 'Consulting the "experts": a pilot study on perceptions of professional support among lung transplant recipients and accompanying relatives', *Progress in Transplantation*, 15(2), pp. 115-122.
- Umberson, D. and Montez, J.K. (2010) 'Social relationships and health a flashpoint for health policy', *Journal of health and social behavior*, 51(1 suppl), pp. S54-S66.
- Urizzi, F. and Corrêa, A.K. (2007) 'Relatives' experience of intensive care: the other side of hospitalization', *Revista latino-americana de enfermagem*, 15(4), pp. 598-604.
- US Departments of Health & Human Services (2017) *History*. Available at: <https://optn.transplant.hrsa.gov/learn/about-transplantation/history/> (Accessed: 24.02.2017).
- Usita, P.M., Hall, S.S. and Davis, J.C. (2004) 'Role ambiguity in family caregiving', *Journal of Applied Gerontology*, 23(1), pp. 20-39.
- Uzark, K. and Crowley, D. (1989) 'Family stresses after pediatric heart transplantation', *Progress in Cardiovascular Nursing*, 4, pp. 23-27.
- Vaish, A., Grossmann, T. and Woodward, A. (2008) 'Not all emotions are created equal: the negativity bias in social-emotional development', *Psychological bulletin*, 134(3), p. 383.
- Vaughn-Sandler, V., Sherman, C., Aronsohn, A. and Volk, M.L. (2014) 'Consequences of perceived stigma among patients with cirrhosis', *Digestive Diseases and Sciences*, 59(3), pp. 681-686.
- Vellone, E., Sansoni, J. and Cohen, M.Z. (2002) 'The experience of Italians caring for family members with Alzheimer's disease', *Journal of Nursing Scholarship*, 34(4), pp. 323-329.

- Venkateswaran, R.V. and Parameshwar, J. (2011) 'Recipient Selection', in Klein, A.A., Lewis, C.J. and Madsen, J.C. (eds.) *Organ Transplantation: A Clinical Guide*. Cambridge: Cambridge University Press, pp. 63-69.
- Waldrop, D.P. (2011) 'Denying and defying death: The culture of dying in 21st century America'. Oxford University Press.
- Ward-Griffin, C. and McKeever, P. (2000) 'Relationships between nurses and family caregivers: partners in care?', *Advances in Nursing Science*, 22(3), pp. 89-103.
- Watson, C.J.E. and Dark, J.H. (2012) 'Organ transplantation: historical perspective and current practice', *British Journal of Anaesthesia*, 108(suppl 1), pp. i29-i42.
- Whitaker, C., Stevelink, S. and Fear, N. (2017) 'The use of Facebook in recruiting participants for Health Research purposes: a systematic review', *Journal of Medical Internet Research*, 19(8), p. e290.
- Whytehead, C., Davis, M. and Bolden, T. (2018) *Catch Your Breath! A guide to lung transplant for families and support people*. [Online]. Available at: http://www.uhn.ca/MOT/PatientsFamilies/Lung_Transplant_Program/Documents/Lung_Transplant_Guide_Support_People.pdf (Accessed: 19.03.2018).
- Wilhelm, M.J. (2015) 'Long-term outcome following heart transplantation: current perspective', *Journal of Thoracic Disease*, 7(3), pp. 549-551.
- Wilkinson, C. and McAndrew, S. (2008) 'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings', *International Journal of Mental Health Nursing*, 17(6), pp. 392-401.
- Williams, L., Eilers, J., Heermann, J. and Smith, K. (2012) 'The lived experience of parents and guardians providing care for child transplant recipients', *Progress in Transplantation*, 22(4), pp. 393-402.
- Williams, M. (1991) *Life on hold: A theory of spouse response to the waiting period prior to heart transplantation*. Unpublished PhD thesis. University of Arizona.
- Wilson, K., Roe, B. and Wright, L. (1998) 'Telephone or face-to-face interviews?: a decision made on the basis of a pilot study', *International Journal of Nursing Studies*, 35(6), pp. 314-321.
- Wingham, J., Frost, J. and Britten, N. (2017) 'Behind the smile: qualitative study of caregivers' anguish and management responses while caring for someone living with heart failure', *BMJ open*, 7(7), pp. 1-9.
- Wittenberg-Lyles, E., Goldsmith, J., Oliver, D.P., Demiris, G., Kruse, R.L. and Van Stee, S. (2013) 'Using medical words with family caregivers', *Journal of palliative medicine*, 16(9), pp. 1135-1139.

- Wittenberg, E., Saada, A. and Prosser, L.A. (2013) 'How illness affects family members: a qualitative interview survey', *The Patient-Centered Outcomes Research*, 6(4), pp. 257-268.
- World Health Organization (2017a) *GKTI Activity and Practices*. Available at: <http://www.who.int/transplantation/gkt/statistics/en/> (Accessed: 13.06.17).
- World Health Organization (2017b) *Transplantation: Transplantation of human cells, tissues or organs*. Available at: <http://www.who.int/transplantation/en/> (Accessed: 24.02.2017).
- Worthington, A. and Rooney, P. (2010) *The Triangle of Care. Carers included: A guide to best practice in acute mental health care*. [Online]. Available at: <http://static.carers.org/files/caretriangle-web-5250.pdf> (Accessed: 15.12.18).
- Wright, J., Elwell, L., McDonagh, J.E., Kelly, D.A. and Wray, J. (2017) 'Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services', *Pediatric Transplantation*, 21(1).
- Xu, J., Adeboyejo, O., Wagley, E., Aubrecht, J., Song, M.-K., Thiry, L. and Dabbs, A.D. (2012) 'Daily burdens of recipients and family caregivers after lung transplant', *Progress in Transplantation*, 22(1), pp. 41-48.
- Yeo, A., Legard, R., Keegan, J., Ward, K., McNaughton Nicholls, C. and Lewis, J. (2014) 'In-depth interviews', in Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (eds.) *Qualitative Research Practice*. London: Sage, pp. 177-210.
- Yilmaz, K. (2013) 'Comparison of Quantitative and Qualitative Research Traditions: epistemological, theoretical, and methodological differences', *European Journal of Education*, 48(2), pp. 311-325.
- Young, B., Dixon-Woods, M., Findlay, M. and Heney, D. (2002) 'Parenting in a crisis: conceptualising mothers of children with cancer', *Social Science & Medicine*, 55(10), pp. 1835-1847.
- Young, L., Janosek, S. and McKenzie, L. (2001) 'Family Health Promotion in Cardiovascular Care: Exploring the Information and Support Needs of Heart Transplant Recipients and Their Families', *Canadian Journal of Cardiovascular Nursing*, 11(4), pp. 10-18.
- Young, L.E., Molzahn, A., Starzomski, R. and Budz, B. (2010) 'Families and heart transplantation: reversing the trajectory of end stage heart disease', *Canadian Journal of Cardiovascular Nursing*, 20(2), pp. 6-17.
- Zhang, W.X., Wei, H., Shen, Z.Y., Peng, X., Chen, X.G., Li, W., Wang, F., Zhang, S.P., Liu, H.X. and Niu, Y.J. (2014) 'Concerns of and coping strategies by parents of pediatric liver transplant recipients: A qualitative study from China', *International Journal of Clinical and Experimental Medicine*, 7(12), pp. 5723-5729.

Chapter 11. Appendices

Appendix 1: Ethical approval



Rebecca Patterson
Institute of Health and Society,
Baddiley Clark Building,

Faculty of Medical Sciences
Newcastle University
The Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH United Kingdom

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Rebecca,

Title: The impact of organ transplantation on adult family members: a qualitative study.

Application No: 00832_1 2015 (Amendment)

Start date to end date: 30 May 2015 to 30 October 2016

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **00832_1/2015**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,
Yours sincerely

A handwritten signature in black ink that reads "K. Sutherland".

Kimberley Sutherland
On behalf of Faculty Ethics Committee

cc.
Professor Daniel Nettle, Chair of FMS Ethics Committee
Ms Lois Neal, Assistant Registrar (Research Strategy)

*Please refer to the latest guidance available on the internal Newcastle web-site.

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Participant Information Leaflet

You are being invited to take part in a research study. The study will involve talking to a researcher – Rebecca Patterson (Becca) from the Institute of Health and Society at Newcastle University. Before you decide whether or not you wish to take part, it is important for you to know why I want to carry out this research and what taking part would mean for you.

This leaflet is for you to keep. Please read it carefully and take time to decide if you want to take part in the study or not.

This leaflet is divided into two parts:

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Talk to others about it if you want to and feel free to ask if there is anything you don't understand or if you would like more information.

Thank you for reading this leaflet

Part 1

What is this project about?

You have been invited to participate in a research project entitled ‘The impact of organ transplantation on adult family members: a qualitative study’. The purpose of this research is to explore the impact of the transplantation procedure on family members, particularly those that take on the role of primary caregiver. This study will look specifically at how the transplantation process affects familial relationships, roles and wellbeing over time.

This research will be carried out by Rebecca Patterson (Becca), a PhD researcher at the Institute of Health and Society, Newcastle University:



Why me?

You have been invited to take part in this study because you are over the age of 18 and are related to someone who has been placed on the transplant waiting list or recently undergone transplant surgery.

What does this research project involve?

Interviews will be conducted by Rebecca Patterson at a time that is convenient for you in a quiet room in your home, a public place or in the Institute of Health and Society at Newcastle University, depending on your personal preference. If you prefer you can be interviewed by telephone. The interview will last between an hour and an hour and a half and will consist of both short questions regarding personal characteristics (e.g. age, location of residence) and slightly longer questions about your experience of the transplantation procedure to date. Providing you give consent, this interview will be digitally recorded. You can stop the interview or withdraw from the project at any time.

Why should I take part?

Living with, or looking after, an ill family member is known to affect an individual’s health and wellbeing. UK research on this topic has focused on the impact of caring for people in older age or stroke survivors. Comparatively little research has been done on the impact of

transplantation and associated caregiving duties on family members. This project intends to explore the impact in such cases and will contribute a new perspective to existing UK transplantation research which largely focuses on patient and/or donor families. You will be fully reimbursed for any travel expenses you may incur as a result of taking part.

Why shouldn't I take part?

Participation will take a certain amount of time and given the nature of the subject it is possible that sensitive issues will be raised that could potentially upset you. You are however able to skip questions if you feel uncomfortable discussing certain issues and can stop the interview or withdraw from the study at any point.

Can I get some more information?

If you would like more information about the study please contact Rebecca Patterson at Newcastle University:

Rebecca Patterson
Institute of Health & Society
Newcastle University
The Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne
NE2 4AX

Email: r.a.patterson@newcastle.ac.uk
Phone: 07796387467

PART 2

What will happen to the interview?

The recorded interview will be typed up and then analysed. This information will then be written up into a doctoral thesis. It is possible that a version of this research may be submitted to a journal accessible to the public. If published this research could have local and national implications regarding support provided for families of transplant patients.

Dissemination

When the study is complete all participants keen to know the results will be sent a summary of the findings. Following this you will be able to ask any questions which may arise.

Will people know that I was involved?

Confidentiality is taken very seriously during research projects. All the information you give will be presented in such a way that it will not be possible to identify you or anyone else you mention. You will never be identified by your own name, and every effort will be made to avoid using information which could be used to identify other individuals or organisations you may mention.

What if I have a problem?

If you have a concern about any aspect of this study please contact Rebecca Patterson (see contact details pg. 3), Prof Catherine Exley or Dr Lynne Stobbart at Newcastle University:

Professor Catherine Exley
Institute of Health & Society
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Phone: 0191 208 5513

Appendix 3: Supervisor safety protocol

Interview researcher safety protocol – Rebecca Patterson PhD student

- Catherine Exley (CE) and Lynne Stobbart (LS) will keep a list of telephone numbers, addresses and emergency contact numbers for the researcher Rebecca Patterson (RP).
Telephone: 079xxxxxxx (personal) 07796387467 (work)
Address: 123 Smith Street
Newcastle upon Tyne
NE1 1SS
Emergency contact – Craig Watson (CW): 079xxxxxxx
- RP should have the following numbers programmed her phones: CE work/personal, LS work/personal, IHS reception 0191 208 7045, Blue Line taxis 0191 262 6666, Noda Taxis 0191 222 1888 University police 0191 222 6666, and the City Police non-emergency number 101.
- RP will email the name, address and telephone number of the interviewee and the time, date and location of the interview to CE & LS, who will acknowledge receipt of these details.
- On the day of the planned interview, the researcher will text or phone CE or LS before starting the interview.
- RP will keep her phone on vibrate and in an easily accessible place throughout the interview.
- If the researcher does not phone CE or LS at the planned start time of the interview, CE or LS will contact the researcher 15 minutes after the planned start time. If they get no answer, they will telephone the interviewee.
- The researcher will phone CE or LS again at the end of the interview.
- If 90 minutes have passed from the start of the interview and the researcher has not phoned CE or LS, they will phone RP. If they do not get an answer they will contact RP's emergency contact CW to check last known contact.
- If CW does not answer or is unaware of RP's whereabouts, CE or LS will contact the City Police and also inform the University Police and pass on the following information:
 - The name and mobile phone number of the researcher.
 - The name, telephone number and address of the interviewee.
- If RP feels uncomfortable at any point throughout the interview, she will terminate the interview and leave the premises immediately.

20th May 2015.

Appendix 4: Topic guide

Topic Guide

This study is looking at the impact of the transplantation procedure on family members of patients (organ recipient). Please ensure you have read the entire information sheet carefully before agreeing to participate. This interview will be conducted in a way that will allow you to recount **your** experience of the transplant process in the way you feel most comfortable. I am going to start by asking one general question and will let you speak for as long as you like in response, with minimal interruption. Following this, if necessary, I will ask a few questions to address any points I would be interested to hear about that you have not yet covered - 'fill in the blanks' if you like.

Acquire verbal permission to digitally record

- The content of this interview will remain confidential. Your name and any you mention will be changed and it will not be possible to associate you with anything that may be written and subsequently published from this interview.
- You do not have to answer all the questions I may ask.
- Feel free to stop the interview for a break if needed.
- You are able to withdraw completely from this interview at any time.

Tell me about your experience of the transplant process to date:

I'd like to hear about the circumstances leading to your relative being recommended for a transplant and any way you feel your life, or that of your family, may have changed as a result of your relative's health condition.

Please talk for as long as you feel comfortable and include any details you feel may be relevant, however small.

Prompts:

How did you feel about X?

Can you expand on what you meant by X?

Points to cover:

- Family routine/roles/responsibilities
 - New roles
 - Loss of 'normal' routine
 - Employment - £ issues
 - Identity
- Family relationships
 - Immediate/wider
 - +VE/-VE
 - Spousal – marital impact
- Wellbeing (self & family unit)
 - Physical
 - Mental

- Social
- Coping strategies – how have you and your family been coping throughout the process?
 - Support
 - Offered/sought?
 - Clinical/family/community/spiritual/support group?
 - Adequate?
 - Managing post-op: Memorials/letter to donor?
- Transition
 - How different is life now than before? [Impact of ‘phases’]
Before: diagnosis, waiting list, ‘the call’, transplant, recovery/rejection/loss of relative
 - Relocating care from hospital to home
 - Managing change in patient
- Expectations – have they been met?
 - Anything you thought would change that hasn’t?

Thank for participation & assess willingness to be contacted again

One of the main aims of this project is to assess the impact of the transplant procedure on individuals like yourself over time, with this in mind I’d like to speak to you again in the future if you are willing. You are under no obligation to say yes and I will not be offended if you chose to end your participation at this point. If you are interested in speaking to me again I will send you a letter within the next 6 months with the details.

Participant Debrief (longitudinal)

What research have I taken part in?

You have been interviewed for a piece of research entitled ‘The impact of organ transplantation on adult family members: a qualitative study’. The purpose of this research is to explore the impact of the transplantation procedure on family members, particularly those that assume the role of primary caregiver. This study will look specifically at how the transplantation process affects familial relationships, roles and wellbeing over time.

What will happen to the interview?

The recorded interview will now be typed up, anonymised and analysed. This information will then be written up into a doctoral thesis. Additionally, it is possible that a version of this research may be submitted to a journal accessible to the public. If published this research could have local and national implications regarding support provided for families of transplant patients.

Pseudonyms (replacement names) will be used throughout to protect your identity and any individuals you may mention - thus it will not be possible to identify you in any publications.

What next?

As one of the main aims of this project is to assess the impact of the transplant procedure on individuals over time I'd like to speak to you again in the future if you are willing. If you expressed an interest in speaking with me again a letter will be sent to you within the next six months detailing how to arrange another interview. This letter will also give you the option to decline a second interview if you decide you no longer wish to take part. Please be aware you are under no obligation to continue your participation and I will not be offended if you want to withdraw from the study.

Dissemination

When the study is complete all participants keen to know the results will be sent a summary of the findings. Following this you will be able to ask any questions which may arise.

Additional information

If any concerns arise about the research you have taken part in e.g. it has raised an emotional issue, please use the support contact sheet provided to speak to someone regarding your concern or contact the researcher using the information provided.

Thank you for taking part!

If you have any questions...

If you do have any queries please do not hesitate to contact Rebecca Patterson, Prof Catherine Exley or Dr Lynne Stobbart at Newcastle University:

Rebecca Patterson
Institute of Health & Society
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Email: lynne.stobbart@newcastle.ac.uk
Phone: 0191 208 5513

Participant Debrief (retrospective)

What research have I taken part in?

You have been interviewed for a piece of research entitled 'The impact of organ transplantation on adult family members: a qualitative study'. The purpose of this research is to explore the impact of the transplantation procedure on family members, particularly those that assume the role of primary caregiver. This study will look specifically at how the transplantation process affects familial relationships, roles and wellbeing over time.

What will happen to the interview?

The recorded interview will now be typed up, anonymised and analysed. This information will then be written up into a doctoral thesis. Additionally, it is possible that a version of this research may be submitted to a journal accessible to the public. If published this research could have local and national implications regarding support provided for families of transplant patients.

Pseudonyms (replacement names) will be used throughout to protect your identity and any individuals you may mention - thus it will not be possible to identify you in any publications.

Dissemination

When the study is complete all participants keen to know the results will be sent a summary of the findings. Following this you will be able to ask any questions which may arise.

Additional information

If any concerns arise about the research you have taken part in e.g. it has raised an emotional issue, please use the support contact sheet provided to speak to someone regarding your concern or contact the researcher using the information provided.

Thank you for taking part!

If you have any questions...

If you do have any queries please do not hesitate to contact Rebecca Patterson, Prof Catherine Exley or Dr Lynne Stobbart at Newcastle University (see reverse for details).

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Phone: 0191 208 5513

Appendix 6: Contact sheet

Support Contact Sheet

If you have any concerns following your participation or feel you need to speak to someone about your situation please get in touch with one of the contacts below:

NHS Carers Direct Helpline

0300 123 1053

(Lines are open 9am to 8pm Monday-Friday, 11-4pm on weekends).

Submit a query by email: <http://www.carersdirectenquiry.nhs.uk/newcarersemail>

LIVErNORTH

<http://www.livernorth.org.uk/pages/contact.htm>

Mrs Joan Bedlington
FREEPOST PLUS
RTHL - UHKL - JKCR
LIVErNORTH
DH9 0BR
0191 3702961
info@livernorth.org.uk

Freeman Heart & Lung Transplant Association (FHLTA)

<http://www.fhlta.org.uk/>

Mr Derek Airey
22 Embleson Avenue
Gosforth
Newcastle Upon Tyne
NE3 3HA
0191 285 5642
derek@fhlta.org.uk

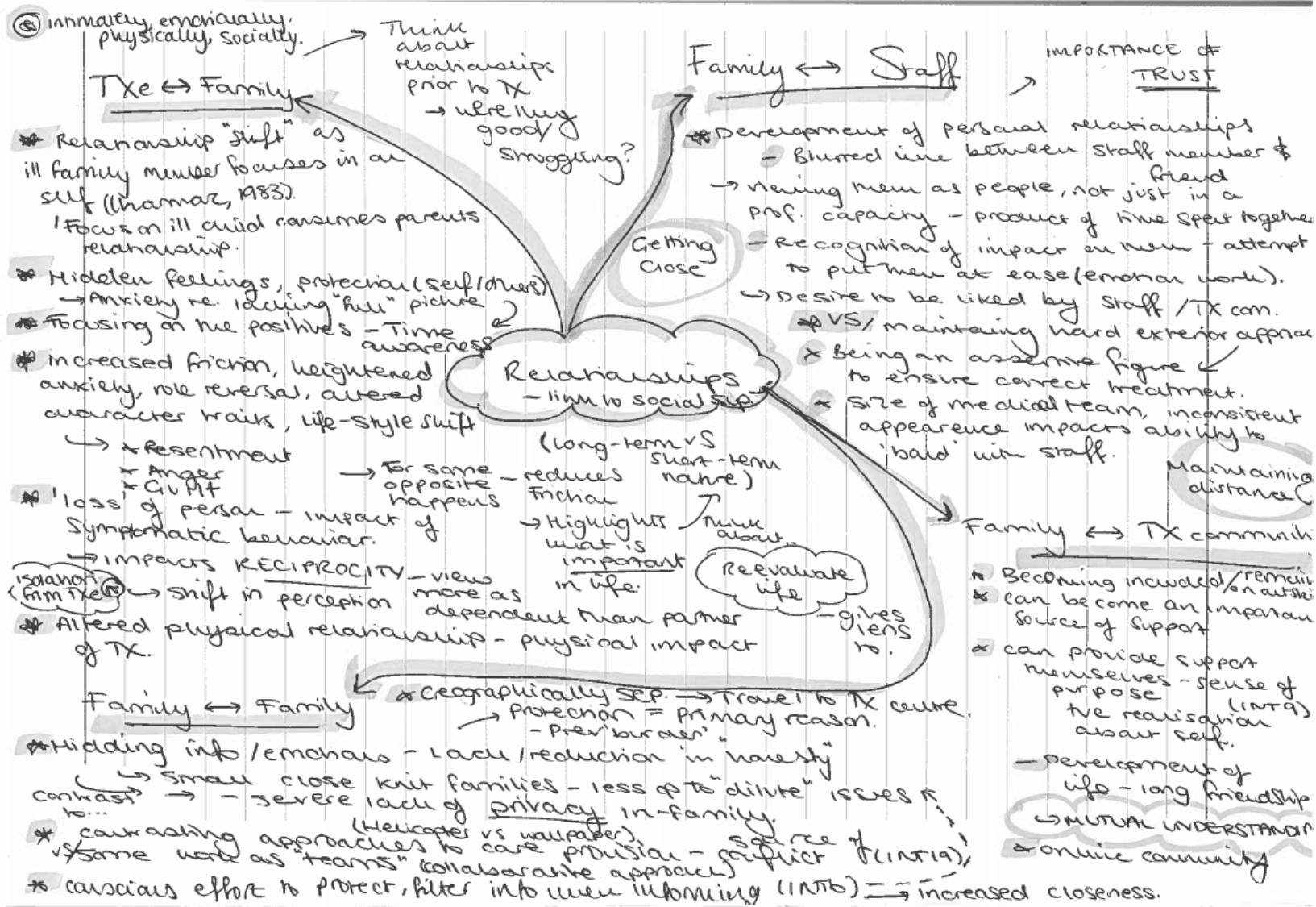
Appendix 7: Notes Template

Notes Template

Participant ID: _____ **Date:** _____

Interview setting (Interruptions? Others present?)
General observations on the process of the interview (detail, flow, openness, detail)
Your identity and relationship with interviewee. Impact?
Key themes or issues
Gaps? Silences? Things you expected to hear about? Areas of sensitivity or tension?
Surprises? Inconsistencies within the interview?
Things you could not cover that perhaps should have been. Need for follow-up?
New issues to incorporate into future interviews:

Appendix 8: Mind map example





Do you know someone waiting for, or who has recently had, a transplant?

If so, I am seeking volunteers for a study to find out more about the experiences of relatives and carers of transplant patients.

Who can take part?

- Relatives and carers (over 18) of adults waiting for, or who have received, a heart, liver or lung transplant within the last 2 years

What is involved?

- An interview (around an hour) within the next few months
- Possibly another interview 6-12 months later

Where will I be interviewed?

- At a location convenient to you, or, if you live outside Tyne and Wear you can be interviewed by telephone

Why should I take part?

- To further research on how families and carers are affected by transplantation
- To raise awareness of issues you may be experiencing

If you are interested and would like further information please contact me, Rebecca Patterson, on **07796387467** or at **r.a.patterson@newcastle.ac.uk**

Thank you for your interest!

Good Practice: How to support family members through transplantation

This document provides an overview of good practice points for transplant teams, derived from this research, which could bolster and/or improve the support provided to family members involved in heart, liver, and/or lung transplantation in the UK, if implemented.

1. Be clear, concise, and frank when communicating with family members, and encourage them to think ahead.

This is particularly important pre-transplantation when they are first learning about the transplantation process.

 - Avoid providing large volumes of information, imbued with medical terminology, as this can be overwhelming and very challenging to understand.
 - Acknowledge the challenges associated with, and potential negative outcomes of, the transplantation process, in relation to patient and family wellbeing. While willingness to engage in a discussion about the potential negatives will vary, this is important to both prepare family members and enable them to feel comfortable discussing any problems that they encounter.
 - Encourage the family to look/plan ahead to life post-transplantation. Family members often refrain from thinking about life post-transplantation, immediate and long-term, fearing they may never reach this stage. This can have a detrimental effect on their wellbeing, as they consequently feel unprepared (anxious and stressed) when they reach this stage.
2. Provide a family-specific resource detailing the family member role in the transplant process, what to expect, support available, and (clinically approved) links to additional information.
 - Family members would benefit from a resource tailored to them and their experience, rather than this information being briefly touched on in a section (or less) in resources distributed to patients.
 - Providing them with a tailored resource would allow them to access and digest information at their own pace and give them something to refer to for clarification at a later date.
 - Including a list of clinically approved websites with additional information about transplantation (such as healthtalk.org) would allow family members to promptly access appropriate additional information, if they desired.
3. Actively include family members in their relative's care in the transplant centre.
 - Family members struggle with role ambiguity in the transplant centre, as they bridge the roles of 'family member' and 'carer'.
 - To address this ambiguity, and reduce the uncertainty experienced by family members, practice must be altered to reflect the six core principles of the 'Triangle of Care'ⁱ:

1. Identify carers, and the essential role they play, as soon as possible. Acknowledge and/or seek their views and/or knowledge, and regularly update them on care plans and strategies;
 2. Ensure staff are 'carer aware' and trained in carer engagement strategies, to encourage awareness of, and respect for, the valuable contribution of carers and their needs;
 3. Implement policy and/or practice protocols regarding confidentiality and information sharing;
 4. Establish defined post(s) responsible for carers (e.g. carers' lead or ward champion);
 5. Provide a carer introduction to the service and staff, with relevant range of information across care pathway;
 6. Provide access to a range of carer support services, with regular assessment and auditing to ensure continuance and efficiency.
- Using these principles to establish their role in care process could bolster family member wellbeing and sense of self in unfamiliar clinical environments/scenarios.
4. Offer family members confidential one-to-one consultations – an opportunity to ask questions and/or discuss their experience.
 - Family members are unlikely to admit when they are struggling or need help, particularly in the presence of their ill relative as they are cautious of diverting attention away from them or making them feel burdensome.
 - Providing a space for family members to ask questions and/or discuss their feelings without fear of jeopardising the way they are perceived by the wider transplant team or upsetting their relative, could relieve some of the anxiety experienced by family members.
 - Family member reluctance to discuss personal feelings and/or issues means that clinicians must initiate and encourage these discussions.
 5. Facilitate relationships between transplant families, past and present, where appropriate and desired.
 - Family members can feel socially isolated during their involvement in the transplantation process, as their experiences differ from those around them (friends, colleagues, neighbours etc.).
 - Facilitating relationships between individuals with similar transplant experiences, where appropriate and desired, could help family members regain a sense of social connection and normalise their experience, enhancing their wellbeing.
 - Not all family members will want or benefit from such relationships, thus this must be approached sensitively. It is important to be open with families about the possible detrimental effects of establishing such relationships (e.g. exposure to emotional distress).
 6. Gauge family member wellbeing post-transplantation and signpost/refer to support if/when required.

- Family members can continue to feel anxious and/or stressed for some time post-transplantation, as they come to terms with their experience and the continuing uncertainty around their relative's health.
- Better recognition needs to be given to family members' continuing emotional and psychological needs over time.
- It is important to continue to consult family members about support their needs and signpost them to the appropriate service, within or independent of the transplant team (including GP, psychologist, social worker, GP, counsellor, support group etc.)

In reviewing and implementing these suggested changes, it is important to remain conscious of the limitations of this research, particularly the limited sample characteristics and lack of a counter-narrative from professionals.

ⁱ Worthington, A. and Rooney, P. (2010) *The Triangle of Care. Carers included: A guide to best practice in acute mental health care*. [Online]. Available at: <http://static.carers.org/files/caretriangle-web-5250.pdf> (Accessed: 15.12.18).