The Gift of Life:
An Existential Phenomenological exploration of receiving a lifesaving organ transplant and how this affects life subsequently.

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"I don't want to be buried with a single organ in my body. Give them to a child that has spent more of their life in the hospital than outside exploring, or a teenager who can't see, or a mother whose heart won't pump on its own. I will no longer need them, give them to someone who does".

(Valdez, 2018).

"It may not occur to people that actually if they are donating, they're not only saving the life of the recipient, but they could be creating new people such as my children. Could be saving the lives of people that don't even exist yet. They are massively impacting upon that whole family, parts of that community. That it's much more than giving your organ to one other person. It's a big thing to do and a fantastic thing to do".

(Participant 5, lines 285 – 289).

Abstract

At present, there is little research conducted on organ transplantation from the perspective of the organ recipient. This study aimed to explore the experience of undergoing lifesaving organ transplantation and how this may affect life subsequently. For the purpose of this research, lifesaving transplants constituted as solid organ transplants, these being heart, lung, liver, and kidney. Six participants were interviewed using semi-structured interviews focusing on the experience of undergoing the transplantation procedure, and how this affected their life following this. The data in the form of the participants' accounts were analysed using Interpretative Phenomenological Analysis - IPA. Five superordinate themes were identified with 19 subordinate themes falling within these. The superordinate themes were; Embodied Experience which related to the participants' physical world and their experiences of this, Life & Death relating to the participants' experience of existence and mortality, Relationships relating to the participants' actual or intended modes of relating to others in the world, Temporality relating to the participants' experience of time, and The Psychological relating to the participants' experiences of their inner world and the relationship they hold with themselves. Consideration and discussion of these themes were conducted, highlighting the implications these findings hold for the field of Counselling Psychology and Psychotherapy, with a nod to Existential literature and philosophy interwoven within this. The study concludes that organ recipients undergoing transplantation experience an array of bio-psycho-social-spiritual issues that professionals working with this population need to be aware of. It is argued that appropriate and sufficient evidence-based interventions should be developed and offered to all those undergoing the transplant treatment as standard in the provision of care provided to this population. Unfortunately, at present psychological support for organ recipients is only offered as and when a need 'arises'.

Keywords

Interpretative Phenomenological Analysis, IPA, organ transplantation, organ donation, solid organ transplants, heart transplant, liver transplant, lung transplant, kidney transplant, Existential, Phenomenology, Embodiment, chronic illness, death, Counselling Psychology.

Statement of authorship

This dissertation was written by Melissa Crutchley and had ethical clearance from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted to the New School of Psychotherapy and Counselling and Middlesex University Psychology Department in partial fulfilment of the requirements for the Degree of DCPsych in Counselling Psychology and Psychotherapy by professional studies. The author reports no conflicts of interest and is alone responsible for the content and writing of the dissertation.

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1. Introduction

This study aims to explore the lived experience of undergoing a lifesaving organ transplant and how this procedure may subsequently affect the lives of those journeying this. This project will consider organ transplantation from an Existential-Phenomenological leaning. Subsequently meaning that theories from this theoretical orientation will be borrowed as a backdrop for the research findings, contextualising these amongst the body of knowledge held on this phenomenon. Whilst an Existential-Phenomenological stance has been taken, the research has also left space for conceptualising the organ transplantation lived experience from differing perspectives. Therefore, the reader will find that this study is not rigidly entrenched with Existential theory, rather more flavoured with this perspective.

It is hoped that the findings from this study can contribute to an increased understanding and awareness of what organ recipients, undergoing this invasive procedure, are expected to endure. Similarly, the findings from this study may prove useful for consideration by those who are responsible for the provision of both the physical and psychological care of organ recipients and their families. Research has shown that the relationship formed between patients and healthcare providers directly impacts compliance with post-operative regimes (Sadala & Stolf, 2008). Therefore, providing insight into the lived experience of organ transplantation treatment can help provide practitioners with a sensitivity to the needs of recipients and how best to support those journeying the transplantation treatment. Promoting the support and wellbeing of organ recipients is what lies at the heart of this study.

The timeline of the organ transplantation procedure from development to the present-day highlights how this process could be considered as a 'relatively new' advancement in science and technology. In 1954 the first successful kidney transplant was conducted, followed by the first successful lung transplant in 1963, and the first successful liver and heart transplants in 1967 (Dabak & Şenbaklavacı, 2016), (NHS blood and transplant, 2020). Subsequently, there is less than 70 years' worth of knowledge and experience to draw upon. Consequently, the current body of knowledge held regarding organ transplantation specifically does not predate this. However, the lived experience of organ transplantation touches upon aspects of the human condition that have been contemplated for hundreds of years, such as death and embodiment. Therefore, this study brings together literature and knowledge from a number of different sources to create a fusion of horizons concerning the phenomenon being explored.

This particular research topic was chosen as a result of my interest in this field, which I will discuss transparently throughout this thesis. In addition to this, another factor that influenced my decision to conduct this research was that at present, organ transplantation from the perspective of the recipient's experiences is an under-researched phenomenon. Research that is concerned with increasing donor rates has been prioritised due to a shortage of donated organs. Therefore, further exploration of the lived experience of those undergoing the transplantation procedure is a worthwhile pursuit, which will aid in furthering the understanding of how to best support this population.

Research conducted concerning organ transplantation has highlighted that the transplantation procedure can have significant bio-psycho-social-spiritual ramifications not only for those directly undergoing this but also for their families. In turn, with the UK government changing the laws surrounding organ donation from May 2020 to an opt-out scheme, it is hoped that there will be an increase in the number of organs donated and subsequent transplants conducted. Organ transplant recipients are a population that will continue to grow in numbers, and the resources invested in caring for this population will be called upon to accommodate this demand. In turn, this will carve out a prominent place for research exploring this phenomenon to help inform the development of evidence-based interventions for this population.

This study will begin with a review of literature that exists regarding organ transplantation and organ donation, in an attempt to provide the reader with familiarity with the body of knowledge held on this. The review will also allow the reader to establish what information has been drawn upon and integrated to construct and conduct this piece of research reliably. In addition, summarising previous research findings on this topic will help to situate this study amongst the existing material held on the lived experience of undergoing organ transplantation.

Following the literature review, this study will move on to outline the research methodology utilised to guide this research piece. It will explicitly highlight the research process from the epistemological position at the foundation of this study, through to the research method that was adopted for data analysis. This chapter aims to transparently communicate the specific research processes followed to allow the reader to comprehend how this research piece was designed and executed. Furthermore, by clearly outlining the research process, this will also allow for the reliability and validity of this study to be determined. It is worth noting that within this section attention has also been devoted to the research method employed and utilised to collect and interpret the data within this study, that of Interpretative Phenomenological Analysis (IPA).

The findings from this research will then be presented, constituting the most extensive chapter of this study. Great attention and space have been afforded to communicating the findings with clarity and accuracy. This chapter will commence with an overview of the themes that have been deduced from the data, moving on to a detailed discussion of each theme individually. Excerpts of the participants' accounts will be provided throughout this to illustrate how the themes were concluded and what interpretations have been made by the researcher. Every effort has been made to ensure that the interpretations remain grounded in the participants' experiences and accounts, in turn preserving the voice of those who shared their stories within this study. The findings section aims to illustrate a logical move from data, to themes, to interpretations.

The discussion chapter will serve to unite the findings from this study with existing literature that has been sourced and cited in the review. Alongside this, further literature will also be introduced that has been drawn upon in light of the research findings. In doing so, this chapter aims to clarify what the findings of this study mean for the body of knowledge held on organ transplantation and the implications this holds for Counselling Psychology and Psychotherapy. This thesis will conclude by revisiting the aim of this study in order for this to be considered in light of what has been set forth. This final chapter will also include a reflection on the most pertinent findings from this research to restate and highlight the importance of these. Finally, areas for possible future research will be proposed, and consideration will be given to the limitations of this research piece so that prospective studies may overcome these.

2) Literature review

2.1 Introduction

The majority of literature and research surrounding the organ transplantation process has been conducted and written from the perspective of the donor. In comparison, little has been carried out concerning the organ recipient's experiences of undergoing this invasive life-changing procedure (Gallego et al., 2018). The emphasis towards research exploring donation could be said to arise from the fact that there continues to be a shortage of available organs and despite advancements in science and medicine, people continue to die as a result of organ failure. Research exploring how to increase donor rates has, therefore been prioritised and has subsequently received greater attention (McGregor, Ferguson, & O'Carroll, 2012).

With respect to the body of knowledge held on organ transplantation, qualitative studies remain relatively uncommon (Tong et al., 2013). However, times are changing, and there is an ever-increasing focus placed on patient-centred research. It is therefore essential that qualitative research is revisited in the context of organ transplantation and that it is afforded a place in the exploration of this phenomenon (Grbich, 1998). Qualitative research in this field can provide insight and understanding into the behaviour, attitudes, and values of those undergoing the transplant journey. Qualitative research has provided insights into some of the critical but elusive questions in transplantation, including non-adherence to immunosuppressive regimens and complex psychosocial outcomes (Tong et al., 2013).

This literature review aimed to investigate and describe experiences relevant to the research question through an exploration of existing literature that engages with the phenomenon of solid organ transplantation. From doing so, I was able to orientate myself with the body of knowledge held regarding organ transplantation, in addition to contextualising this piece of research amongst this. Regarding how this review was formed, I will now outline the process followed, and the inclusion/exclusion criteria for literature included within this.

I initially searched for material that originated from a psychological discipline. However, as previously mentioned, due to the scarcity in literature and research concerning the experience of undergoing the organ transplantation process, the search did not yield as fruitful as I would have hoped. Consequently, I then began searching beyond the psychological field and used literature that originated from outside of this, such as nursing, psychiatry, medicine, and philosophy. Once again, due to the limited body of knowledge held on this subject, I did not discriminate literature based on age or impact of the study in relation to the number of citations. The inclusion/exclusion criteria for the literature included in this review were based on whether it had produced findings that are imperative to the psychological and phenomenological investigation of undergoing organ transplantation. Therefore, the literature needed to add to our understanding of the experiential sense of the organ transplantation procedure and in turn, begin providing context and 'answers' to the research questions posed. I also chose to add literature to this review that originated from an Existential philosophical perspective. My reason for choosing this particular psychotherapeutic modality to feature within this research piece is as a result of my training and practice as an Existential Psychotherapist. I have decided not to include literature from other psychotherapeutic modalities as I wished to keep this review entrenched in research findings, with a flavour of Existential theory.

A wide range of published articles was explored using databases such as Google Scholar, PsychArticles, and PsychInfo. In addition, the resources of the British Library, Middlesex University, and The Open University were used to explore books and other papers that were concerned with organ transplantation. The literature review was conducted by firstly exploring facts and figures about organ donation and transplantation, and then previous research on organ transplantation, including generalised findings and specific organ-related studies. Having done so the information gathered highlighted other areas for consideration; these being embodiment, systemic issues, temporality, and facing death and surviving. These aspects of the transplantation phenomenon will be discussed individually below. The search terms I utilised for this literature review corresponded to the experience of undergoing the organ transplantation procedure: organ transplant, organ donation, heart transplant, liver transplant, lung transplant, kidney transplant, end-stage organ failure, chronic illness, pain, terminal diagnosis, facing death, temporality, systemic issues, embodiment, phenomenological, existential, qualitative.

2.2 Facts and figures

For the purpose of this research project, the term ‘lifesaving transplants’ refers to kidney, liver, heart, and lung, otherwise known as solid organ transplants (Lock, 2002). The rationale behind using this terminology is that these are all organs vital to survival, and failure of these leads to a terminal prognosis (Black et al., 2018). Therefore, in undergoing this treatment, it is essentially saving and preserving the life of the recipient.

At the time of writing, the UK laws surrounding organ donation operate on an opt-in basis, meaning individuals who wish to donate their organs need to register to do so. However, with effect from 20th May 2020, the UK government has proposed a deemed consent system and people who do not wish to become an organ donor will be required to opt-out (www.organdonation.nhs.uk). The impetus behind changing the law with regards to organ donation is in the hope to increase donor rates, thus overcoming the deficit in organs being donated. At present, approximately one person dies every day in the UK waiting for an organ transplant (British Islamic Medical Association, 2020). Increasing the number of organs available will, in turn, increase organ recipient rates. Therefore, this clinical population will become more prevalent, reinforcing the need for further research and consideration of this phenomenon. The experience of undergoing an organ transplant and how this affects life subsequently is a necessary and worthwhile pursuit.

In order to be found suitable for solid organ transplantation in the UK, the individual must be considered to meet the criteria for end-stage organ failure/disease. End-stage renal disease (ESRD) is defined as kidney failure, where the individual concerned cannot survive without dialysis or transplant (American kidney fund, 2018). End-stage liver disease (ESLD) is considered to be liver failure, whereby transplantation is required for survival as the disease can no longer be controlled by other treatments (UCSF, 2018). Late-stage congestive heart failure (late-stage CHF) is defined as heart failure that requires extensive surgical treatment or transplantation in order for survival (Johnson, 2018). Respiratory failure is a collective term for diseases of the respiratory system that may require transplantation due to no longer being manageable through other treatment methods (Cardiothoracic Advisory Group, 2017). Therefore, at the point of transplant, the recipient is considered to be living with a chronic illness which may have impacted their life in a significant way.

The NHS organ donation and transplantation activity report (2018) covering the period of 1st April 2017 to 31st March 2018 declared that 24.9 million people in the UK were registered for organ donation. During this time frame, 6,044 people were on the waiting list for organ transplantation. Unfortunately, 426 people sadly died whilst waiting for a transplant, plus a further 3,404 patients were suspended from the active national transplant list due to being deemed as medically unfit or otherwise unavailable for transplantation. There were 6,038 eligible deceased donors in that time frame, resulting in only 1,574 actual cases of donation. In addition, 1,051 live donations were made, resulting in a total of 5,090 organs transplanted from 1st April 2017 to 31st March 2018 in the UK. Of the 5,090 organs transplanted during this time frame, 3,597 were kidney, 1,059 were liver, and 412 were heart and/or lung. The remaining 22 transplants were not solid organ transplants. The total approximate number of patients in the UK with a functioning transplant, as reported on 31st March 2018, is 52,200. This number excludes those who are known to be lost to follow-up, meaning the actual number of patients in the UK with a functioning transplant is in excess of this (NHS Blood and Transplant, 2018).

Organ donation can occur from both deceased donors and living donors, organ dependant. Live donation can materialise when the donor is considered medically fit to live normally following the donation of their organ. Organs that can be donated from a live donor are liver and kidney. For an organ donation to occur from a deceased donor, the individual must have died from either brain death (DBD) or circulatory death (DCD). Liver, kidney, and lung donations are possible from both types of deceased donors; however, heart transplants can only occur through DBD's. Multiple organs can also be transplanted at the same time, with the most common form of these being heart and lung transplants. The availability of heart and lung transplants are substantially lower than those of kidney and liver due to these organs only being available from deceased donors, whilst liver and kidney donations can also originate from a live donation. This is evidenced in the figures provided above in regard to the amount and type of transplants completed in the given time frame of 1st April 2017 to 31st March 2018 (NHS Blood and Transplant, 2018). The type of donation may hold important implications for the recipient and the relationship they develop with their new organ. This is discussed further within the consecutive section of this literature review.

Alongside the national organ donation register, for kidney transplants there exists the paired and pooled scheme. This scheme is orchestrated through the UK Living Kidney Sharing Scheme (UKLKSS) ran by NHS Blood and Transplant (NHSBT). This scheme can only be used under the circumstances that a live donor has been found, but they are incompatible with their recipient for whatever reason. A paired donation is where the donor and recipient are matched to another couple so that both recipients receive a suitable organ. A pooled donation is where there are more than two pairs of donors and recipients involved in the process (Human Tissue Authority, 2019). Kidney transplants only occur when both kidneys are no longer functioning as an individual can survive with only one functioning kidney. In turn, the organ recipient will only receive one kidney through transplantation (Watson, Johnson, & Mumford, 2020).

Before undergoing organ transplantation, prospective recipients will engage with various medical and psychosocial assessments to ascertain whether they are physically fit enough to survive the treatment and if positive treatment outcomes are feasible (Olbrisch et al., 2002). This can be an incredibly stressful time for the recipient, with these assessments highlighting the need for transplantation for them (Rainer, Thompson & Lambros, 2010). The goals of psychological evaluation are to identify potential risk factors such as compliance issues, psychopathology, and substance misuse that may influence the rate of noncompliance and morbidity. A psychological evaluation can also help to inform post-treatment planning for individuals who have been identified as ‘high risk’ (Dew et al., 2000). At present, there remains a significant variance with how each transplant team navigates these assessments. This is due to there being no existing set standard pertaining to how this should be done. There have been several brief instruments designed to aid in the psychological assessment of transplant patients, such as the Psychosocial Assessment of Candidates for Transplantation (Olbrisch, Levenson, & Hamer, 1989) and the Transplant Evaluation Rating Scale (Twillman, Manetto, Wellisch, & Wolcott, 1993).

Donated organs have an extremely short shelf life from the point of obtaining the organ to the point of transplantation. A heart and lung can be kept viable for six hours, a liver for 12 hours, and a kidney for up to 30 hours. If the harvested organ is not transplanted within these time constraints, the organ will no longer be viable and cannot be used (The Alliance, 2020). Subsequently, transplant teams are forced to work quickly when an organ is identified for transplantation. This process involves advising the recipient of the availability of the organ, transporting the organ to the required hospital site, and performing the transplant procedure. The recipient will also be required to act quickly upon being advised of the sourced organ and get themselves to the hospital to undergo the transplant within the appropriate time frame. This may result in the organ transplantation process being experienced as abrupt for the recipient and in turn, impacting their ability to process this occurrence (Health.org, 2016) effectively. This is discussed further within the temporality section of the literature review.

When undergoing the procedure, depending on which organ is being transplanted, the surgeon will decide whether to leave the original failed organ intact within the recipient's body or remove it. In the case of a heart, lung, and liver transplant, the recipient's own failed organ will always be removed and replaced by the donated organ. The patient will, therefore, no longer possess their own organ and will live from that point onwards with someone else's organ inside of their body. However, in some kidney transplant cases, if safe to do so, the surgeon will leave the original organ in the recipient's body and add the donated organ to this. This, in turn, can mean that a kidney transplant recipient may exist with more than two kidneys in their body. The kidneys that are no longer functioning will eventually wither away to virtually nothing, leaving the transplanted kidney in its place (Piedmont Healthcare, 2020). Receiving a new organ has been shown to affect the dynamic the recipient possesses with their physicality and is further addressed in the embodiment section of this literature review.

With regards to survival rates, these need to be considered in relation to the survival of the patient and survival of the transplanted organ. The organ transplantation process inevitably brings with it the risk of death not only for the recipient but also in relation to the graft. Whilst the operation may appear a success in terms of patient survival in some cases, the organ is not accepted by the host's body and will fail. Information about survival rates has, therefore, been collected in relation to the graft, where possible, and the patient. Several factors have been shown to affect survival rates, such as the origin of the organ donation being either live, DBD, or DCD, and the time elapsed between receiving the organ and the present day. Whilst transplant patients are considered to be at the highest risk of imminent death immediately after the transplant, risks around graft survival remain as a result of the donated organ possessing a ‘shelf life’. This means that the transplanted organ will not be viable for the same length of time the host’s own organ would have been if this were healthy (NHS Blood and Transplant, 2018). Information concerning survival rates has been included within this research piece, please see appendix one for this.

Solid-organ transplantation is not a cure for end-stage organ failure; rather more, it is considered to be an effective treatment (Williams et al., 2016). Transplants can save the lives of those who are affected by end-stage organ failure and improve their quality of life. This method of treating end-stage organ failure has been shown to be more effective in regard to longer-term patient survival rates in comparison to other treatments such as dialysis (Grinyó, 2013). However, solid organ transplant recipients are affected by transplant-inherent-related comorbidities, such as new-onset diabetes mellitus, infections, hypertension, cardiovascular events, and cancer. Organ recipients are also required to take immunosuppressive medication indefinitely to prevent their immune system from attacking and rejecting the transplanted organ. The immunosuppressive medication increases susceptibility to infections and leads to difficulties in fighting these. It also increases the risk of developing diabetes, cancer, and other conditions (Contie, 2012). Therefore, organ transplant recipients continue to experience difficulties with their physical health post-transplant. The expectation that the patient will be ‘cured’ of their ills having undergone transplantation is unhelpful and needs to be abandoned. Possessing unrealistic post-operative expectations may adversely impact the recipient's medical compliance and wellbeing (Hathaway et al., 1990).

Immediately after transplantation, post-operative delirium can occur in which the patient experiences confusion, loss of memory, sleep pattern disturbances, language disturbances, emotional changes, visual and/or auditory hallucinations, and delusions. This is often an unsettling and distressing experience for the patient and their families (Cibelli, 2016). Post-operative delirium is thought to occur due to the physical challenges the body undergoes following a significant medical procedure and stress caused by this interferes with how the brain operates. Acute brain dysfunction is considered a common occurrence in intensive care patients or those who have undergone surgery, both of which are applicable to organ transplant recipients (Sanders et al., 2011). Immunosuppressive medication is also known to contribute to post-operative delirium. Whilst the symptoms of this are considered to be reversible in the majority of cases, post-operative delirium has been shown to increase the recovery time, the length of stay in the hospital, and mortality rates (Rudolph & Marcantonio, 2011).

At present, the NHS does not provide or offer psychological support to every individual undergoing the organ transplantation process; instead, this is only offered as and when a need arises (NHS marketing communications, 2018). Research conducted by Goetzmann et al. (2006) and Schulz et al. (2007) observed that the need for psychological support and care for those undergoing the organ transplantation process was found in up to 50% of patients. This finding is in stark contrast to the current climate and provision of care offered by the NHS transplantation services. Patients are often directed to charities that offer support services to those affected by this process. However, this is often peer-led (Health talk, 2016) and is not an adequate replacement for psychotherapeutic interventions led by appropriately qualified practitioners. Psychotherapeutic support offered to those undergoing the organ transplantation process should be informed by prior psychological research findings applicable to this clinical population. Therefore, this research project aims to contribute to the body of knowledge surrounding the experience of the organ transplantation process and subsequently provide practitioners with an understanding of how to support individuals journeying this adequately.

2.3 Prior research on organ transplantation

Commonalities amongst the lived experiences of solid organ transplantation types will be presented in this section of the literature review. The subsequent sections will then turn their attention toward particularities of each solid organ transplantation type to ensure every basis is covered. Considering findings that relate to both commonalities and divergences between and across the specific solid organ transplantation types will aid in the conceptualisation of this research study's findings. It will also help to shed light on what these findings ultimately mean for the body of knowledge held on organ transplantation from the perspective of the recipient. Prior research conducted on organ transplantation from a psychological perspective has been kept to organ-specific cases (Rainer, Thompson & Lambros, 2010). This research project will pursue an alternative method of exploration into this phenomenon by approaching the experience of solid organ transplantation as homogenous. By doing so, it is hoped that a holistic understanding of this lived experience can be achieved. It is also worth noting that transplant teams working within units in the UK care for transplant patients across the different solid organ types. Therefore, this study's holistic approach to exploring and understanding the lived experience of organ transplantation correlates with the 'real world' application of organ transplant treatment. In addition, the findings from this research piece could also be said to possess a greater degree of generalisability regarding the lived experience of the transplantation procedure, as a result of not discriminating between specific organs. The findings from this research may serve to unite and bridge the gap between the findings from organ-specific studies.

Whilst the physical health of the organ recipient is addressed by undergoing transplantation, the psychological ramifications of this treatment are rarely considered by healthcare practitioners (Savitch, Gilmore, & Dowler, 2003). In regard to the psychological health of organ recipients, depression has been observed to affect up to 60% of patients post-transplant (Corbett, et al., 2013). In addition to this, 20% of kidney, 30% of liver, and up to 60% of heart recipients develop anxiety disorders within the first year following transplantation (Favaro et al., 2011). Despite these findings, there are very few studies conducted with regard to exploring and developing appropriate and effective interventions for this population (Engle, 2001). Therefore, this research project hopes to contribute an understanding of how to best support the transplant population with the difficulties they may face having undergone the transplantation treatment. The figures presented above also further support the need for adequately informed therapeutic interventions being offered to all those undergoing this invasive procedure.

Research conducted by Rainer, Thompson, and Lambros (2010) found that there were three distinct phases of the organ transplantation process and that each held relevant issues for psychotherapy. The three temporal phases identified were the pre-transplant stage, preoperative/candidacy waiting period, and the post-transplant stage. The commencement of formal medical assessments defines the pre-transplant stage. By undergoing formal assessment, the seriousness of the illness and the need for organ transplantation are highlighted. This can undermine certain coping mechanisms such as denial that are potentially used by the patient and/or their families. Therefore, during this phase, the patient may experience a mixture of challenging and conflicting feelings, distress, and ambivalence. During this stage, patients are also faced with several difficult concepts such as the fact that organ transplantation is required for their survival, what it means to live with someone else's organ, and what it means to have a limited and uncertain life expectancy (Schulz & Kroencke, 2015). Psychotherapy offered at this point may help to discover and rectify unrealistic expectations or confusion about the transplant process, which could later be detrimental to the patient's physical and psychological recovery. It may also help the patient to manage emotionally with the challenges they have to face during this phase (Tringali, Arria, & Trzepacz, 1994).

Patients often identify the preoperative/candidacy waiting phase as the most psychologically challenging phase of their transplant journey (Stukas et al., 1999). It is defined as the period in which all medical assessments have deemed that organ transplantation is the most appropriate treatment, and the patient is entered onto the transplant waiting list. The patient then awaits news of a suitable organ that has been sourced for them, with this potentially occurring at any time of day or night. Many patients have described this phase as a 'lottery' or a 'waiting game' due to the understanding that a suitable organ may not be sourced in time. This meaning that the patient is left to wait for the situation to unfold (Havekost, 2019). This can create significant stress and angst for the recipient and their families. The issues experienced by the patients during this phase are indicative of populations living with chronic illness. Transplant patients are found to have an increased risk of psychological distress, clinically significant depression, and anxiety disorders (Dew, Switzer, & DiMartini, 1998). Patients report experiencing distress as a result of living with an uncertain prognosis (Brennan, 2001) and adjusting to surviving their life-limiting illness (Chan, Cardoso, & Chronister, 2009). Some of the issues that fundamentally concern psychotherapeutic work during this phase relate to adaptation to changing physical needs, living a healthy lifestyle, and compliance with medical procedures (Baines & Jindal, 2001). Particular existential issues that can be worked with in this stage include helping the individual to accept their limitations, create a working present, and enduring the unpredictability of their illness (Rainer, Thompson & Lambros, 2010).

The post-transplant stage is epitomised as the phase of significant physical and emotional transition following the initial transplant surgery. Whilst the psychological burden of the transplantation journey is usually considered to be less severe in this phase than during the pre-transplant and preoperative stages, the patient is still considered to be chronically ill. Therefore, they will inevitably face many physical health risks following the transplant, such as the need for re-transplantation, severe comorbidities, and death (Schulz & Kroencke, 2015). With regard to psychological issues, some patients have reported experiencing difficulties in coming to terms with and accepting their new organ (Burra & De Bona, 2007). Many patients see their new organ as a separate entity from their sense of self, which resides inside the boundaries of their bodies. However, paradoxically they are aware that the organ is functioning as an integral aspect of their bodily systems and is fundamental to their survival. Some transplant recipients have reported suffering feelings of guilt concerning their donor and the understanding that their new lease of life occurred unfortunately at the expense of another's ending (Goetzmann et al., 2009). Therefore, psychotherapeutic intervention within this phase could focus on aiding the recipient in developing a more cohesive relationship with their new organ and resolving feelings that may arise as a result of gaining a new organ, with the view to integrating this into their sense of self.

Other psychological after-effects in the post-transplant stage include issues with emotional stability, changes in social roles, and occupational choices. Psychotherapy could focus on assisting the patient with adapting to fundamental life changes and developing realistic expectations with regards to their physical recovery and organ function. The most notable psychological presentations in this phase are that of depression and anxiety. Therefore, psychotherapeutic work aiding in working through these emotions could also be incredibly beneficial (Rainer, Thompson & Lambros, 2010).

Organ recipients are required to take lifelong immunosuppressive medication to prevent the transplanted organ from being rejected by their bodies. Research into the psychological effects of lowered immunity has shown that there appears to be a correlation between clinical depression and alterations in cellular immunity (Herbert & Cohen, 1993). Therefore, this is another aspect of the organ transplantation process that the recipient may be affected by and in turn, professionals should be mindful of. A study by Andersen et al. (2004) found that the implementation of psychological intervention not only improves mood states and behavioural responses but was also seen to improve immunity levels. This subsequently strengthens the case that adequate psychological interventions should be made available to the organ transplantation population.

Research conducted by Engle (2001) reported that the medical field's attitude toward organ transplantation is that of it being a 'routine medical procedure'. The impact of holding this belief can mean that the psychological needs of the recipient are often neglected. Engle (2001) reinforced that this is a significant issue and highlighted some of the psychosocial issues patients of organ transplantation experience, these include; psychiatric diagnoses, individual/family adjustment, and relationship problems, sexual dysfunction, return-to-work difficulties, compliance problems, and variables related to noncompliance. He stressed that there is a great need for empirically supported interventions to address these areas of concern. He concluded that problems experienced by organ transplant recipients were likely to be underreported; therefore, the impact this procedure has on an individual's wellbeing is potentially underestimated at present (Engle, 2001). As this study is dedicated to capturing the experience of undergoing transplantation treatment, it is hoped that it may go some way to highlighting the significant impact this lived experience potentially has on the individuals journeying this.

Research conducted by Sanner (2003), exploring the conceptualisation of the organ transplant process by transplant patients, revealed four distinct categories. These were guilt, joy and sorrow, gratefulness and indebtedness, and inequity. The transplant patients reported thinking and feeling these states both in relation to the organ donor personally and toward the organ transplantation process generally. This highlights the complexity of cognisance experienced by transplant recipients and the plethora of emotions that can be evoked from undergoing the transplant procedure. This study also highlights the paradoxical nature of the recipients' responses, in that they are often in contrast - such as joy and sorrow experienced in unison.

Deurzen (2015) emphasises that paradoxes are an inescapable aspect of the human condition; however, how these are navigated holds important insights into the individual's life struggles. Therefore, aiding transplant recipients in living alongside these paradoxical thoughts and feelings is an important consideration for therapeutic intervention with this population.

Further research conducted by Sanner (2001) explored people's thoughts and feelings about receiving organ transplants and whether this influenced their attitude toward receiving one. Several patterns in attitudes emerged, firstly that of objectifying the body and considering it to possess a machine-like quality. Those that held this belief did not feel a strong correlation between their physicality and their sense of self, leading them to conceive the idea that body parts that are broken or faulty require replacement by spare parts from others. These participants shared that they would accept an organ transplant if they required one. A differing attitude that emerged was the belief that the new organ would transfer the donor's qualities to the recipient, which in turn would influence the identity of the recipient with regards to their behaviours, appearance, and personality. Participants possessing this attitude reported they would be unsure as to whether they would accept an organ transplant if they required one (Sanner, 2001). This study suggests that how the individual conceptualises organ transplantation may significantly affect their willingness to engage with this process if necessary. It may also impact on how successfully they are able to recover psychologically following this procedure, more specifically in regard to adjusting to changes in physiology. This particularly highlights the importance of exploring how organ transplant patients conceptualise the treatment they undergo and the dynamic this may pose regarding their experience of embodiment.

2.4 Particularities of Heart transplantation

Whilst heart transplantation treatment offers a lifeline for those in end-stage heart failure; many recipients continue to face psychological distress beyond this (Cierpka, Małek, & Horodeńska, 2015). Some research suggests that this is concerning the fact that the heart itself is symbolic of life and death, it has been used to depict emotions experienced such as love and grief, and it has been thought of as 'responsible' for certain types of decision making – following your heart. These conceptualisations, in turn, make the heart not only an organ that is essential for physical existence but it takes on a personified quality to it, laden with connotations around its responsibility for the human experience (Lakoff & Johnson, 2003). The heart is culturally considered to be the locus of the soul, and because of this, some heart transplant recipients have reported concerns around the loss of their heart impacting their sense of self (Bunzel, Wollenek, & Grundböck, 1992). Research by Rodgers (1989) found that certain psychological difficulties experienced by heart transplant recipients were caused as a result of losing their own heart and in turn, the process of accepting someone else's. Recipients expressed concerns about losing aspects of themselves along with their heart and in turn, gaining facets to their personalities and characteristics as a result of 'inheriting' these from the donor (Svenaeus, 2012). Therefore, a heart transplant can raise important questions around the recipient's identity and sense of self that other organ transplantations may not do.

Heart transplant recipients have also reported fears surrounding the fate of their heart and experience grief as a result of the loss of this (Kaba, Thompson, Burnard, Edwards, & Theodosopoulou, 2005). The patient understands that their own heart is no longer functional, and implicitly knows that this will be taken away and discarded. Whilst this may not be an issue for other organs, due to how the heart is conceptualised, this process can be one of significant loss and grief. What happens to the feelings and experiences of which the recipient has attributed to their heart when this is no longer in existence remains a burning question for them (Svenaeus, 2012).

Recipients have also reported experiencing feelings of loss and guilt concerning their donor. The patient is aware that their transplant has only been made possible by the donor's death (Rauch & Kneen, 1989; Kaba et al., 2005). Many heart transplant recipients have spoken about the grief they experience in relation to the donor and the donor's families, more so than other organs. This may be possibly due to the heart depicting the line between life and death itself, therefore bringing the donor's mortality into conscious awareness for the recipient.

Another aspect of heart transplantations that may not necessarily relate to other organ transplants is the felt sense of the heart on a constant basis. The recipient experiences the heart beating, with this speeding up during times of exertion, and slowing down during periods of rest and recovery. The sensation of the heart is a constant, relentless reminder of its presence, which can be unsettling for those who are struggling to integrate this into their sense of self (Svenaeus, 2012). Other organs such as kidney or liver do not emit a sensation that is directly accessible to the recipient and therefore can 'fade' into the generalised experience of existence.

2.5 Particularities of Lung transplantation

Lung transplantation has been shown to be an effective treatment for those in end-stage organ failure; however, this does not mitigate the life-threatening illnesses and risks associated with this treatment. Organ transplantation always carries a risk of being unsuccessful, with survival rates being applicable for both patient and graft. Acute graft failure is more common in the case of lung transplantation than any other solid organ transplant, meaning that those undergoing this procedure are at greater risk of not surviving this (Wilkes, Egan, & Reynolds, 2005). This is a significant concern for those considering undergoing this treatment and one of which creates inevitable stress for all those impacted by this. The recipient is faced with their mortality if they do not undergo the treatment, however, in turn, faces the fact that this 'lifesaving' treatment could be the reason as to why their life comes to an end. Whilst this applies to all organ transplantation treatments in some manner, it is more probable in the case of lung transplantation. In addition to the risks around graft rejection, lung transplants have shown to produce the lowest long-term survival rates in comparison to other solid organ transplants (Barbour, Blumenthal, & Palmer, 2006). Therefore, Barbour et al. (2006) stress the importance of supporting lung transplant recipients in improving psychosocial functioning as timely as possible.

Due to the nature of respiratory diseases limiting mobility and physical function substantially, those who suffer from these difficulties report significant impairment in regard to their quality of life. Successful transplantation treatment can improve the patient's quality of life regardless of organ type, however, in the case of lung transplantation, this has been shown to be a drastic and immediate change (Gross, Savik, Bolman, & Hertz, 1995). The patient is able to regain mobility and physical function almost immediately following successful transplantation. This is considered to be a significant factor in the increase in quality of life experienced following lung transplantation treatment (O'Brien, Banner, Gibson, & Yacoub, 1988). If lung recipients are more sensitive to the ‘measure’ and conceptualisation of quality of life due to theirs being severely impacted by their illness, then this factor may potentially take up a greater space in their lived experienced than other organ transplant recipients report.

A significant improvement in mental health status has also been observed within this population, once again relating to the drastic and sudden improvement in the quality of life post-transplant (Seiler, Klaghofer, Ture, Komossa, Martin-Soelch, & Jenewein, 2016). In being found suitable for lung transplantation, the recipient is required to be in end-stage organ failure, meaning that without transplantation their prognosis is terminal. Undergoing lifesaving but life-threatening transplantation treatment is once again a significantly stressful event for the recipient. The psychological benefits of undergoing and surviving lung transplantation treatment are often overlooked at the expense of physical health outcomes. A study conducted by Fox et al. (2014) explored the psychological benefits of undergoing lung transplantation treatment in which they referred to this as post-traumatic growth. They found that this growth exceeded levels observed in other chronic disease populations. Therefore, lung transplantation treatment, when successful, may uniquely foster positive psychological change in survivors.

2.6 Particularities of Liver transplantation

In order to be found suitable for liver transplantation, the individual must be considered to be in end-stage organ failure, which inherently brings forth physiological complications. Hepatic encephalopathy is a decline in brain function that occurs as a result of severe liver disease. During liver failure, the organ is not able to adequately remove toxins from the blood, causing a build-up of toxins in the bloodstream, which can lead to brain damage (Bass et al., 2010). Therefore, many liver transplant recipients report a decline in cognitive functioning, particularly memory impairment and psychomotor slowing (O'Carroll, Couston, Cossar, Masterton, & Hayes, 2003). This can be distressing for the individual and may be a contributing factor towards significantly elevated levels of anxiety and depression amongst those waiting for liver transplantation (O’Carroll et al., 2003). It is uncertain how reversible these cognitive symptoms are after liver transplantation, meaning that the recipient may be faced with the prospect of living with lifelong cognitive functioning difficulties.

Many liver transplant recipients prior to undergoing the transplantation procedure suffer from a type of liver disease, rendering their organ as insufficient for functioning. Research into the experience of this has shown that there continues to be a stigma directed towards those suffering from liver disease, due to the connotations surrounding this. Liver disease is often attributed to alcohol or substance misuse, in turn meaning that those suffering from this are assumed to fall into one of these two categories (Sogolow, Lasker, Sharim, Weinrieb, & Sass, 2010). Those subjected to the stigma of these 'socially unacceptable behaviours' can often find this distressing, even in cases where the individual is aware that this is not the cause of their liver disease. Actual or perceived stigma amongst those suffering from liver disease has been associated with adverse attitudes and behaviours, such as a reluctance to seek healthcare when required. Subsequently, practitioners must be aware of the perceptions liver transplant recipients may hold around their illness and the impact this may have on their interaction and compliance with medical care (Vaughn-Sandler, Sherman, Aronsohn, & Volk, 2014).

Body image is an aspect of the liver transplantation treatment that, to date has been neglected, with only a handful of studies exploring this. Body image relates to the intrapsychic processes that integrate and combine the perception of one's body, cognitive schemas, and affective dimensions. Concerns around body image have been consistently reported to play a significant role in the recipient's psychological adaptation following organ transplantation treatment (Zimbrean, Gan, Deng, & Emre, 2019). Therefore, it is essential to turn our attention toward factors that influence and impact body image. Research into body image concerns amongst liver transplantation recipients has found that post-operative weight gain is more prevalent in this population than any other organ transplantation type (Beckmann et al., 2017). This raises the question as to whether liver transplant recipients may be more predisposed to concerns around body image post-transplantation.

2.7 Particularities of Kidney Transplantation

Kidney transplants are the primary type of solid organ transplantation that can originate from a living donor. Acknowledging that donation from deceased donors brings forth issues and concerns around values and spirituality, as discussed in this literature review, the dynamic that live donation presents is also worth consideration. Live donation has become the preferred method of kidney transplantation due to this holding advantage over deceased donation when considering time frames of transplantation and long-term survival of graft and patient (Davis, & Delmonico, 2005). Whilst some live donations are anonymous, the most frequent source of kidney donation is made from someone known to the donor. Very few studies have explored what impact this may have on the relationship between donor and recipient. Research conducted by Simmons (1981) found that in these circumstances, the relationship between donor and recipient was reported to function more effectively following a successful outcome of transplantation. Simmons (1981) also found that adverse post-operative outcomes impacted donor-recipient relationships.

If kidney transplantation does occur from a live donation, then this can be done on a pre-emptive basis and in some cases bypass the need for medical treatment like dialysis, resulting in better post-operative outcomes for both the patient and graft (Voiculescu et al., 2003). In cases of anonymous donation, the recipient will have very little involvement in arranging the logistics of this. However, as discussed above the majority of live donations come from either related live donors or unrelated live donors known to the recipient (NHS Blood and Transplant, 2018). In these cases, the transplant recipient would have been personally involved to some extent in this decision. In order for a live donation to take place, the donor and recipient would have agreed to this prior to approaching the transplant team. Several research studies have explored variables behind barriers to live kidney donation, with the willingness and ability of the recipient to engage in dialogue with others surrounding this being one of them (Barnieh et al., 2011). Several studies have reported factors that influence the recipient’s willingness and ability to ask for a kidney donation; such as guilt and fear around the request and what this would mean for the donor should they agree (Gordon, 2001), a reluctance and discomfort around asking someone to donate a kidney (Coorey et al., 2009), fears for the donor’s health should they opt to undergo this invasive procedure (Kranenburg et al., 2005), fear of a negative response from the prospective donor (Schweitzer et al., 1997), and feelings of guilt and responsibility towards the donor and the impact of this may have on their health and life. (Kranenburg et al., 2007). Therefore, initiating a dialogue around donation is not an easy task for the recipient, potentially evoking some challenging feelings and cognitions for them. Live donation is of huge benefit to the recipient, therefore overcoming this barrier is a worthwhile pursuit and support should be offered to those having to engage in these challenging conversations.

2.8 Embodiment

Criticism has been levelled at psychotherapeutic interventions for not considering and exploring embodiment thoroughly enough in the therapeutic space. It is also said that there remains a need for a more sophisticated understanding of embodiment in psychotherapeutic encounters (Butt, 1998). This research project may contribute toward a better understanding of how organ transplant patients experience embodiment, in turn, informing professionals as to how they are able to work with this in the therapeutic space.

Western medicine is dominated by the Cartesian dualistic notion of viewing the body and mind as separate entities. This way of thinking has been shown to be fundamental in the development of clinical detachment, in which practitioners psychologically distance themselves from their patients in an attempt to provide care from an objective standpoint (Richardson, 1988). Clinical detachment has been found to benefit clinicians by allowing them to implicitly manage anxieties that arise when considering the fallibility of humankind. If medical practitioners can conceptualise their patient as an object rather than a subject, they perhaps are not reminded of their own impending fate (Robbins, 2018). However, in consideration of the patient's perspective, clinical detachment can often result in their psychological domain being overlooked and neglected. Therefore, how the individual experiences themselves and the world through their physicality may not be considered or accounted for by clinicians when providing care. This has particularly pertinent issues for the experience of those undergoing the organ transplantation process.

The Cartesian dualistic consideration of the mind and body is also shared by most Western models of conceptualising embodiment (Haddow, 2005). However, the Existential perspective does not draw this distinction and purports that all aspects of the human experience are embodied. Merleau-Ponty (1962) describes being-in-the-world as also being-in-the-body, therefore, mind, body, and the world are inseparable, and one cannot exist without the other. Merleau-Ponty (1962) refers to the human condition as an incarnate subject, given life through the flesh and only possible through physical existence. Therefore, we must consider the impact of undergoing physical change, such as organ transplantation, has on the physical, social, psychological, and spiritual dimensions of human existence.

A transplanted organ is always considered medically to be borrowed due to the host's immune system reacting to the new organ as alien tissue. In response to this, the recipient's immune system will attack and reject the new graft. For the new organ to be functional in the recipient's body, they are required to take lifelong immunosuppressant medication. Compliance with this regime increases the likelihood that the new organ will not be rejected, and the patient can function as intended with the new organ (Rainer, Thompson & Lambros, 2010). The awareness of this 'borrowed' quality to their new organ is likely to create difficulties in the recipient considering this to be part of their physicality, and subsequently integrating this into their embodied sense of self (Dicks et al., 2018).

In a study conducted by Goetzmann et al. (2009), it was discovered that 2.7% of recipients had difficulty integrating the new organ into their sense of self due to experiencing significant guilt about the donor's death. It was subsequently found that experiencing this guilt predicted higher rates of noncompliance with post-operative healthcare and low rates of disclosure which detrimentally impacted the recipients utilising social support. It is hoped that in order not to experience a dislocated sense of embodiment the patient is able to move beyond the place of viewing the donated organ as a separate entity to themselves, to one which conceptualises it as enabling life. However, it is acknowledged that initially a 'weirdness' and 'foreignness' can often be experienced in the post-transplant stage whilst the patient is conceptualising the change to their physicality (Nancy, 2008).

To overcome issues concerning where the organ may have originated from, at times professionals will actively advocate the conceptualisation of the new organ as an 'exchange of spare parts' (Mauthner et al., 2015). It is considered to aid the recipient in overcoming the idea of receiving a new organ if they can disassociate this experience from the donor (Sharp, 1995). However, this perspective may lead to a rejection of the organ psychologically and therefore, holds limitations. Siminoff and Chillag (1999) highlighted an alternative metaphor that could aid the organ transplant patient in coming to terms with their new organ - considering it as a 'gift'. However, this has been seen to possess issues, specifically when the recipient was in contact with the donor’s family. It was highlighted that the gift metaphor did not adequately address the pain of the donor’s family and therefore, contributed further to the distress the recipient was experiencing. It is worth highlighting that a ‘one size fits all’ approach to helping organ recipients integrate their new organ into their sense of self, is not appropriate. Instead, each recipient should be encouraged to find their own way of accomplishing this important goal by constructing their own meaning of this. This is, in essence, an existential pursuit and subsequently holds important implications for this philosophical practice. Furthermore, it raises the question as to whether there needs to be an integration of the new organ, or whether an individual can live harmoniously with a ‘borrowed’ body part.

Sanner (2001) discussed how transplant patients often project their post-transplant characteristics onto their representation of the donor, thus attributing changes within themselves to the result of inheriting characteristics from the donor. Sanner (2001) highlights that the role of staff working is to create a space for this conceptualisation of change to be spoken about. Pearsall et al. (2002) and Wright (2008) argue that heart transplant recipients can change as a result of transplantation due to memory being stored in cells of the body and that these memories could be incorporated into the recipient’s personality and sense of self. This, therefore, needs to be kept in mind as these changes post-transplant to the personality and behaviour of organ recipients could lead to a disruption in their own identity and sense of self (Mauthner et al., 2015). Recipients may experience difficulty in balancing the integration of their new organ and maintaining a sense of self and identity that is distanced from that of their donor (Kaba et al., 2005).

Research conducted by Engel (2001) found commonalities across the experience of post-transplant recipients changes in body image. Apart from the acknowledgement that they are now living with someone else’s organ, other changes that physically occurred and impacted body image were weight gain and surgical scarring. Many individuals who have received organ transplants have reported significant shifts in their physical and psychological domain, specifically in a disruption of liveliness, feelings of being less sexually attractive, and less emotionally warm (Tringali, Arria, & Trzepacz, 1994). These shifts in physical and psychological domains subsequently impact how individuals relate to themselves and in turn, to others.

Therefore, it is vital not only to consider how organ transplant patients relate to themselves but also how they relate to others and the impact of this procedure on those around them.

Research by Charmaz (1995) reported that chronic severe illness disrupts the unity between body and self, resulting in changes to the individual's identity. She found that one way in which individuals repair this fracture is through adapting. She defined adapting in this context as altering one's life and self to assimilate bodily losses and limitations, to resolve the disruption in unity between body and self. This means that those living with severe chronic illness struggle *with* it rather than against it. It was found that this adaption occurred in three distinct stages; experiencing and defining impairment, making bodily assessments and subsequently identity trade-offs due to weighing up losses and gains and revising identity goals, and surrendering to the sick self by relinquishing control over illness and by flowing with the experience of it (Charmaz, 1995).

Research conducted by Clarke and Griffin (2008) with older adults suffering from chronic illness found a relationship between illness and identity. The themes that arose from this were perceptions that their bodies are failing in terms of their appearances, functional abilities, and impending mortality. Turning our attention towards those who are suffering from chronic illness in the form of end-stage organ failure, it is essential to note the way in which they may experience their bodies as 'failing' and consequently bringing about their eventual death. As previously mentioned existence is only made possible through the physical and therefore if this deteriorates then the existent is thrown into the face of death. The next section will begin to consider this notion further.

2.9 Facing death and surviving this

Barnett (2009) acknowledges that the theme of death has received little attention in general psychotherapeutic literature and training due to the emotions that this topic can evoke. She stresses, however, that there is great value in allowing oneself to grapple with this enormous and inescapable characteristic of the human condition. It is paradoxical in that focusing on death in the therapeutic space allows for the focus on life, illuminating existence, and all its possibilities.

Macquarrie (1972) emphasises that death has held a prominent place in Existential literature due to this being the basis of life's facticity. He stresses, however, that rather than attempting to understand death from an observable outsider position, we must give account to the subjective experience of facing death as experienced by the existent. He also raises the question as to whether we will ever be able to possess a full understanding of death due to this being an end to physical existence. Therefore, we can only try to understand what it is like to be dying but not what it is like to die. This is something that all organ transplant recipients have had to experience and grapple with.

It is said that in facing death, we inevitably experience existential anxiety which can arise as a result of the realisation that life will inevitably come to an end (Deurzen, 2010). As death is an inescapable aspect of the human condition, therefore, so is existential anxiety (Cohn, 2000). Sartre (1943) felt that people develop strategies to help manage the enormity and complexity of this human condition - such as people may deny aspects of their existence and, therefore, live inauthentically or in bad faith. They may reject the idea that they will eventually cease to exist and in turn, not make use of the time that they have (Deurzen, 2012). Existential psychotherapy searches for a way of living with these emotions and for a way of facing life's facticity with courage and honesty (Deurzen & Adams, 2016). Therefore, offering this to those living in the face of death may allow them to live more authentically and richly in the time they have left.

The concept of death has been explored with patients of heart transplants and has yielded some interesting existential thoughts and considerations. Research conducted by Palmar-Santos et al. (2019) into the conceptualisation of life and death for those who have undergone a heart transplant, found three distinct themes concerning this; these were towards death, the frontier between life and death, and towards life. Advancements in medicine, precisely that of organ transplantation, have manipulated the constraints of life and death. Prior to these procedures, individuals who would now be considered as appropriate for organ transplantation would, unfortunately, have died. As new possibilities exist for medical treatment of end-stage organ failure, so do new possibilities concerning the parameters of life and death for organ transplant recipients. It has been found that the concept of resurrection has featured within organ transplant recipients' conceptualisations of the organ transplant process and what this means to be given the gift of life. Organ transplantation, therefore, plays with the limits of life and what it means to be dying for the individuals making this journey (Palmar-Santos et al., 2019).

Research conducted by LeMond and Goodlin (2015) explicitly exploring those with late-stage congestive heart failure, reported that existential consideration of the patient's experience is an essential component of their care. LeMond and Goodlin (2015) urged practitioners to discuss how the patient views the meaning of their life and how they can find peace and purpose. It was found that contemplating these Existential issues with the patient as part of their care appeared to protect against the development of depression, something of which has shown to have a high prevalence amongst this clinical population.

Research conducted by Coyle (2006) with patients who have terminal cancer found that there were three distinct themes concerning the individual's experiences of having to face their imminent death. These were orientating themselves to the disease and maintaining control, searching for and creating a system of support and safety, and struggling to find meaning and create a legacy. It was concluded that living with a terminal diagnosis and thus living in the face of death requires great commitment from the individual concerned.

Organ transplant recipients not only have to face their death, but they are also faced with the death of the donor. The success of the organ transplant is dependent mainly on how well the recipient is able to cope and comply with their treatment regime. Many factors can affect this, in particular, the resolution of the ethical dilemma of being given a new lease of life at the expense of someone else's life-ending (Rivard et al., 2005). It has been observed by Kaba et al. (2005) that organ recipients often express recognition regarding the donor's death and experience a regret that death had to occur for their transplant to become possible. Therefore, the conceptualisation of death lies very much on the organ transplant recipient's horizon, even when their own may have been prevented. In receiving an organ from a deceased donor, the organ recipient may consider themselves bound up in the ending of an individual's life. Should this be the case, this will hold implications for the post-operative support offered to those journeying the organ transplantation process.

Research conducted by Jones et al. (2007) explored the impact of surviving intensive care/intensive therapy units. It was found that the prevalence of post-traumatic stress disorder (PTSD) amongst this clinical population was on average, over nine per cent. This is three times as high as some other clinical populations, such as victims of assault or non-injured war veterans. Barnett (2009) found that three distinct themes emerged from patients' experiences of intensive care, these being survival, lost time, and vivid dreams/hallucinations. This clearly illustrates the significant psychological impact the treatment journey has on those undergoing the transplant process.

Barnett (2009) highlights the notion of 'lost time' by those experiencing intensive care units, undoubtedly applicable to the population considered by this study. The organ transplantation treatment process holds many challenges for those journeying this, with the experience of time potentially being one of them. The next section of this literature review will outline what temporality means and how this may be applicable to the phenomenon under investigation.

2.10 Temporality

Temporality relates to the experience of time, something which is intrinsic to the human condition. Man is a creature of time. We are born into this world and travel through time until the day of our death is upon us. Existence itself could therefore be considered to constitute the stretch of time between birth and death, meaning that time and existence are inextricably bound up in one another. In turn, this would imply that in order to consider the experience of existence, one must also turn their attention to the experience of time (Cohn, 2000).

It must be firstly highlighted that from an Existential perspective, the experience of time is not considered to be as linear as the chronological lifespan appears to be (Macquarrie, 1972). Time can exist in differing forms, these being time as the existent experiences this, and time that is measured by the clock. Bergson et al. (2001) highlighted how the experience of time remains unbroken and is continuous as a result of consciousness. This is in contrast to the broken-up series of 'instants' that constitute clock-time. The disparate nature of these two experiences can at times result in a jarring sense of temporality, particularly when the existent may have 'lost' time for various reasons, such as through the loss of consciousness. If clock time has significantly passed whilst the existent no longer has access to consciousness, then once this is regained, there may be a fragmented quality to their experience of being in the world. This originates as a result of clock time and time as experienced by the existent lacking a sense of correlation. There may be a loss experienced regard to knowing that clock time has passed, but the experiential quality to their consciousness reflects a sense of time having stood still (Cohn, 2000).

Within Existential philosophy, time is also considered to be multidimensional in that the past is carried along by the present, which is already anticipating the future. It is not a linear succession; instead, it exists together "each moment in time calls all the others to witness" (Merleau-Ponty, 1962, p69). This means that the past, present, and future exist in unison in each moment we encounter, making it an impossibility to discriminate these into singular entities. Therefore, the consideration of the experience of time relates to past, present, and future dimensions.

Moving on to consider the implications temporality has for this research project, Charmaz (1991) discusses how chronic illness throws people into a 'separate reality' concerning how time is experienced. Time begins to exert an overt sense of control in their lives, possessing its own rules, rhythm, and tempo. The once stable and predictable routine of their life begins to take on the characteristics of chaotic and unpredictable phases of time. The illness changes the relationship that the individual has with time. They may 'gift' a greater proportion of their time and life to their illness, which can lead to feelings of loss in relation to this being 'stolen' away. The individual may also feel as though they have less time for other activities or modes of being, and as though they are forced into giving way to a new lived experience of existing in time.

A review conducted by Jowsey (2016) on the relationship between chronic illness and temporality stated that four distinct temporal structures held a strong presence amongst the literature held on this. These were found to be calendar and clock time, biographical time, past-present-future time, and inner time and rhythms. Calendar and clock time relates to the measurement of time passing. Biographical time relates to how people story the time they have experienced and how they narrate this through their conceptualisations. Past-present-future time relates to how these phases of time exist in unison and are called together in every moment experienced. Inner time and rhythms are the embodied experiential experience of time and the felt sense of this. The first three themes involve an openness to others and therefore, are considered to exist in a more social sense. The last theme is a more private mode of relating to temporality and that this is an internalised felt sense.

Individuals can experience all of the above themes at various stages throughout their chronic illness. Hyden & Brockmeier (2008) build upon Jowsey's (2016) proposition suggesting that 'narrative' storytelling can be used as a temporally informed analytic device, in the hope that this may aid in the reconciliation of tensions that can emerge from having these multiple and changing relationships with time. They also reiterate how important it is for practitioners and health care providers to be cognizant of this relationship with time that the individuals they are caring for may possess.

The final section of this literature review will turn its attention towards that of the relational quality to the human lived experience. It will consider the systemic issues faced by patients of organ transplantation treatment and how undergoing this impacts not only them but also those surrounding them.

2.11 Systemic issues

Within Existential philosophy, the social world is considered to be an unavoidable aspect of the human condition and constitutes the Mitwelt dimension of being in the world (Binswanger, 1958). This, in turn, means that one cannot exist without always being in relation to the other in some way, shape or form. Therefore, in order to understand being in the world, we must also consider how others shape this experience.

The environment in which the organ transplant recipient will recover has been found to be an essential factor in achieving positive post-transplant outcomes for all types of transplants (Molassiotis, Van Den Akker, & Boughton, 1997). Therefore, it is crucially essential for systemic issues to be considered when reflecting on the phenomenon under investigation. Professionals are encouraged to assess the quality and quantity of the organ recipient's support network to establish whether this promotes or hinders successful recovery. Ways in which this can be achieved is through the implementation of family interviews which can provide transplant teams with information regarding how the family may manage this treatment process and the type of support the patient has access to. This can also be a method of allowing family members to express their fears, concerns, and attitudes about the patient's transplant journey and their role within this (Strouse, 1996).

Organ transplantation not only affects the individual undergoing the procedure but also those around them. Interviews conducted with organ transplant recipients by Healthtalk.org (2016) found that patients reported their experiences to have significantly affected their family members. The reasons found for this were that family members had to pick up additional responsibilities, such as household chores and to care for the patient. It was also reported that a change in role from spouse to the primary carer placed a strain on the relationship. Research conducted by Girgis et al. (2013) on families with critically ill members found that informal caregiving occurred in the majority of cases. Caregivers reported having taken on this role due to there being little or no choice in who could/would provide the care. Caregiving was found to become the equivalent of a full-time job for some and held significant consequences for health, psychosocial issues, and financial burdens.

Not only are the family of transplant patients' experiencing the chronic illness of their loved one, but they are also implicated in making important, difficult decisions concerning undergoing the transplant process and the after-effects of this (Canning, Dew, & Davidson, 1996). Family members may feel obligated to become live donors where this is feasible. This raises issues for them concerning donating an organ and undergoing the medical procedures to make this possible (Olsbrich et al., 2002). Further research conducted by Golics et al. (2013) demonstrated significant and similar impacts of illness on the quality of life of the organ transplant patient's family, as well as on the patients themselves.

It may not always be feasible to offer mental health resources to transplant patients' families due to the scarcity of resources available. Research conducted by Martire et al. (2004) explored the benefits of involving family members in psychosocial interventions for chronic illness. It was found that in cases where this had occurred, there were greater positive effects on depression amongst patients and their family members. In addition, an increase in patient compliance and education around the effects of organ transplantation was achieved, and an increased sense of control was experienced by all involved. Consequently, offering support and counselling to patients' families to manage the impact of their illness has been found to be incredibly beneficial for all those concerned.

Smith (1990) stresses the importance of offering support to families in which a terminal diagnosis may be the case. He acknowledges the significant impact of this on the family's psychosocial functioning and therefore approaching patient care as a family unit is greatly beneficial. Smith (1990) discusses how supporting the family to face the reality of the patient's imminent death not only helps them to cope better with the illness but reduces the likelihood of later complications as a result of not accepting the bereavement and not engaging with the natural grieving process. Consequently, the findings from this research project are not only applicable to supporting the patients of organ transplantation but also to assisting in supporting those around them.

2.12 Conclusion

The research findings and literature discussed above highlights how important it is for the body of knowledge held regarding the organ transplantation process, particularly from the recipients' perspective, to be further explored and developed. The organ transplantation treatment holds significant bio-psycho-social-spiritual challenges for those undergoing this, and it is our duty as healthcare providers to understand how best to support this population. It is only through investing time and effort into researching this phenomenon are we able to reach that juncture. With the UK's laws changing in May 2020 to an opt-out system, it is hoped that cases of donation and transplantation will increase. Subsequently, this will be an ever-growing population of individuals, further justifying the argument that this population should be afforded adequate space within the research landscape.

The consecutive chapter is dedicated to outlining the research methodology and method utilised by this study. I will discuss the reasons for adopting a qualitative phenomenological methodological approach to this research and why I chose to employ Interpretative

Phenomenological Analysis as the designated research method. I will also devote some time to critical consideration of other phenomenological methods that could have been drawn upon. I will then move on to describe the study’s design, participant pool, data collection, steps of analysis, and ethical considerations.

3) Methodology

3.1 Introduction

There is often confusion surrounding what is constituted by research methodology and research method; at times, the two terms are used interchangeably to refer to the same process. However, I feel that clarification around this terminology is required for me to accurately describe the processes I went through in order to design and conduct this research project. Research methodology differs from that of the research method, the former provides an overarching approach to studying a particular topic, whereas the latter constitutes the specific technique utilised to conduct the research and analyse findings (Silverman, 2014). In order to design a research project that is reliable and valid, the process should be approached in a 'funnelled' fashion. Ergo the research methodology must first be established, which will then inform the researcher as to the most appropriate research method to employ. Following the process described above, this chapter will firstly discuss the methodology this research project employs, before then moving on to describe the research method utilised.

3.2 Development of the research question

My interest in this subject area is owed to the fact that I have been personally involved with organ donation when a family member sadly passed away. This experience touched my life profoundly and irreversibly, and I have since involved myself in the ongoing dialogue surrounding organ donation and transplantation. My family continues to receive letters from the organ recipients and their families, describing how this courageous decision has impacted their lives. It was from reading these letters that I became fascinated by the organ transplant process and found a desire to want to explore this further.

My aim for this research project was to investigate the impact of receiving a lifesaving organ transplant, and how this invasive and life-changing procedure is experienced from the perspective of those undergoing this. Having reflected on this further, I arrived at a research question that I felt delved into the experiential quality of undergoing the organ transplant process and aimed to capture how this affects life subsequently. Having established an area of concern regarding what I wanted this research piece to explore and forming a research question that fits with what I wished to achieve from this, I moved on to consider what principles would guide my research practice – the research methodology.

3.3 Qualitative research vs Quantitative research

Quantitative research methodology aims to produce empirical evidence to support or refute a hypothesis. It is concerned with objective data collection to establish cause and effect relationships between variables by obtaining measurements (Holton & Burnett, 2005). This type of research methodology would not adequately address the research question at hand due to its approach to the attainment of knowledge being entrenched in the 'measurement' of variables. This research piece is not looking to understand cause and effect relationships in the experience of undergoing organ transplants. Instead, it is attempting to capture the essence of what the lived experience is of undergoing this procedure and the effects this may have on life subsequently. Therefore, a qualitative research methodology is considered to be a more appropriate approach for this specific research piece.

A qualitative research methodology is concerned with exploring phenomena from a subjective, experiential perspective. It does not begin with a predetermined hypothesis; instead, it aims to enquire into the experience of a particular phenomenon in an attempt to understand this further. Qualitative research produces in-depth, rich data about the participants' subjective experience of the topic under investigation (Ritchie, Lewis, Nicholls & Ormston, 2013). As this research project is aiming to explore the experience of undergoing the organ transplantation process, a qualitative research methodology was selected to achieve this. The research question lends itself to eliciting in-depth accounts of the phenomenon under exploration and therefore fits effectively with this type of research methodology. As mentioned within the literature review, the scarcity of qualitative research on the experience of undergoing a vital organ transplant supports the relevance and timeliness of a qualitative, in-depth study of this phenomenon (Tong et al., 2013).

3.4 Phenomenological research

Phenomenology is the study of phenomena as it appears in the world, and by observing this, it is hoped that the essence of the phenomena can be captured (Lewis & Staehler, 2010). The phenomenological methodology aims to elicit the experience of a particular phenomenon and what meaning has been taken and attributed to that lived experience (Moustakas, 1994). As my research question is aiming to explore and capture the essence of experiencing the organ transplantation process, a phenomenological research methodology will be suitably placed to provide some answers to this line of enquiry.

There are several methods in which phenomenological research can be utilised and applied; I have opted to adopt an Interpretative Phenomenological methodology that is based on the Heideggerian hermeneutic and ontological approach (Heidegger, 1962). The lived experience of a phenomenon is made available through a description of this. In order to describe the experience of a phenomenon, one must interpret this to begin with. Therefore, Heidegger (1962) purported that phenomenology inevitably involves interpretation and that for us to gain an understanding of being, hermeneutics must be drawn upon and utilised. Heidegger (1962) hoped that through describing and understanding the essence of phenomenon, universal or ontological qualities of human existence could be uncovered (Davidsen, 2013).

Interpretative Phenomenological methodology employs research methods that capture detailed descriptions of lived experiences and the meaning of these for the participant. This perspective draws on insights from hermeneutic traditions that claim all descriptions are interpretations in some way (Van Manen, 1990). In doing so, it acknowledges that the researcher also interprets the participant's interpretations of lived experiences. Therefore, these descriptions will hold meaning for both the participant and the researcher alike. Consequently, I am approaching this research project with the philosophy that it is impossible to separate description and interpretation into ‘pure forms’. The participant will provide their description/interpretation of the phenomenon under investigation by verbalising their lived experience of this. I, as the researcher, will then explore these accounts, inevitably adding another layer of interpretation to these. I will finally highlight themes that have appeared across the participants' accounts in an attempt to elucidate the experience of undergoing the organ transplantation process. Through exploring the descriptions/interpretations of undergoing the organ transplantation procedure, I am hoping to investigate whether there are any universal commonalities regarding the lived experience of this phenomenon.

3.5 Epistemological position

Epistemology is the theory of knowledge that concerns itself with two fundamental questions; what can we know and how can we know (Willig, 2008). The epistemological position taken in regard to the acquisition of knowledge will be informed by the type of research methodology being employed. A qualitative research methodology, for example, will answer the questions of what can we know and how can we know, differently to that of a quantitative research methodology. This research project will adopt a critical realist epistemological position; meaning that it assumes that the acquisition of objective and absolute knowledge is unattainable. Critical realism accepts the possibility of valid alternative accounts of a phenomenon and that theories about the world are grounded in perspective. This ultimately means that the knowledge we collect and gain from conducting research is partial, incomplete, and fallible (Spinelli, 2005). Therefore, the critical realist epistemological position is complementary to the qualitative phenomenological research methodology this research piece is framed within.

Applying the critical realist epistemological position to this specific research project means that the data collected from this study will provide us with information as to how people have experienced life-saving organ transplants. The data will take the form of people's subjective accounts of their lived experience of undergoing this process. The accounts provided in this research project are viewed as holding validity as to the lived experiences of individuals who have undergone organ transplantation. There will be both similarities and differences amongst these accounts, illustrating that people experience the world in a multitude of ways (Maxwell, 2011). However, this research will not be staking claims as to the universal nature of undergoing the organ transplantation process; rather more it will highlight possibilities as to the essence of this lived experience.

3.6 Personal epistemological position

As the sole researcher working on this project, it is worthwhile noting my own epistemological position and how this corresponds with that of the research project's epistemological position. If I were to answer the questions stated above - what can we know and how can we know - I feel that my response would be similar to that of the critical realist epistemological position. I have always believed that people experience phenomena from their own perspective and that this is reflective of their subjective reality and their experience of being in the world. Their account may hold similarities and/or differences to other people's experiences of a particular phenomenon; however, this cannot be taken to hold universal objective truths. I believe we can gain insight into what a phenomenon is like to experience, but I struggle with the position of making 'claims', 'laws', and 'absolute truths' from this insight.

Therefore, my personal epistemological position appears to mirror that of the critical realist epistemological position, which I feel benefits the research project I have embarked on. Possessing a similar theory of knowledge to that of the research methodology employed means that the research process can occur as smoothly and fluently as possible. I feel that if my theory of knowledge were to be different from the research methodology's theory of knowledge, this might interfere with my ability to collect, explore, and interpret the phenomenon and data through the lens of the appropriate epistemological position needed.

3.6 Interpretative Phenomenological Analysis

There exist several different methods within a phenomenological research methodology framework that could have been called upon to conduct this research. The specific phenomenological research method I have chosen to aid me in exploring and interpreting the data from this project is that of Interpretative Phenomenological Analysis (IPA). IPA aims to consider and explore the lived experience of a phenomenon from the perspective of those who have journeyed it. In doing so, IPA is attempting to "*make sense of the participant trying to make sense of what is happening to them*" (Smith & Osborn, 2015, p1). The methodological assumption IPA makes is that people self-interpret, in turn creating and deriving meaning from their experiences. This, in turn, will shape the individual's sense of lived experience (Taylor, 1985).

IPA purports that an individual's lived experience is their subjective reality, simultaneously recognising that this may not necessarily represent a shared reality. However, we cannot exist in isolation, and we are always in relation to the other, inextricably bound up in the social dimension of human existence. Therefore, perceptions are not experienced in isolation and can be shared. These expressed perceptions form the data that IPA collects, which is considered to be a snapshot of how the participant verbalised and interpreted their lived experience of the specific phenomenon under investigation (Pietkiewicz & Smith, 2012). IPA is not attempting to make claims that the data represents a universal essence of what it is like to experience the phenomenon, meaning that 'theories' are not being compiled. It is highlighting shared aspects of lived experience amongst the participants, meaning that this method is a 'bottom-up' means of conducting research (Willig, 2008).

The role of the researcher in IPA is both that of discoverer and interpreter. The data collected from this research method belongs to the participant, with the researcher witnessing and discovering this. However, the researcher will perceive the participant's perceptions from their own position in the world; therefore, this inevitably involves interpretation on behalf of the researcher. To attempt to preserve the participants' accounts of their lived experience, IPA demands that the researcher make every attempt to bracket their assumptions and preconceptions. In order to move from an account of experience to deriving themes, which aim to provide insight into a phenomenon, the researcher is required to interpret the data to some degree. These interpretations are still required to be grounded in the participant's lived experience; therefore, the findings from IPA are an amalgamation of the participant's perceptions and the researcher's interpretations of these. The results of the analysis depend on how the researcher has interpreted the participant's accounts (Pearson, 2018). In turn, there is an emphasises on the researcher's need to take a reflective stance and approach to the research, considering what they may have personally brought to this process and how they have shaped the research journey. In being explicit about this, it allows others to understand to what degree the researcher has shaped the research process and findings (Willig, 2008). Therefore, my reflections on this research will be later discussed in an attempt to transparently inform the reader as to how I could have personally shaped this study.

IPA is usually implemented with transcripts of semi-structured interviews conducted with the participants, in which they are asked to provide an account of their lived experience of a particular phenomenon, as richly as possible. Having collected this data, the researcher then follows a series of systematic steps to analyse the data, allowing them to arrive at themes across all of the participants' experiences. The first stage of analysis involves the researcher familiarising themselves with the data by reading the transcript many times. Once this has been achieved, the researcher begins to annotate the transcript with what they feel the participant is expressing. The researcher is then able to take these initial notes and transform them into concise phrases that aim to capture the quality of what can be found in the text (Smith & Osborn, 2008).

The next stage of analysis involves the researcher looking for connections between the emergent themes. In doing so, some of the themes will cluster together and may form superordinate themes. The researcher will complete this process for each participant's transcript, and once this is done, the researcher will look across the themes to pull all data sets together. This stage of analysis aims to highlight convergences and divergences across the data. Finally, the researcher will arrive at a list of master themes that are indicative of the experiences of the participant pool as a whole, providing some insight as to the essence of the phenomenon under investigation (Smith, Flowers & Larkin, 2009).

The researcher will then present the findings of the research by translating the themes into a narrative account. In doing so, the analysis takes on another layer of interpretation in the form of the themes being explained, illustrated, and nuanced. Successful analysis of the data should be interpretative, and therefore the results of this should not be afforded the status of fact. The analysis should be transparent in that what has been inferred; it should always be grounded in the data, and be plausible (Reid, Flowers & Larkin, 2005).

The participants' descriptions of their lived experience of undergoing the organ transplantation process are influenced by many different factors, such as their perception of the interviewer, their language use and abilities, and by the values they hold. As such it is essential to note that the researcher is not eliciting a pure description of the phenomenon under investigation, rather more the interviewer is witnessing the participant's memory of their lived experience of the phenomenon within a particular moment. In addition to this, the findings presented in this research piece are also my interpretation of my experience of the participant discussing their experience. This is known as a double hermeneutic in that there are several layers of interpretation bound up in these reported findings (Smith & Osborn, 2003). This, therefore, means that IPA is not about merely describing the participant’s experience as they may have done, but it is a going beyond these descriptions to contemplate the underlying positions and assertions these descriptions may be making. It is a contemplation of the meaning attributed to these descriptions and what this may mean universally. However, it is crucially important that these interpretations continue to remain grounded in the participants' accounts and, therefore, are not transformed or laden with ‘theories’.

3.7 Consideration of other phenomenological research methods

Structured Existential Analysis (SEA) and Fractions of the Lifeworld approach of Peter Ashworth (2003) are alternative phenomenological research methods that were considered for this piece of research. Both of these methods are appropriate to the research question proposed and could have been utilised to explore the lived experience of the organ transplantation process effectively and insightfully.

SEA was developed by Emmy van Deurzen (1998, 2010) as a way of systematically exploring and investigating the lived experience of individuals. This research method can be applied in a variety of ways; the heuristic device that I had considered utilising in this research project was that of the four world’s model. The rationale for doing so is that this model ensures that the entirety of the lived experience is approached and covered in the investigation process by the researcher’s lines of enquiry encompassing the four dimensions of the lifeworld. These dimensions are as follows; the physical dimension representing the individual’s engagement with the material world and their physicality, the social dimension representing the individual’s relation to others in the world, the personal dimension representing the individual’s inner world, and the spiritual dimension representing the individual’s ideas about meaning-making and purpose (Deurzen, 2014). Using this method to explore the lived experience of undergoing organ transplantation could and would yield fruitful findings.

Fractions of the Lifeworld (Ashworth, 2003) aims to explore experience by considering aspects of existence that are considered to constitute the lifeworld. These are; selfhood representing the individual’s sense of self, sociality representing the individual’s relation to others, embodiment representing the individual’s sense of their physicality, temporality representing how an individual experiences time, spatiality is concerned with how the individual experiences their environment, project concerns itself with the activities to which the individual commits themselves to, discourse represents the individual’s use of linguistics to communicate, and moodedness represents the individuals' feelings or the tone of a situation they may find themselves in (Ashworth, 2015). Ashworth (2016) argues that an individual’s experience is always implicated by these fractions and therefore using them to explore an experience systematically, enriches the data collected from this. Therefore, this method would have also been appropriate for this research project and would have produced some interesting findings.

3.8 Why IPA?

IPA was subsequently chosen as the preferred research method to employ for this project for several reasons. IPA is considered to be one of the most frequently used approaches in qualitative psychological research (Brookes, 2015). Therefore, it has a sound theoretical foundation that has proven to hold validity and reliability due to its rigorous testing and use by the psychological research field. IPA is particularly well suited to researching areas of concern where a theoretical pretext may be lacking. The phenomenon under investigation in this research project has shown to be a relatively under-researched area of concern, therefore bypassing the closed systems of borrowed hypotheses and theories, IPA can provide meaningful and unexpected analysis of bio-psycho-social-spiritual issues (Reid, Flowers & Larkin, 2005). Also, utilising a method of analysis that has been rigorously tested will provide a solid foundation to base future research on.

IPA was initially developed and used within health psychology (Brookes, 2015); therefore, the medical/physical health aspect of this research topic lends itself well to the roots/origin of IPA. However, this research method has since branched out and has been used to effectively explore areas of concern beyond that of the health psychology field, to social psychology, nursing studies, religious and existential studies, music, art, occupational therapy, and the ‘traditional’ journals of the medical profession (Duncan et al. 2001).

3.9 Possible limitations of IPA

IPA asserts that the researcher is always implicated in the findings and although it demands that they are to bracket off any assumptions that may hold, it is considered impossible to take a ‘gods eye view’ in relation to anything (Pinkard, 1996). It is for this reason that IPA relies on the researcher to be self-reflective in order to understand how they have implicated the data collection, analysis, and subsequent research findings. Therefore, it is a real possibility that the researcher may unknowingly overlook the extent to which they have shaped the research findings if they are not sufficiently self-reflective throughout the research process (Mills, Durepos & Wiebe, 2010).

Phenomenological research methods, in general, assume that language provides participants with the necessary tools to capture their experience of the phenomenon under investigation. However, holding this assumption raises questions such as how successfully participants are able to communicate their experience in the richness it was experienced and are participants able to use language to capture the subtleties and nuances of their physical, social, psychological, and spiritual experiences (Willig, 2008).

Small sample sizes tend to be used in research where IPA is being utilised, with 10 participants being at the higher end of most recommendations (Smith et al., 1999). This has led to some criticism from the research field in general; however, Smith (2004) argues that smaller sample sizes allow for a richer depth of analysis to be achieved by the researcher. This arguably makes the research findings more meaningful and more faithful to the roots of phenomenological enquiry; aiming to capture the essence of a phenomenon in all its richness.

3.10 Validity

Validity regarding research is a way of assessing how well something is ‘measuring’ what is claims to be measuring. This is important to contemplate if the research findings are to be considered as reliable. At present, there are many different ways in which validity in qualitative research can be ‘tested’, one of which I will draw upon to illustrate the validity of this research piece (Vicary, Young, & Hicks, 2017). Yardley (2000) proposed four principles in which the validity of a research study can be assessed; these are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

Sensitivity to context relates to the researcher’s groundedness in the research philosophy, the socio-cultural setting of the study, and the researcher-participant relationship. I have attempted to illustrate that this study evidences a sensitivity to context by discussing the philosophy of this research piece, the information presented in the literature review contextualises this research in the socio-cultural setting it was conducted in, and reflectiveness regarding what I may have brought to my relationship with the research participants in this study as discussed below.

Commitment and rigour relate to how the research was conducted and how the methods were honoured throughout the study. I have attempted to illustrate this by considering and discussing the evidence concerning the methods utilised in this research. A dialogue has been presented regarding how I specifically utilised these throughout the different stages of this study. I have also engaged in research supervision which could be considered as an ‘audit’ regarding the commitment and rigour of this research.

Transparency and coherence relate to how transparent the research is and the coherence of what this is attempting to communicate. I have made every attempt to ensure that I have outlined this study from beginning to end in a transparent manner, also checking and editing this dissertation to ensure that what I am communicating is coherent to the reader. This allows for others to understand what processes were followed and how the conclusions that are presented were drawn. Should someone wish to replicate this study, I feel that my transparency and coherence would allow this to be done with ease.

Finally, impact and importance related to the study’s findings and what these may yield for the body of knowledge held about those specific disciplines. I hope that the findings from this study hold value not only to those journeying the organ transplantation process, but to their families, friends, and professionals working to support them. I also hope that these findings are fruitful for the Counselling Psychology and Psychotherapy field, enhancing the perspective that we may already hold concerning this phenomenon or similar lived experiences.

3.11 Reflexivity

Given the importance of researcher reflexivity when using IPA, I will attempt to disclose aspects of myself that I felt were essential to bracket, which had the potential to influence this research piece.

I have been personally involved in the decision to donate organs when my brother was involved in an accident that unfortunately claimed his life many years ago. Following this, my family decided to donate his organs in an attempt to prevent others from losing their lives prematurely. My family was contacted by those who had received transplants from my brother or their families. Letters were exchanged, of which the contents of these evoked a state of curiosity and wonderment within me, and many years later providing me with the inspiration for this research project. It was crucial for me to recognise the associations I experienced about these accounts to ensure that I adequately bracketed these off from this research piece. When embarking on this research piece, I made a conscious decision to make every attempt to leave my observations and assumptions at the proverbial door. However, it would be naive of me to claim that I did not influence the completion of this research piece in some manner.

Owing to the fact I have been personally touched by organ donation, it became crucially important for me to develop strategies that would allow for me to bracket my thoughts, feelings, and motivations adequately. I utilised a research diary throughout this project, in which I could detail my processes and cognitions whilst I compiled this study. In doing so, I was able to acknowledge the aspects of myself that came into play and ensure that I could observe these coherently. This allowed me to limit ‘myself’ in this study to what was necessary.

I engaged in personal psychotherapy throughout this research journey, which became invaluable to me. I found I was able to explore my own experiences and subsequently understand the depth and breadth of these in relation to my position in the world. I was able to discuss the content of my research diary, which also illuminated aspects of myself that previously lay in my blind spots. In doing so, I could harness the influence my life story may have had on this research and to limit this as much as I possibly could from affecting the process.

Research supervision was also another strategy of almost filtering myself appropriately from the study. My research supervisors had access to all of the work which went into this research piece, casting their eye over this process diligently. They have supervised all of the information and interpretations I have given in this dissertation. If these were not sensical or not grounded in the participants' data, this would have been highlighted to me.

I also have to discuss the fact that my training has an Existential orientation and therefore, both my clinical work and academic reading have an Existential philosophical leaning. I was very aware of this during the data analysis stage in which I noticed how the themes could be considered to fall into the four dimensions of human existence (Deurzen, 2010). Whilst this theory could be an overlay for the themes I have discovered, I was conscious of bracketing off these frames of reference and allow for the themes to find their own way.

Finally, it is worth noting that I believe there is enough distance between myself and this research project to explore this safely and from a place of genuine curiosity. In the role of scientist-practitioner, I would not have taken on a piece of research if I felt that I could have inherently flawed this as a result of my own processes and associations. I strongly feel that I used my clinical judgement when taking on this research topic and did so ethically, reflectively, and appropriately (British Psychological Society, 2018).

4) Method

4.1 Design

The purpose of considering research design is to arrive at a conclusion as to what type of ‘evidence’ is required to ‘answer’ the research question validly and reliably. The evidence collected should answer the research question as unambiguously as possible. To obtain such evidence, we need to specify the type of evidence required to do so (Vaus, 2001). The research question this project is attempting to elucidate is ‘what is the lived experience of receiving a lifesaving organ transplant, and how does this affect life subsequently?’. To answer this question as competently as possible, individuals who had undergone this procedure were asked to share their personal subjective experiences of this. As previously highlighted, in regard to this research project’s methodology, the accounts of those who have experienced the phenomenon under investigation were considered to hold valid insights into the lived experience of the organ transplantation journey for them (Moustakas, 1994). Therefore, the type of evidence that will adequately answer the aim of this research is verbal accounts of undergoing the organ transplantation process.

Prior research conducted on organ transplantation from a psychological perspective has been kept to organ-specific cases (Rainer, Thompson & Lambros, 2010). This research project pursued an alternative method of exploration into this phenomenon by approaching the experience of solid organ transplantation as homogenous. By doing so, it is hoped that a holistic understanding of this lived experience can be achieved. It is also worth noting that transplant teams working within units in the UK care for transplant patients across the different solid organ types. Therefore, this study’s holistic approach to exploring and understanding the lived experience of organ transplantation correlates with the ‘real world’ application of organ transplant treatment.

4.2 Interview questions

In order to gain verbal accounts of the lived experience of the organ transplantation process and how this affects life subsequently, I was required to consider what questions would elicit this information as comprehensively as possible. IPA emphasises studying people in an idiographic manner to generate rich and detailed descriptions of how individuals experience the phenomena under investigation. Its concern with the in-depth exploration of lived experience and how individuals make sense of their experiences helps define the type of questions that are suitable for an IPA study (Pietkiewicz & Smith, 2012).

The interview questions I constructed ensured that the participants' experience of the phenomenon under investigation was explored thoroughly. To arrive at relevant questions that would fully account for the participants' lived experience, I used the four dimensions of the lifeworld as a guide (Deurzen, 2010). Deurzen (2012) purports that these dimensions encompass being in its entirety and are often used as a heuristic device in Existential research and psychotherapy (Deurzen & Adams, 2016). Therefore, by using the four dimensions to guide me in compiling the participant interview questions, the participants' experience of undergoing the organ transplantation process could be fully and adequately explored. Below are the interview questions that I felt were pertinent to exploring the phenomenon in question, all of which I utilised for this research project. The text in brackets acted as prompts for myself when considering follow up questions within the interviews.

1) Can you tell me about your experience of the organ transplant process? (before/during/after)
2) Can you tell me how the transplant affected you? (physical/psychological/emotional)
3) Can you tell me about your relationships during the transplant process? (during/after)
4) How do you feel about having the transplant? (at the time/now)
5) What does the transplant mean to you? (at the time/now)
6) How would you say you coped going through this experience?
7) Can you tell me about the support you had/would have liked to have?

To monitor the information I was eliciting from the participants during their interviews, I devised an interview matrix (appendix two) which allowed me to quickly reference what had been discussed and what had not been discussed. This ensured that I could identify gaps in the participants' account that I had not potentially enquired about and therefore provided me with the opportunity to ask questions regarding these. This interview matrix was based on the three temporal phases of the organ transplantation process as set forth by Rainer, Thompson, and Lambros (2010) and the four dimensions of the lifeworld as set forth by Emmy Van Deurzen (2010).

4.3 Procedure

Six participants were recruited for this research piece, and their accounts of undergoing the organ transplantation process were obtained through the implementation of a semi-structured interview. Semi-structured interviews allow the researcher to maintain a level of control in the data collection process by ensuring that specific vital questions are asked. However, as the interviews are semi-structured, they allow for flexibility in questioning that the researcher can use responsively to open up the phenomenon under investigation. This method results in a richer quality of data being collected (Smith & Osborn, 2008).

The interviews lasted approximately 60 minutes and were audio-recorded to allow for these to be transcribed with precision. Five of the semi-structured interviews were conducted via Skype due to the geographical location of the researcher in comparison to the participants, and one research interview was conducted in person. This was held in a private clinical room in a psychotherapy setting to ensure privacy throughout. This particular interview was recorded on a Dictaphone that was password-protected, meaning that this recording was only accessible to myself. Regarding the Skype interviews, these were recorded using Skype software which allows for calls to be recorded. Skype uses software that ensures there is an end to end encryption; therefore the information from these interviews cannot be accessed by anyone but myself and the participant, with these recordings expiring 30 days from the date of the interview.

I transcribed all of the interviews onto Microsoft word documents and deleted all audio recordings once each interview transcription was complete. The transcribed interviews were assigned a code to allow me to identify which interview corresponded to which participant, allowing for the preservation of the participant's anonymity. Following transcription IPA analysis of the interviews was conducted using the software NVIVO. This involved commenting on different interpretational levels, resulting in themes that were gradually clustered together to create a picture of the lived experience of undergoing the organ transplantation process and how this affects life subsequently. These will be presented in the findings section of this dissertation.

4.4 Participants

Purposeful sampling was utilised within this research project, to allow me to better identify and select information-rich cases. The sampling for this study involved me identifying and selecting individuals that have experienced the phenomenon of interest, this being the organ transplantation process (Cresswell & Plano Clark, 2011). Purposeful sampling offers the most effective use of limited resources. Owed to the fact that I conducted this piece of research without assistance from others, I felt this method of sampling was the most appropriate to employ (Patton, 2002). Therefore, the participants who took part in this research piece were selected to do so by myself, following receiving contact from them in response to the research advert and ascertaining that they met the inclusion criteria.

Prior research regarding organ transplantation has primarily been conducted with participants who have undergone their transplant in the same hospital or are from a specific location. These studies, therefore, raise questions about the generalizability of the research findings. This research project recruited participants from across the UK, who have undergone their transplants in multiple sites, in an attempt to address these issues (Olbrisch, Benedict, Ashe & Levenson, 2002). Consequently, it could be argued that the findings from this study possess a greater degree of generalizability due to geographical location and transplant site not being a criterion for participation.

Six participants were recruited to engage in this study; this figure was based on guidelines written by Turpin et al. (1997) who state that within psychology doctoral programmes, six to eight participants are an appropriately sized pool for an IPA study. Smith et al. (1999) also assert that IPA studies focus on depth rather than breadth; therefore, 10 participants are considered as being at the higher end of most recommendations for sample sizes. Whilst the participant pool for this study does sit at the lower limit of recommendation, it is clear from the depth and breadth of the findings presented in this research piece that this was a sufficient amount to provide adequate data.

Regarding the inclusion/exclusion criteria used for this study, all participants were over the age of 18 and were considered as possessing the ability to provide informed consent. They were also required to have undergone a life-saving organ transplant; these constituted as heart, lung, liver, or kidney. The organ transplant must have been conducted in the UK, and participants were required to be at least 18 months post-transplant to ensure that sufficient time had elapsed between the procedure and asking them to revisit this experience. Participants were also required to be considered medically stable at the time of engagement with this study, meaning that the transplanted organ was functioning as intended. All participants were required to speak English fluently in an attempt to overcome any issues that inevitably occur with translation or misinterpretation.

The participants were recruited by placing an advert in an organ transplantation group on the social media platform Facebook (see appendix three for the advert). They were provided with my university email address in order to contact me to express their interest in participating. Upon receiving a request for more information, an information sheet explaining the research in more depth was emailed to them in order to gain informed consent (see appendix four). Once the participants had read this and were provided with the opportunity to ask further questions, the consent form (appendix five) along with the emergency contact form (appendix six) and the demographic information form (appendix seven) was sent to them. Once all necessary paperwork had been completed and received, the interview was scheduled and conducted. The demographic information of the participants is presented in table one below.

Table 1: Participant demographic information

Participant number	Gender	Age at time of study	Time since transplant	Location of transplant	Organ transplanted	Donor status	Transplants received (number of procedures)
1	Female	54	2 years	Addenbrookes Hospital	Liver	Deceased	1
2	Male	51	33 years	Freeman Hospital	Heart	Deceased	1
3	Male	68	7 years	Nottingham City Hospital	Kidney	Deceased	1
4	Female	54	3 years	Freeman Hospital	Double lung	Deceased	1
5	Female	49	32 years & 7 years	St Mary's Hospital Hammersmith Hospital	Kidney	Live	2
6	Female	69	4 years	St James Hospital	Liver	Deceased	1

It is worth noting that two of the participants had received their transplantation over 30 years prior to this research piece. Whilst this may appear to be a considerable span of time passed, which perhaps makes reflecting on an experience a difficult task, it became very clear from engaging with these participants before the research interview that this was not the case for them. The heart transplant participant has engaged in continual dialogue surrounding their experience of undergoing organ transplantation for other research projects and charity work over the years. Therefore, accessing the memory of this lived experience was a natural ongoing process for them. The kidney transplant participant had received two separate procedures, with the last one being seven years ago, therefore in the not too distant past. At present, there is no existing literature that would suggest that time elapsed between transplantation and conceptualisation of this experience impacts the ability to discuss the lived experience of this. Subsequently, as long as the participant was able to access their memory of this experience and articulate this in a rich descriptive manner, this should not discount them from engaging in research projects exploring this phenomenon. Reflecting on the data provided by these two participants, it is clear from the depth and breadth of their accounts that this was achieved.

4.5 Ethical issues

Ethical considerations pertain to the safety and well-being of research participants. It is the researcher's responsibility to ensure that those involved are not harmed in the research process, that participants are provided with privacy and anonymity, that all identifying information is treated confidentially, and informed consent is gained (Padgett, 2012). As a member of the British Psychological Society, I have committed to ensuring that I always work in accordance with their codes of conduct, I also ensured that I held indemnity insurance throughout conducting this research piece.

There was no deception of the research participants, I constructed and disseminated paperwork to them which included an explanation about the project's intentions and purpose, a description of the confidentiality procedures, the schedule regarding their participation, and a brief description of the method of data collection. All paperwork used has been made available in the appendices of this dissertation. The paperwork also states the participant's right to refuse to provide information they do not wish to and the right to withdraw from the study, up to the data analysis stage, without any consequence or explanation. At the point of gaining consent, I requested that the participants provide a contact name and number of a nominated person, this could be their next of kin or their GP, whom I could contact to advise of any concerns if these should arise. I advised the participants that this will only be the case if they disclosed a risk of harm to themselves or others. I did not find myself in a position where this was a course of action I needed to take, and none of the participants disclosed any concerns to myself.

The subject of the research is very personal and relates to a deep and significant lived experience held by all the participants. As such, I needed to consider that engagement in this research may evoke the recollection of painful memories and emotions that may be a challenging experience. Therefore, should the participants have asked for further support, or I felt that they could have benefited from this, an information sheet as to where they could access this would be disseminated under these circumstances (appendix eight). I also provided the details for my supervising institutes within a debrief letter, so the participants were able to contact them to raise any concerns they may have had (appendix nine). The participants who engaged in this research project did not disclose any issues or raise any concerns with me about the research project or what this may have brought up for them.

I was the sole researcher in this research project; therefore, I collected the data in the form of participant's verbal accounts. The interviews were audio-recorded, which were then immediately copied across and stored on my password-protected personal computer. I transcribed the interviews myself, with all identifying information on the participants changed to preserve anonymity. Once transcription was complete, the audio recordings were destroyed. Each participant interview transcript was provided with a name from participant one through to participant six, so these could not be identifiable to each participant other than to myself. Once the research was completed and submitted, the data was uploaded to the University's secure online portal and destroyed on my personal computer. The University will keep this data for ten years, after which this will be destroyed. This data will only be accessed should there be a need to revisit this in relation to this specific piece of research.

4.6 Method of analysis

As earlier discussed, this study utilised the Interpretative Phenomenological Analysis (IPA) research method to analyse the data collected. The data took the form of verbatim transcriptions of the research interviews. IPA on the part of the researcher involves a sustained engagement with the text and a process of interpretation (Smith & Osbourne, 2003). This can be attained by following a step by step procedure of analysis, of which my application of this is discussed below. It is worth noting that I completed the analysis of each transcript separately before I joined the data set together. This allowed for each participant's account to undergo analysis before being collated as a data set to commence considering similarities and convergences across these.

Firstly, I read each transcript several times to familiarise myself with the content of these. I then began making annotations on a line by line basis about what the participant had discussed. These annotations included things I felt were interesting or significant about what the participant said. I then returned to the beginning of each transcript and began making notes documenting emerging themes from the initial notes. The aim of doing so is to evolve the initial annotations into concise phrases that capture the essence of the experience being discussed. These emerging themes and annotations must remain grounded in the participant's subjective experience. My task was to then begin connecting the emerging themes that I had identified and interpreted from the transcript. I did this by looking for connections between the emergent themes and attempted to make sense of these connections. By doing so, I found that at this stage, some of the themes clustered together, meaning superordinate concepts emerged.

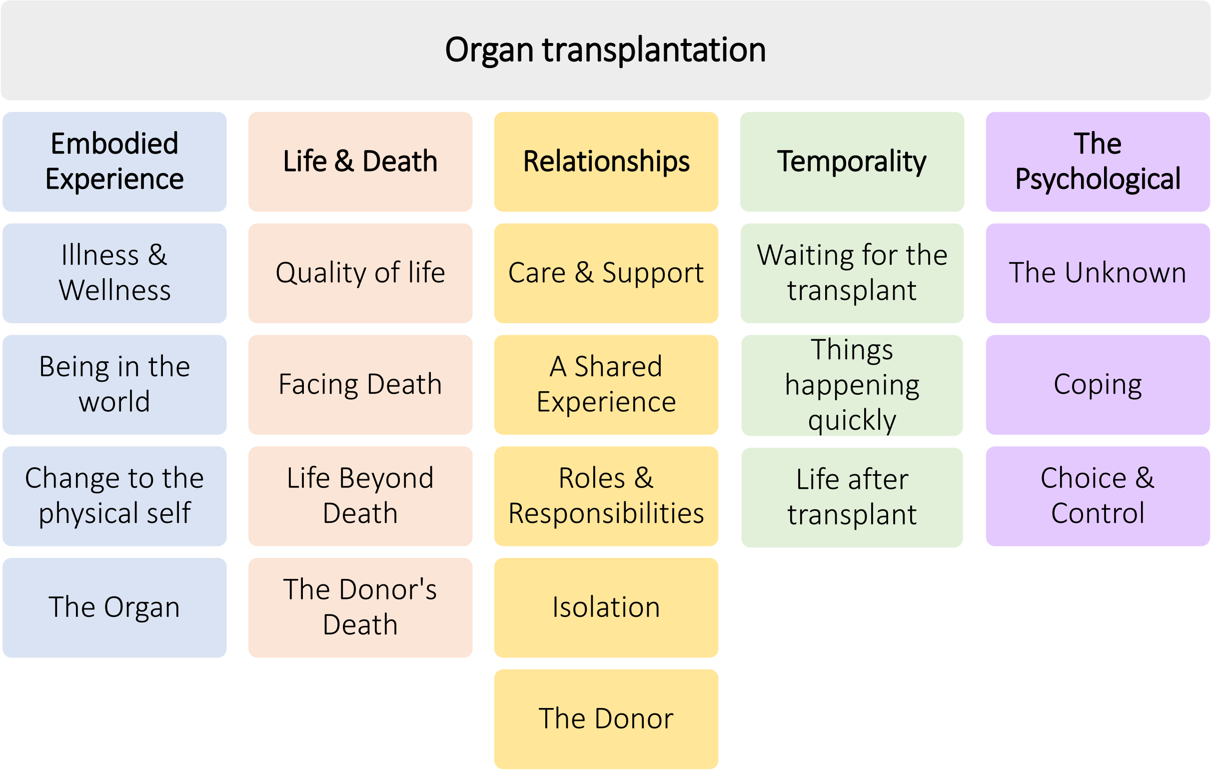
I continued to check the themes and concepts against the transcript to make sure the connections were evident in the primary material. Once each transcript had been analysed, the findings were brought together to begin to look for similarities and divergences across these. Once again at this stage some of the themes clustered together, making new superordinate concepts. The final stage of analysis was to produce a table of the themes (appendix 10), which most strongly captured the participants' experiences of the organ transplantation process. This table lists each superordinate theme along with the subordinate themes that fell under each of these. It also details which participants feature within each of the themes to allow the reader to comprehend the prevalence of these. The table, along with the findings from this research project, will be discussed in the subsequent chapter, constituting the most significant body of work in this dissertation.

5. Findings

5.1 Introduction

Two hundred and forty-nine initial emergent themes were found in the analysis; these were condensed and clustered together to form five superordinate themes, with 19 subordinate themes falling within these. These have been presented in figure one below.

Figure 1: Illustration of Themes



Organ transplantation

Embodied Experience	Life & Death	Relationships	Temporality	The Psychological
Illness & Wellness	Quality of life	Care & Support	Waiting for the transplant	The Unknown
Being in the world	Facing Death	A Shared Experience	Things happening quickly	Coping
Change to the physical self	Life Beyond Death	Roles & Responsibilities	Life after transplant	Choice & Control
The Organ	The Donor's Death	Isolation		
		The Donor		

The Five superordinate themes that were found encompassed the following:

- Embodied Experience - relating to the participants' experiences of the physical world.
- Life & Death - relating to the participants' experience of existence and mortality.
- Relationships - relating to the participants' actual or intended modes of relating to others.
- Temporality – relating to the participants' experience of time.
- The Psychological - relating to the participants' experiences of their inner world and the relationship they held with themselves.

This chapter is dedicated to discussing the in-depth consideration I provided to the participants' descriptions of their experiences within each theme introduced above. I conducted my interpretation of what I felt the participants were expressing through their accounts. This was done with caution, and the utmost care was taken to ensure these interpretations were grounded in the data. Line numbers following each quotation have been provided in order to allow the reader to identify these within the original texts. This will allow for the passage to be identified, read, and in turn, the interpretation to be justified as a logical move from the text to meaning. Each superordinate and subordinate theme will now be presented individually below.

5.2 Embodied Experience theme

5.2.1 Illness and Wellness

This theme relates to the participants' physical experiences of being ill and well throughout the organ transplantation process. Within this, the theme considers the experience of pain, medical procedures and practices, complications, and the recovery period. All of the participants discussed experiences that fell into this theme.

It is perhaps a common misconception that those who are found appropriate for organ transplantation are already aware of their physical illness. However, several of the participants shared that they did not know of their illness, and therefore this news was difficult for them to comprehend:

> *"That's very difficult to get your head around when you're feeling well, but the doctors are telling you that you are actually dying"* (P1, lines 114 – 115).

> *"I was, yeah, erm real shocked. I thought well I don't you know, feel poorly"* (P3, lines 53).

> *"I have to say I hadn't realized until I'd had the operation, how well I had been"* (P5, lines 29 - 30).

The participants discussed how their embodied experience was one of wellness; however, this was not representative of the objective reality of the situation. Therefore, this discrepancy was challenging to integrate into their sense of self and their understanding of their being in the world. This potentially may have added a different dynamic to what the participants were facing during this difficult time.

In the lead up to receiving an organ transplant, end-stage organ failure brought with it many challenges for the participants. The experience of pain was highlighted as a particularly prominent feature of this journey:

> *"When I finally got to end-stage renal failure, the headache was so bad that I couldn't--I didn't know where to put myself. I couldn't lie down. I couldn't sit up, I couldn't stand up, I couldn't walk around, I couldn't eat or drink. I couldn't do anything. There was no position I could be in to alleviate it at all. It was like my head was going to explode. It's hard to describe the level of pain"* (P5, lines 122 -125).

The pain experienced appeared to disrupt life in some manner and acted as a way of shutting down activity and engagement with the self and the world. The experience of pain made existence an uncomfortable experience and almost imprisoned those experiencing this. The participants hint at their being in the world becoming arduous and strained. However, paradoxically for others pain provided a sense of meaning throughout these difficult life circumstances, allowing the individual to transcend the limitations this may have held for them:

> *"The pain was kind of, it was okay, it wasn't as bad as I'd expected and at least I knew I was still there as long as I was getting pain"* (P4, lines 243 - 244).

In this case, being in pain worked as a means of validating existence in that the very nature of experiencing this is only possible through life. Therefore, pain took on a new dimension and meaning for this participant, moving beyond the notion that this is a wholly negative experience.

Whilst organ transplantation is a treatment option that can save many lives; it can also result in serious complications post-surgery. This participant discussed how this was the case for them:

> *"I was in hospital almost six weeks because afterwards, after the transplant I couldn't hardly speak and I couldn't walk, so they have to do a lot of scans. They thought I had a stroke, but I haven't. It turned there is one of the drugs I was on that I couldn't tolerate it. Once they changed that, I had to learn to speak again. I couldn't swallow very well. I had to learn to walk"* (P6, lines 54 - 57).

Complications that may occur following the transplant procedure can result in the journey of recovery becoming much longer and drawn out for some. Complications and recovery periods are perhaps overlooked, and the fact that life is being preserved overshadows the downsides to this treatment. Individuals may find themselves having to navigate their way through new illnesses brought about as a result of the transplant. In addition, not only does this treatment present with complications, but it also has life long-lasting effects. These participants discussed how they are having to readjust to the aftercare that is involved in maintaining their new organ and health:

> *"I think that's the hardest part is the aftercare, the routine, remembering your medication and this is for life, so it becomes part of your daily routine, and you just get out of bed in the morning and do it and then do it and go to your bed at night, so it's just another ten minutes out of your day, but it's part of your living and it means I'll see the morning" (*P4, lines 287 - 290).

> *"Having to take medication is a pain in the butt. The fact that it has side effects that keep you alive, but also make you ill, is not the best thing in the world, but is better than not being here" (*P2, lines 273 - 275).

Both participants acknowledged the difficulties that came along with the lifelong aftercare, and how this has changed their life irreversibly in some manner. However, they also touch upon the fact that without the transplant, they would not be alive. Therefore, whilst the requirement for aftercare may not be ideal, it can be tolerated in light of the fact that organ transplantation preserved their life. Despite this, it is undeniable that organ transplant recipients have to face a multitude of challenges, some are potentially short term such as postoperative complications, others may be longer-term such as lifelong medication or side effects. These participants highlighted that a significant challenge they face is the possibility of the organ failing or being rejected by their body;

> *"No rejection episodes, no problems whatsoever and I know a couple of the people I was in with they had rejection episodes and the chap next door to me, Tom, he had a kidney from his partner he had all sorts of problems. So, in that respect I've been very fortunate"* (P3, lines 48 – 51).

> *"I've only ever had one rejection, and that was straight after the lung transplant, when I was still in there the two weeks. That was dealt with medication and isolation"* (P4, lines 139 – 140).

> *"Obviously, there are challenges because the possibility of rejection or failure never goes away"* (P5, lines 133 - 134).

The awareness that at any point, they could become unwell again, is a challenge that organ transplant recipients have to endure. They may have undergone successful treatment at that moment in time; however, this could change at any point for them.

5.2.2 Being in the world

This theme relates to the participants' experiences of being in the world. The prominent features highlighted within this theme were uncertainty about the world, changes in physical states brought about by medication, and the environments participants experienced when undergoing the organ transplantation procedure. Four of the participants discussed experiences that fell into this theme.

Organ transplantation is a major operation that places the body under enormous stress, and hospital stays are inevitable. Hospital environments in which people recover was something that was highlighted when exploring the experience of this invasive procedure. Several of the participants shared what this was like for them:

> *"It was very weird because you never really knew whether it was day or night or where you were, what time it was, who was there, who wasn't there, whether it was your mom or a nurse or whether your dad was there, or your sister was there or anybody. It was all just weird. I was in an intensive care type of ward which didn't have any view of the outside world. It was just like being in a bubble the whole time"* (P2, lines 92 - 95).
>
> *"Cause you're just nodding off and then they sort of go clip-clop, clip-clop, clip-clop and jump out your skin and then there was some dialysis machines in the next bay going clunk-clang-clunk, so you come out after your seven days you're absolutely shattered"* (P3, lines 42 - 44).

The artificiality of the hospital setting created a sense of disturbance in the individuals' sense of being in the world. It did not reflect the world outside, which the participants are accustomed to and are at home within. The hospital became a space in the world that had its own rules, such as no fluctuations in temperature, a sense of never sleeping, it was not an open space in which one may move freely. Participant two describes that the hospital felt like a bubble that was particularly difficult to penetrate from the outside world. Participant three goes on to discuss how being in this environment with little control was exhausting for them and that returning home was an opportunity for them to rest. The hospital environment may aid in physical recovery from the procedure; however, this experience is not without its issues.

Due to the cocktail of painkillers and medications the participants were receiving immediately post-transplant, many of them reported that this impaired their memory of the events following. These medications also kept the participants in a state in which they lingered between being conscious and unconscious for some time. This, in itself, prevents the individual from being actively aware and engaged in the world. They continue to exist within this; however, they do not have an awareness of their being:

> *"I was in and out of consciousness quite a lot of the time, not really knowing what they were doing. I was on very strong painkillers, morphine and intravenous most of the time. It just happened really"* (P2, lines 84 - 86).

> *"It was similar to, I guess, whisked up by aliens and taken away and all sorts done to you, and then plunked back" (*P2, lines 154 - 155).

> *"I don't remember a thing after that for a few days because you're in high-dependency unit. Usually, about three or four days, but I have no idea how long I was in" (*P6, lines 48 - 49).

The participants highlight how they received medication which temporarily changed their physical state of being and their physical functioning. In doing so, the participants are not entirely aware of their physical presence throughout the early days following transplantation, involving what care they received and how others interacted with them. The participants are aware that this would have happened; however, they have limited recollection of it. Living through something with partial to no memory can be unsettling. It also calls into question how autonomous one can be if they are unaware of what is going on and what their choices are. The participants, through no fault of their own, were almost forced into the role of passivity.

Another aspect of being on strong medication is the distortion of reality. A few participants discussed how they experienced things in the world around them that they later discovered were not objectively 'real':

> *"That was just a really strange and surreal time. You don't know what's real and what's not. Even looking back on it now you think did that really happen or was that all in my mind. You sort of have to work out what was real and what wasn't" (*P1, lines 344 - 346).
> *"I think I knew that they weren't there because I couldn't possibly have all these children sitting on my bed and all these people there because I knew that was against the rules of the ward. Children weren't allowed in, so I think I knew they weren't real all along. That's only looking back on it now, you sort of think that's pretty weird. That's really weird. It wasn't something I'd ever experienced before"* (P1, lines 339 - 342).

> *"I didn't know what was real and what wasn't"* (P6, lines 213).

> *"I had these weird dreams and things, because I couldn't figure out whether they were real or not and I didn't like to tell anybody at first because I thought they'd think I was mad"* (P6, lines 255 - 256).

The effects of medication distorted the world around the participants, causing them to question what was real and what was not. This experience was often described as 'weird' by the participants, possessing a quality of strangeness to it. The participants became distrustful of their senses, questioning the feedback they had from these, and could no longer rely on them to help them navigate and understand the world. This blurring of reality was challenging for the participants and something that continues to hold a reservoir of emotions for them to this day. The participants shared that they were also wary of telling others of their experiences due to the potential reactions they may have received, leaving them to battle this on their own.

5.2.3 Change to the physical self

This theme relates to the participants' experiences of their physicality changing in some way as a result of the organ transplantation process. This theme encompasses physical changes to the body itself, image, limitations, and gains to physical function as a result of the transplanted organ. All of the participants discussed experiences that fell into this theme.

Undergoing an organ transplant inevitably involves a change to the physical self. Beyond the obvious, of having a new organ, there occur other physical changes to the recipients. Several of the participants discussed how their self-image transformed as a result of undergoing transplantation. Participant two discussed how their image in the eyes of others was something that held importance for them:

> *"It was very difficult because I was still in a wheelchair. I wanted to appear normal. I wanted to forget everything that had happened to me. Obviously, that wasn't possible"* (P2, lines 134 - 135).

Participant six discussed how the physical changes to their body altered the relationship they held with their spouse, and the level of tactile engagement between them:

> *"I didn't want to have sex with my husband at all. I found that very difficult because I was scared. I couldn't anyway for a long while because of the scars, because they cut right across your stomach, and like a T thing. That was a bit difficult, but it's all healed up now and everything"* (P6, lines 135 - 137).

Whilst other participants discussed the changes to their body image and how this impacts the way in which they experience themselves:

> *"It sticks out [the scar]. It's hasn't erm helped my sort of body image, but you don't worry about that when you get to my age. Nah, it's there, and it's functioning, and that's it"* (P3, lines 295 - 296).

> *"I lost my hair because I'm on Prednisolone, which is a corticosteroid, and I ended up with, I think with avascular necrosis or AVN, which effectively stopped the blood supply to my right hip joint and my hip joint collapsed"* (P5, lines 140 - 142).

> *"The worst thing was when I had the hernia. My skin went so thin you could actually see underneath things floating around. That was awful. I didn't dare look at myself. I had lost a lot of weight through the liver disease. Then after the transplant, I started to put weight on which I never could before. I could eat, but it never came on"* (P6, lines 191 - 194).

Whilst each participant discussed their idiosyncratic changes to their self-image, the thread that connects them all is that a change took place. Undergoing the organ transplantation left a physical reminder with them in the altering of their bodies. They were thrown into a different embodied self, and this was a new experience for them.

The side effects of undergoing organ transplantation treatment was another aspect of physical change that was highlighted by some of the participants. They discussed how this has now left them with limitations which they have found challenging to accept and accommodate:

> *"I just get really really tired. I haven't got a lot of energy to do anything"* (P1, lines 229 - 230).

> *"Sometimes it upsets me that I can't do all these things I used to be able to do, but I just do as much as I can and even if it's just sitting here talking to my kids and erm*" (P1, lines 245 - 246).

> *"I still have a weakness down the right side after the op. It's not as bad as it was, but I can't walk as far as I used to. I can walk maybe a couple of miles, and then I get tired. Doing housework and things, I can do more than I could before. I think you just get on with it and you learn to sit down and have a break if you get tired. That's the difference"* (P6, lines 103 - 106).

Life after the transplant appears to be different for the participants in many ways. Before the transplant, they discussed how they were more physically able; however, having now undergone this procedure, they are unable to do things they previously had. The participants discussed how these limitations have been problematic for them to accept and overcome.

The changes to physical self discussed so far appear to cast a negative overtone concerning this; however, not all change that was highlighted was unpleasant or unsatisfactory. One participant discussed how receiving a new functioning organ allowed them to achieve improved physical performance:

> *"That first breath, I'll never forget that first breath, I was looking for oxygen and inhalers because I wasn't used to it. I think from the minute I got the tube out my throat, and I could breathe on my own, it was all good. It was all good"* (P4, lines 69 - 71).

> *"What's nice is I can get out of breath now, but I can recover, whereas before, I couldn't recover and that was the strangest feeling. When the occupational therapist took me up some steps, and I was so out of breath, but he just talked me through it you know,*

> *"Just breathe," because I wasn't used to doing it for myself. I was looking for help, I think with tubes and oxygen, and when he talked me through it, and I was able to regain that, that was an amazing feeling, just being able to-- Although I can get out of breath, I can recover it back again, whereas I couldn't before. That's a huge difference. It's nice to be able to breathe"* (P4, lines 97 - 103).

The participant highlights how receiving their new set of lungs allowed their body to begin functioning more effectively. It allowed them to experience a sense of being without the constraints their illness had previously placed on them. The participant could experience breathing naturally and how their body could recover without assistance following exertion. Whilst this change still required a period of acceptance and accommodation, it was a change that improved the quality of life for the participant.

5.2.4 The Organ

This theme relates to the participants' experience of receiving a new organ and their relationship with this. Five of the participants discussed experiences that fell into this theme.

In receiving an organ transplant, the individual concerned will live from that point onwards with someone else's organ inside of them. How this is conceptualised differed from participant to participant. The origin of the organ was considered by some of the participants, with the level of detail concerning the donor differing:

> *"For the first few months I couldn't even think about where that had come from. Yes I knew in my mind that someone had died and that's where my liver had come from, but I couldn't think of it in terms of that"* (P1, lines 268 – 270).

> *"I don't really think too much about where that organ came from"* (P2, lines 242 - 243).

> *"I know that I've got a good set, so they must have been-- All I know is that it was a 50-year-old male, and he must have been healthy because he's gave me a damn good set of lungs"* (P4, lines 215 - 216).

Participants one and two shared that the origin of the organ was something they do not think about. Participant two did not elaborate on why this may be the case for them; however, participant one shared that in considering where the organ had come from they had also consciously considered the death of the donor. Participant one felt that this could have been quite overwhelming for them to comprehend and manage in the early days following transplantation. Therefore, they tried to not reflect upon this at that time. Participant four discusses the origin of their organ and openly acknowledges that the lungs they received were from someone else. Consideration of the origin of the organ appears to differ with some participants not wanting to consider this at all, through to others engaging in an active reflection of this.

Having received the new organ, some of the participants discussed the relationship they formed with this. Participant three expressed how there was no emotional involvement in the way they considered their new organ:

> *"We're not emotionally attached we're just physically attached"* (P3, lines 298 - 299).

The participant acknowledges that the organ is now a physical part of them and that this is the extent to which they have become attached to the organ. Other participants conceptualised their relationship with the organ through the metaphor of this being a 'spare part':

> *"I just had to think that was a spare part"* (P1, lines 281 – 282).
> *"I think it just means that I'm still alive as opposed to not. I don't have an emotional attachment to it or not. It's a pump as far as I'm concerned. It works, it keeps me alive"* (P2, lines 272 - 273).

> *"I think I've only got them on loan, maybe that's what it is. I think that's it. I'm not guaranteed, I might get five years, I might get 50 years, we don't know. I'm down as a donor; hopefully they'll be able to be used again"* (P4, lines 232 - 234).

For these participants, their understanding of the transplant and their new organ is that this was a 'spare part' that they acquired in order to save their life. Participant two described their new heart as a pump that keeps them alive, attributing a machine-like quality to the organ. Participant four discusses how they consider the organ to be a loan for an unforeseeable amount of time. When this time is up the organ will be passed on to someone else to make use of this whilst this is still viable and functioning. Moving beyond this, participant one discussed how they see their organ as taking on characteristics, more specifically the age of the donor, and that the organ has continued to age as the donor would have:

> *"Yeah, that is what I think; my liver is 76 years old"* (P1, lines 299 - 300).

For this participant, the organ has taken on the lifespan of the donor, meaning that the liver they received is chronologically older than they are. This gives the organ a human-like quality to it and departs slightly from the 'spare part' way of thinking the participant shared they previously held.

A few of the participants discussed the feeling of gratitude they experienced as a result of obtaining a new organ and how this has affected the way in which they responded to this:

> *"That I've got to look after my new liver as best as I can for my donor and for all the surgeons and doctors that put in all the hours of work"* (P1, lines 307 – 308).

> *"I just want them to know I'm looking after them till they maybe go to the next person"* (P4, lines 234).

Participant one expresses gratitude over the care and support they received and that this influences them to take care of the liver, whereas participant four discussed how they would like the donor to know in some way that they are looking after their lungs. Both participants appear to have attributed meaning to receiving their new organs and that this leaves them with a sense of purpose - to value the organ and to look after this.

Participant five shared that they continue to worry about the function of the organ:

> *"I wish I didn't have to still worry that it might fail"* (P5, lines 196).

In acknowledging that the organ could reject and no longer function, draws awareness to this continually. The participant appears to be hinting at a weariness regarding this and perhaps conceives of a life in which they do not have to consciously consider the organ and its role within keeping them alive.

5.3 Life & Death theme

5.3.1 Quality of life

This theme relates to the quality of life the participants experienced both before and after the transplant. For the purpose of this theme, quality of life is judged by the participant regarding how fulfilling and purposeful they found this to be. Five of the participants discussed experiences that fell into this theme.

To qualify as suitable for an organ transplant, the individual will be close to or at end-stage organ failure, meaning they are considered to be critically ill. How this affects the individual's life has shown to differ from person to person. Participant one shared that their illness did not affect their life in the lead up to transplant:

> *"I just got on with my life, I didn't think about it that much apart from every month having to go to the hospital it didn't really interfere with my life"* (P1, lines 117 - 118).

The participant did not notice any significant change as a result of their illness, meaning that their life remained as it was before. However, other participants discussed how becoming unwell and requiring transplant, effected their quality of life substantially:

> *"I was starting to get confined to bed, and mobility was bad, and it was just a quick deterioration, so I had to give up work. I went from sitting on the sofa to my bed, to sitting on the sofa to my bed. That was my life for a while"* (P4, lines 15 - 17).

> *"That was just the existing. By then, I was on ventilators and, as I say, that was just existing, it wasn't even living, it was just existing"* (P4, lines 52 - 53).

> *“They said, "I think it's time that you thought about having a transplant." I said, "Yes, that's fine." I was quite willing because my life wasn't very good at that time. I couldn't do much, and whatever I did, it just tired me out, and I felt quite ill”* (P6, lines 20 - 23).

> *“I thought if this is the end of life. I don't want it*” (P6, lines 166 - 167).

Participant four described their life as ‘just existing’ meaning that their basic physiological needs were being met, but beyond this, they were unable to engage with their life in a meaningful manner. Participant six discussed how the prospect of the transplant was a relief for them as life had become something they had to endure as oppose to embrace and enjoy.

Having undergone the organ transplant procedure, some of the participants shared how this affected the quality of life they experienced positively and beneficially:

> *“I can do things for myself now. I couldn't do nothing. The one thing I wanted to do was get home and take my dog down the beach because I hadn't been able to walk him for a long time, I never even had the strength to groom him or anything, so that was my big challenge was to get down the beach with the dog. That's the first thing I wanted to do when I came home, and I achieved that. That was my goal. To be able to sing, I just wanted to be able to sing again. Cleaning’s my thing and sorting and fixing, that, arts and crafts. Hugely, just hugely. I can get out again without having to take a wheelchair and oxygen and tubes and it's all good. I'm living again”* (P4, lines 86 - 92).

> *“For the first time I sat in my bed, I listened to a bit of Wet Wet Wet, whom I loved at the time, put some makeup on, glammed myself up a bit and I was elated to be able to do that because it had eaten into a big chunk of my teenagerhood. I mean in terms of going out and having a laugh and things that you do in the age and I was absolutely elated, and it went really well”* (P5, lines 103 - 107).

> *“Once I came around properly by the Monday, I was able to start doing a bit of exercise and doing things to help myself. Being empowered like that made me feel fantastic”* (P5, lines 109 - 111).

> *"It gave me a very good quality of life presence-wise, excellent quality of life. I went from very little quality of life to excellent quality of life"* (P5, lines 213 - 214).

Both participants spoke about their physical health, improving quite drastically following the transplant, which allowed them to regain autonomy, function, and pleasure back within their lives. Not only were they given a lifeline regarding physical existence, but they were also given an opportunity to return to a life within which they could create meaning and purpose.

Organ transplantation can have side effects and complications that impact the individual's life in quite profound ways. These participants discussed that although they had undergone surgery, this led to further issues concerning their quality of life:

> *"I had to go back to my home, which wasn't what was going to be happening before I had my transplant because I would have been off to university"* (P2, lines 136 - 137).

> *"We haven't got any children. I haven't had children because of the fact that I've always been concerned that I wouldn't be able to be around to be a father"* (P2, lines 217 - 218).
> *"Mentally, there was a time when I just wanted to die because I thought, I've been through all this and now I've lost my hip. Furthermore, I was told that I could lose all my other joints as well through avascular necrosis and for an actress singer-dancer, that was horrendous"* (P5, lines 145 - 148).

Participant two discussed how they were not able to achieve the life they had initially planned due to their sudden illness and the need for a transplant. They also discussed how the uncertainty around life span following transplant led them to avoid starting a family through fear that they would not be alive to be a part of this. Participant five discussed how the side effects of the immunosuppressive medication cost them the life they hoped to have. This suggests that the quality of life the participant experienced at this time negatively impacted the value they placed in their physical existence.

5.3.2 Facing death

This theme relates to the participants' experience of facing their death. This encompasses the experience of being told they were terminal, considering the transplant treatment, how they coped with facing death, and what meaning this held for them. Five of the participants discussed experiences that fell into this theme.

To be found suitable for organ transplantation the illness that the individual is suffering from is considered to be terminal and therefore without treatment, they would unfortunately die. Becoming aware of this forces the individual to confront their mortality in a very real way. Death is no longer something that is stretched ahead of them in their future; death is no longer something that comes for the elderly, it is now very close and only a short time away for these individuals. Therefore, not only was death brought forward prematurely for the participants, but this was also brought about abruptly. Some of the participants discussed how they felt about being given the news of their terminal prognosis:

> *"I just sat and cried all day because I think it was just the shock of knowing that I have just been told I was that ill"* (P1, lines 52 – 53).

> *"I think it was a horrendous experience. Obviously at the age of 18, being told you're pretty much going to die in the next few weeks, then being given this lifeline but not knowing what that really meant"* (P2, lines 23 - 24).

> *"Still, now I find it quite difficult. I just don't want to ever go through that lead up again. I didn't know if I was going to live or die. My children were asking me, "Are you going to die?" I was saying, "Of course not" but I didn't know"* (P5, lines 222 - 224).

> *"The consultant came in and said, "I'm really sorry, but the other pair have pulled out overnight, and they've left the hospital, and they've turned their phones off." Mentally that was, my world just fell apart in that moment, and I just thought well, I'm going to die then"* (P5, lines 55 - 57).

The participants highlight that this was a challenging time for them and that facing death has had a significant impact on their emotional wellbeing. Participant two talks of the 'lifelines' they were thrown with being offered an organ transplant. This procedure carries challenges and risks, with the individual being made aware that this could also result in their death. Several of the participants shared what their thought processes were about agreeing to the transplant and how this brushed up against death for them:

> *"I think I felt that if it was the only way to survive, that's it, I'll do it. If there had been another option, I would have taken it, but there wasn't. It was a last resort. It wasn't something I wanted to happen, but it was something that had to happen. I clearly remember asking the doctor who came to get me to sign the consent form saying, "You're sure there isn't anything else you can do that will keep me alive?" He was like, "No, this is your only, only chance." That's when I signed the thing to say, "Yes, I'll have a transplant"* (P2, lines 251 - 255).

> *"I think we knew that if it hadn't been then, I wouldn't have been coming home. That would have been me, I think"* (P4, lines 59 – 60).

> *"Knowing that there was an option and the percentage wasn't great, because I wasn't great. We had to rely on that tiny, tiny, tiny bit of a window, but I got there. We did know the odds weren't great, but determination again, it was still a hope. There was no hope before that; we knew what was coming. This was a chance, and if it didn't work, we tried. We had done our best"* (P4, lines 312 - 315).

> *"Without it, I wouldn't have lasted very long"* (P6, lines 163).

The participants' talk of hope, hope for a chance at extending their now shortened lifespan, and that taking the risk of undergoing the organ transplant felt worthwhile for them. Participant two shared that this was their survival instinct kicking in and that this is what drove them to make the decisions they did. The participants fought to keep their life, and their brush with death motivated them to try and escape this. This could suggest that facing death reinvigorates the passion for life.

To grasp the opportunity for transplant, the individual must try and find a way of coping with facing into their death. If one cannot accept this, then they may deny or avoid making decisions concerning this. Several participants discussed how they learned to cope with facing death:

> *"I know if I don't do it, I will possibly die, so you just get on with it don't you. There's no good moaning about it I've just got to do it"* (P1, lines 403 - 404).
>
> *"I think it just meant life or death. It was a life that I chose. Death was the other option, which was not to have a transplant"* (P2, lines 266 - 267).
>
> *"We knew the end was going to happen anyway, so I think I'd already prepared myself"* (P4, lines 150 - 151).
>
> *"I knew when it got to the breathless stage that this part would come next. I knew what was coming. I think maybe that's the difference, whereas had it been new, maybe I wouldn't have known what step came next, or anything like that. I knew what was coming"* (P4, lines 205 - 208).

The participants shared that having been made aware that they were terminal, they had a choice to make. Whether this was giving in to the feeling that this conjured within them, or to make a choice to fight to live. In embracing their finality, the participants were able to make active choices about what treatment they received. They were aware that they were going to die, but when this occurred was something that they wanted to have a degree of control over.

5.3.3 Life beyond death

This theme relates to the participants' experiences of living beyond their death and subsequently, life after this for them. This theme encompasses the participants' reflections on how living beyond death continues to affect them, the opportunities they have been afforded through their gift of life, and ways in which their perspectives may have changed about life having faced death and escaped this. All of the participants discussed experiences that fell into this theme.

Providing the organ transplantation was successful; the recipient can be seen as having faced their death and living beyond it. The technological and scientific advances in the field of organ transplantation have meant that people are now able to live beyond what they would have naturally; given the fact they were suffering from end-stage organ failure. Several of the participants acknowledged this and discussed what their experiences are of life beyond facing their death. Participant one and two nods to the challenges they have faced in overcoming their terminal prognosis:

> *"I sort of sit and think yeah that was pretty traumatic, but I've survived it and now let's just cope with the next hurdle and get over it"* (P1, lines 419 - 420).

> *"It's caused what I would say, ongoing anxiety issues from then on really because you never know what's going to happen and you're fully aware. Obviously, everyone is aware that they can die tomorrow, but with me, that's how I like it. I do try and pack things in as much as I can and do an awful lot, but I guess at the back of your mind, it's always there that, you're not going to wake up in the morning. I don't dwell on that, but it is something that's always there"* (P2, lines 206 - 210).

Participant two discusses how this encounter with death has stayed with them and continues to create anxiety concerning when death will finally come. Whilst we all know on some level that death will arrive, our journey to that destination is often not consciously contemplated. However, this participant approached death and therefore has an experiential sense of what it is like to be dying. They now live with the memory of this, understanding that they will have to make this journey once again one day. The time when this will happen is unknown, reinforcing the fragility and unpredictability of life.

Following on from this, several of the participants expressed a 'positive' perspective in living beyond death, taking meaning from this experience. These participants discussed how living beyond death has provided them with opportunities they may have never been able to seize:

> *"It made me determined to live my life to the full, I guess, and well, I'm trying to be a sailing instructor, I went to university, had jobs, got married, et cetera"* (P2, lines 195 - 197).

> *"Absolutely a whole new world. It's just a whole new life. I can't say any more than that, it's a whole new life, and we're just grateful for every extra day that we get"* (P4, lines 239 - 240).

> *"Well, both times they've given me a life, they saved my life, and between the first and second, I have had two children, which of course they wouldn't have existed if I hadn't recovered. They're my world. I would say they've both times they've absolutely made my life, given me life. Obviously, there are challenges because the possibility of rejection or failure never goes away"* (P5, lines 131 - 134).

Both participants acknowledged a fulfilment of opportunities that death would have extinguished for them. They speak of the achievements they have attained, such as going to university, getting married, having children. It has allowed them 'extra time' and 'extra opportunities' that nature would have robbed them of. Participant five highlights this even further by acknowledging that without the transplant, not only would their life cease to exist, but the life they went on to create would also be non-existent. Therefore, the opportunities that successful organ transplantation offer is endless and transgenerational. Other participants discussed how living beyond their death has changed their perspective on the life they have had following this:

> *"I've got to live the best life I can. That's why I volunteer for things like this"* (P1, lines 309).

> *"If the worst happened tomorrow, I'll look at it that I've had an extra three years now, and I'm thankful for that. I'm thankful for that. It's made me revalue everything and reassess everything. We've recently downsized house, I've got my paperwork in order, so I'm taking care of that because the last few times, I worried that if it did happen, because we think, "Well, a cat's only got so many lives." I wanted everything sorted; I*

> *wanted it all fixed. We're in the process of doing that now, and if the worst happened tomorrow, everything's all right. I've had three years. If I get more, brilliant, and if not, hopefully, my lungs can go into somebody else"* (P4, lines 164 - 170).

> *"There's more meaning to life. I'd like to do things. I like travelling so we try and go various places that we can"* (P6, lines 172 - 173).

> *"It changes your outlook a lot in life. I don't think about things that are negative so much as I used to. Especially, you can think, "Oh dear, what a dreadful day," and things like that. Then I have to remind myself it's a day you may not have had, had you not had the transplant"* (P6, lines 181 - 184).

The participants discuss how their attitude toward life and how they engage with their existence has transformed having lived beyond their death. They talk of their life taking on new meaning, one of embracing the life they have been gifted past that of their possible mortality. Participant four discusses how this has led them to 'sort' things out in their life at present so that if anything did happen to them imminently, they would be at peace with how things have been left. Therefore, holding the memory of death and the gratitude of life simultaneously.

Finally, participant three expresses the meaning the transplant held for them and the difference to their life this has made:

> *"Sense of relief, yeah, erm no more dialysis, hopefully, it's going to work and erm yeah, just get on with my life really now, not, not attached to tubes. Pretty much as simple as that"* (P3, lines 248 – 249).

The participant discusses the sense of relief that not only are they still alive, but they no longer have to live their life as they were immediately before transplantation. The participant discusses how they are grateful that life has changed in this way and that they are now able to get on living their life in the way in which they intend to.

5.3.4 The Donor’s death

This theme relates to the death of the organ donor from the perspective of the participant. This theme encompasses the grief participants felt about the death of the donor, how they coped with this grief, and the meaning they have attributed to the donor’s death. Three of the participants discussed experiences that fell into this theme.

For those who have undergone organ transplants from deceased donors, the death of someone else has had to occur. Organ recipients may give thought to this; some may not, however, some of the participants within this study discussed that this was an important aspect of undergoing the transplant that they have had to manage. A couple of the participants expressed that they experienced a sense of grief for the donor’s death:

> *“I got accidentally sent all the details of my donor, and that really hit me hard because I was suddenly faced with the fact that where that had come from. That the person had died and all this. But now because I know so many facts about my donor I’m more at ease with it”* (P1, lines 273 - 275).

> *“I sat and cried for half an hour. Erm, then I got in touch with the hospital and said I don’t think I should have this information should I, and they all said no and apologised”* (P1, lines 291 - 292).

> *“At first, I remember they told me it was a 34-year-old woman's liver. That upset me because my daughter was a similar age. I remember a few nights that I just cried. I can't tell you why, probably because of powerless, was not being too well, but it was like I was grieving this young woman that had died. It only lasted a short while; it would be a week or so”* (P6, lines 89 - 92).

> *“Each year, it comes around. You never stop thinking about that family. I have no idea who it was apart from it was this young woman, but you learn to live with that and get over it after a while”* (P6, lines 97 - 99).

Despite having never had a relationship with the donor, these participants felt a sense of grief about the donor's loss of life. In the lead up to having the transplant, the participants knew that someone would die for them to receive an organ. However, at this point, it has not happened yet; therefore, the donor's death is not in existence. Having undergone the transplant, this then symbolises that death has occurred, and this realisation may hit the recipient in a very real way. Having faced the fact that someone died for them to get their transplant, some of the participants shared how they coped with this knowledge:

> *"Well my liver came from a 74-year-old who died having a heart operation, so that wasn't from a young person who died suddenly. That was from a person who had been ill. So, I think that I don't know how I would have coped if that had been from a younger person. The fact it came from a 74-year old whom I know had a daughter, had grandchildren, that she lived a life that wasn't suddenly cut short at a younger age. I think that's quite a reassuring thought, rather than from somebody who was young"* (P1, lines 277 - 281).

> *"I wrote a letter to the family of this girl, and they send you letters of what other people have written, and so you can write whatever you want, so I wrote to them. I wrote it six months after. I didn't do straight away. That was hard, knowing what to write to them"* (P6, lines 94 - 97).

> *"You also know that somebody's going to die for you to have it, and that's not a nice thought. You've got to put that behind yourself really. Not think about that"* (P6, lines 169 - 170).

These coping strategies ranged from acknowledging the life of the donor, reaching out to their family to express gratitude, and trying to put this out of mind. Some of the participants went beyond this and tried to find meaning in the death of the donor:

> *"At first I was totally in shock, but once I had sat and thought about it, you think well yeah 74. For a start, I didn't think you could transplant, anybody that age could donate organs because you always think of it from being from younger people. But the more I*

> *thought about it, the more you think well yes she was 74 she had a family, she had grandchildren, in a way she had lived more of a life"* (P1, lines 296 - 299).

> *"I've mentioned it to one or two friends, and they said to me you've got to think that that young woman's life had gone, and she's helped because I got part of her liver, a child got the rest of it. That made a difference because I knew that someone else benefited as well"* (P6, lines 92 - 94).

Participant one felt that because of her donor's age, then this means she got the opportunity to live a life, as opposed to if the donor were younger. The older we get, the closer we move to death naturally; therefore this notion may have helped the donor's death feel more natural to the participant, easing the burden this may have placed on them. The participant appeared to be searching for meaning in the death of another. Participant six found support in considering how the donor's death has saved many lives, including their own. Therefore, this death was not in vain, and it meant that others had the opportunity at life.

5.4 Relationships theme

5.4.1 Care and Support

This theme relates to the participants' experiences of receiving care and support during the organ transplantation process, both physically and psychologically. All of the participants discussed experiences that fell into this theme.

Having undergone the organ transplant procedure, several of the participants highlighted that the care and support they received from medical staff was a positive experience for them:

> *"I don't think a single one of the doctors hadn't sat and held my hand whilst I cried, or the nurses"* (P1, lines 318 - 319).

> *"Nurses were all fantastic. Doctors, we became really good friends, I still see them now for some things, and they love to hear about things, and I think it was all good"* (P4, lines 162 - 164).

> *"My consultant fought hard for it; he fought really hard for that. He's my angel. He's my guardian angel. He's the one that started the ball rolling. I still see him as a very close friend, when I'm in hospital or having a bad time, he still visits me, he comes in and sees me, he comes up the stairs. I think that gave me the hope, and it gave me something to fight for, knowing that it was a possibility"* (P4, lines 303 - 306).

> *"One of my sons came from Hong Kong. He came for two weeks while I was in, and it was really good, but when he went back, I got upset, of course. One of the nurses came, she pulled the screens around and just sat and talked to me and even said, "Would you like a hug?" I said, "Yes." She was absolutely brilliant that nurse"* (P6, lines 76 - 79).

The participants discuss how the medical staff moved beyond physical care and were also crucial in providing them with emotional support throughout this challenging period. It is clear from these excerpts that the relationships between staff and the participants were authentic, compassionate, and a human to human way of relating. Participant four discusses how they feel the relationships they held with staff became friendships, transforming due to the genuine connection between them. However, a few of the participants highlighted the need for professional psychological support which they felt was lacking at times:

> *"My doctors are absolutely brilliant, and they will sit and listen to me, but I don't think they really realise how that affects you"* (P1, lines 413 - 414).

> *"Something that I think was missing at the time because they were obviously it was an experimental program. They were concentrating on keeping people alive; they weren't particularly worried about their emotional state then"* (P2, lines 296 - 298).

> *"I think mentally you need to have people to be able to talk to if you want. There were people that would come around a bit, but they never asked you questions or how you were actually feeling"* (P6, lines 242 - 244).

Whilst the participants received physical health support to ensure recovery, some of them felt their psychological health was neglected. Whilst it may be 'understandable' that physical health is a priority in organ transplantation, the psychological health of those undergoing this must not be forgotten about.

Moving beyond staff, several participants discussed how their family was a key source of care and support for them:

> *"I think if anything it brought me and my husband closer together because he had to look after me for so long and. All the times he's had to run about after me and one thing or another. I think it brought up closer together"* (P1, lines 366 – 368).

> *"I was completely reliant now on the care of my parents. Yes, I had to go home. I had to go back to my home, which wasn't what was going to be happening before I had my transplant because I would have been off to university. I had to get into the home, be cared for pretty much all the time by my mother, and that lasted for about another year or so while I was having intensive physiotherapy. Yes, that was a hard time too"* (P2, lines 135 - 139).

> *"Right from my first visit to that doctor when I, when I got that phone call saying it's probably your kidneys. Yeah, so she's been with me all the way along, all the way through"* (P3, lines 195 - 196).

> *"Well, it probably made it stronger, but it was strong anyway. If it was possible to make it stronger, then it probably did, but yeah, we've been through a lot together"* (P3, lines 198 - 199).

> *"He's just a pillar of strength. He takes my frustration, he takes my anger, but he knows when to rein me in. He just laughs at me; we've always made a joke of it. My family used to call me Darth Vader because I used to speak through the mask, so it's always been good-humoured, we've never being morbid or sad or anything. My husband's been my wee treasure; he's just been my wee nurse; he's been so good. He's so good, so I depend on him a lot, and I always have done. I've got a good family, good support group, and we've been so lucky, so lucky"* (P4, lines 194 - 199).

> *"I had my mum and dad both times. They were brilliant. The second time I had counselling. For the dialysis, I was very lucky because my sister at the time was in a position to keep taking me to the dialysis unit so at least I could be taken there three times a week and brought back. She was amazing. She came with me; she stayed with me, she brought me home for all that time. Four months. She was amazing"* (P5, lines 256 - 260).

Not only did family members take on care roles in which they physically and psychologically supported their loved ones, but they also provided support in other ways such as; child care, and driving the participants to and from hospital appointments. Several of the participants shared that as a result of the care and support received from their families, the relationships between them grew closer and stronger.

5.4.2 A Shared Experience

This theme relates to the participants' feeling of connectedness to others who share the experience of organ transplantation. All of the participants discussed experiences that fell into this theme.

The organ transplantation journey is a physically and psychologically challenging time, placing tremendous pressure on those involved in this. Some of the participants in this research highlighted how they were able to connect with others that were also undergoing transplantation. This served many different functions, whether this is to support the participant, provide them with a sense of normality, provide an understanding they are not alone in this lived experience, and/or as a place to discuss ongoing issues or concerns with someone who may also be experiencing the same:

> *"I think that's the one good thing is that you're on a ward which everyone on the ward has had transplants, kidneys, or livers, so at least other people are in the same situation"* (P1, lines 355 – 357).

> *"I know there were two transplants that day, from that donor one to me, one to a woman and then the chap in the next bed he'd actually had a transplant, a kidney from his partner. So erm, yeah, the three of us in there had transplants that day"* (P3, lines 38 - 40).

> *"I've realised how uncommon it is because they don't do them up in Scotland so you've got to travel, so I'm quite often a bit of a novelty because people haven't come across it before, but I think we spent that long going down to Newcastle, being surrounded by people in the same situation that we thought it was quite normal"* (P4, lines 266 - 269).

> *"When I was in hospital having the transplant, there was a Scottish lady in there that lives in Preston, and she had exactly the same liver disease as me. She hadn't had it as long as me, but she had the transplant and she was fine. She had no problems. She was able to walk and to talk, and I couldn't understand why I couldn't until they found out that it was this drug, I was allergic to. That's how it was, but I've kept in touch with this lady since. We meet up every now and again and compare notes"* (P6, lines 67 - 71).

The participants were able to connect to others through the medium of shared experience and felt a sense of togetherness with those that found themselves in the same situation. From doing so, it appears that the participants felt understood regarding their lived experiences of the organ transplantation process and that they were not alone in this. In living through these challenging times together, there appears a sense of solidarity amongst those journeying this. However, some of the participants spoke about how this 'togetherness' with other organ transplant recipients was, at times difficult to navigate:

> *"Sometimes you hear of other recipients whom you've got to know really well dying or having to do another one, and that's quite difficult to hear, but I'm very grateful to have them"* (P5, lines 197 - 199).

> *"Initially, when I first had it done because of the other problems, I saw all the others who have the liver transplants seem to be fine. I couldn't understand why I wasn't"* (P6, lines 144 - 145).

Participant five spoke of the difficulties experienced when a fellow organ transplant recipient becomes unwell or dies, and participant six speaks of the issue with others in the same position recovering a lot quicker. Both of these experiences could lead to alienation instead of a sense of togetherness. Therefore, the shared experience can also lead to challenging and difficult emotions arising.

In living beyond the organ transplant surgery, several of the participants spoke about using their lived experiences of this to reach out and support others who may be journeying this too:

> "*I talk to a lot of people now who are waiting for transplants or who have had transplants and try and help them to get through it"* (P1, lines 248 – 249).

> "*If I can stop one person from having to go through all this by actually thinking about what they are doing to their liver, then that helps me"* (P1, lines 255 – 256).

> *"I'm quite positive on social media now, which obviously is a relatively new thing in trying to encourage people who are waiting for transplants and stuff that this can be a good thing, this can be a positive thing. Just that you understand what they're going through, and I give them encouragement and all that kind of stuff, people that are on the waiting list, people that have just had their transplants, people that have a few years on, I'm more than open to talking to them about the positives of what's gone on. I've done that for a number of people over the years, which I think has been a positive experience for them, hopefully. And probably a bit of a positive experience for me giving back"* (P2, lines 338 - 344).

> *"I know that if people talk to me about things, I'm able to explain what happens. My sister's grandson had to have a kidney transplant two years ago. Unfortunately, he's rejected his. He's just having to have an operation to remove the one that was transplanted. He's back on dialysis. I've been able to talk to him that this does happen, setbacks and things. I think it helps when you're able to talk to people"* (P6, lines 150 - 154).

The participants are drawing on their experience to help others navigate this challenging and confusing time. They are able to bring a sense of normality and comfort to others who are not yet through this process or are experiencing setbacks. In doing so, the participants are finding meaning and fulfilment from their connection with others. They feel a sense of reward and accomplishment in helping others through a process they may have personally found difficult. In addition, discussing their experiences may help to process and accept these for themselves.

5.4.3 Roles and responsibilities

This theme relates to the participants' experiences of changing roles and responsibilities as a result of undergoing the organ transplantation process. Five of the participants discussed experiences that fell into this theme.

Undergoing the organ transplantation procedure will have life-changing effects for all of those journeying this. The roles and responsibilities the recipients may possess in their lives are likely to undergo some form of transformation due to their illness and recovery period following the transplant. Some of the participants discussed how their role as a parent/caregiver in the household changed as a result of their physical health issues:

> *"I've always been the one looking after everybody else. I've always been the one doing everything for the family, and all of a sudden I couldn't do it. Even though my husband had to do all the washing and you think ooh he's never had to do that before. That's always been my job. I should be the one, and my younger daughter had a parents evening at school, and I couldn't go, so my elder daughter went. And you think no that should be me talking to her teachers, not her sister"* (P1, lines 372 - 376).

> *"My children were at a stage where they were very needy. I was having to work really hard for them which I didn't in any way begrudge, but I'd be feeling really awful tidying the house and then later that day the house would be really messy again. That hasn't changed, but I didn't have that the first time because I was still a child myself and living at home with my mum and dad. A couple of times I would break down, I didn't really manage it. That was horrible too because I just wanted to be a good mum, a good wife, follow my dreams, all the things that you want to do. I found it very difficult because I was feeling like absolute rubbish"* (P5, lines 244 - 250).

The participants found they were no longer able to meet the demands of the caregiving role due to the deterioration in their physical health. Both participants talk of having expectations of being there for their family and being able to look after them in the ways they could previously. Therefore, not being able to perform this role and sustain their responsibilities was quite challenging for these participants. The participants also spoke of how this affected their families:

> *"I never wanted to impact them; I never wanted them to be affected. But obviously, they were, they had to be because I wasn't here. My daughter never really knew when I was going to be here. She would come home at night, and her mum would be back in hospital again"* (P1, lines 223 - 225).

> *"They kept seeing mummy just being collected off in an ambulance and didn't understand what was going on. That was very difficult for them. Then when I said I'm going to have my transplant in that January, that operation and I'll be back, and I'll be fine. Then the next day, I was back in filled with tears, and that was difficult for them as well. It particularly affected my younger son. He did have obsessive thoughts and got OCD"* (P5, lines 179 - 183).

The participants discuss how they were no longer able to offer their families the stability and predictability of the parent/caregiver role they had done previously. Because of this change in role, their family members, specifically their children, were impacted emotionally in quite a significant manner. Therefore, changing roles and responsibilities affect all those involved in the fulfilment and receipt of these. Some of the participants spoke about how the organ transplantation process affected their spousal roles and responsibilities:

> *"Sexually it did, I mean he's got vascular disease. I couldn't really run, and he couldn't have chased me, which is what we used to say. I couldn't even just lie there, so we've not had a sexual relationship for a long time" (*P4, lines 192 - 194).

> *"It did a bit because I didn't want to have sex with my husband at all. I found that very difficult because I was scared. I couldn't anyway for a long while because of the scars, because they cut right across your stomach, and like a T thing. That was a bit difficult, but it's all healed up now and everything" (*P6, lines 135 - 137).

> *"My husband-- I don't know why it was, but maybe he couldn't cope with hospitals. He found it difficult to support me through dialysis by which I mean he didn't ever come with me to dialysis or make any adaptations for me because I was feeling ill. I found that quite difficult. I was told by one of my consultants that I was lucky he was still with me because usually, people let partners leave. [laughs]. Actually, it does make you feel-- Well, no. That's not fair. I'm not generally, but that made me feel I had a lower status in the relationship"* (P5, lines 172 - 177).

Participants four and six both discuss how they were unable to engage in sexual relations with their spouses because of the decline in their physical health and side effects of undergoing organ transplant treatment. Participant five discussed how they felt the power balance in their marriage was skewed due to their illness and treatment commitments. They discuss how their spouse was unable to be there for them emotionally and physically, leading to a distance being created between the both of them. The participant hints at the prospect that they felt like a hindrance and that they were less capable of fulfilling the role of a spouse now because they were unwell. Therefore, being unable to meet the roles and responsibilities that the individual may have assumed is quite challenging for the recipient in an emotional respect.

5.4.4 Isolation

This theme relates to the participants' experiences of feeling isolated during the organ transplantation process; this may relate to physical isolation, such as being hospitalised or psychological isolation, such as missing certain relationships. Five of the participants discussed experiences that fell into this theme.

Undergoing the organ transplant procedure is a significant operation and as such, involves hospital admission. When the transplant was conducted, and how successful the recovery period is, will influence how long the recipient has to remain in hospital. Participant two discussed how their transplant was conducted in the 1980s, and as such, the procedure was not as advanced as today's standards. This involved a lengthy hospital stay for the participant, with the majority of this being in confinement to prevent the risk of infection. The participant shared their experience of isolation and loneliness throughout this period:

> *"There was very little interaction with people. I was in a single bedroom which had a window, and it had an airlock door. I had four nurses that looked after me 24/7, and they rotated round. It was just those four because they didn't want to introduce more risk of infection. I wasn't allowed visitors. My mom and dad were allowed to wave through the window. That was it"* (P2, lines 106 - 109).

> *"I came out of the intensive care bubble into a lesser intensive care, let's say. I was allowed visitors. My mom and dad could come and visit. Again, I was still in a single room. It was still restricted. It had a window; I could see outside. They had a shower so, I was allowed to have a shower, that kind of thing. I was moved into there for about a month. During that time, they started allowing you to go around the hospital. I could go around the hospital in a wheelchair, and I could go outside. Things were improving slowly"* (P2, lines 119 - 123).

> *"I was moved to, still in the intensive care but a bigger intensive care where there were a few more people. You're allowed visitors, you could go in and out when you wanted, with reason. Obviously, I couldn't walk because of the stroke. I had to go in a wheelchair.*

> *Yes, I guess that was life for the next three months or so. Then after that, I was finally allowed home. Probably five months after my transplant, I was allowed home"* (P2, lines 126 - 130).

The participant speaks of being almost completely isolated to begin with, then as recovery improved, they were slowly reintegrated into society and being around others. It was five months from the date of transplant until the participant was allowed home. The majority of contact the participant had during this time was with medical staff as their family was not initially permitted contact. The participant went on to discuss how this affected the relationships they held during this process:

> *"You were completely isolated in your own way. The only relationship you ever have was like with a nurse or doctor or physiotherapist. Friendships disappeared pretty much. All my friends went off to university; I was left back in my hometown with no real friends. It was very difficult to make friends when you're disabled in a wheelchair. I was quite isolated for a few years really"* (P2, lines 224 - 227).

The participant highlights that friends moved on with their lives whilst the participant's life was almost put on hold. Furthering this the participant shared that their relationships consisted of medical staff and that because of their physical health needs, they experienced difficulties in engaging in new relationships. Other participants also shared their experiences of being hospitalised and the impact this isolation had on their emotional wellbeing:

> *"That was hard, being away from my family, my daughter who was pregnant at the time and I thought, "Oh gosh, we're here for three months, this is going to kill me"* (P4, lines 80 - 81).

> *"I just wanted to get home, and I couldn't understand why I had to keep waiting, stay in the hospital. I think when you've been there so long, you just want to get home"* (P6, lines 231 - 233).

Participant four expressed how challenging it was for them to be away from their family and that the idea of this being for a prolonged period was somewhat unsettling for them. Participant six discussed how they were kept in hospital for longer than others undergoing the same operation and that this was a source of frustration for them. Following the transplant, the participants want to go home and reconnect with those that are important to them.

Participant one discussed how the recovery period impended their ability to go out into the world, and therefore they experienced a sense of isolation from this:

> *"I didn't drive for the first 9 months. Where I live is very limiting; basically we live in the middle of nowhere. If you don't drive you're stuck at home"* (P1, lines 379 - 380).

The participant reported that whilst they were at home with their family, they found it challenging to connect with the rest of the world due to recovery-related issues. Participant five discussed how the isolation was experienced inside of the home, with their spouse being distant due to the inability to cope emotionally:

> *"My husband-- I don't know why it was, but maybe he couldn't cope with hospitals. He found it difficult to support me through dialysis by which I mean he didn't even come with me to dialysis"* (P5, lines 172 - 173).

Therefore, isolation can occur when being physically removed from others due to hospital stays and also inside the home environment in the form of emotional isolation.

5.4.5 The Donor

This theme relates to the participants' relationship with the donor. This encompasses a physical relationship experienced in the case of a live donor, and a felt sense of a relationship in the cases of deceased donors. Five of the participants discussed experiences that fell into this theme.

Organ transplantation can occur through deceased donation and in some cases, live donation. Regardless of the origin, the donor is another person; therefore, the recipient will be related to these in some way shape, or form. One of the participants in this study received two organ transplants from two live donors, these being from their father and uncle. The participant described how their relationship with their father and uncle changed as a result of these donations:

> *"With my dad, that was difficult for a while because we had a father-daughter relationship where, quite normal, I supposed we irritated at each other. We loved each other and irritated each other and all the normal things when you're a teenager. There was this added dimension of my dad had saved my life. I was enormously grateful to him, which meant that if I did ever get irritated with him, I felt so guilty. It was a real Jekyll and Hyde situation within me. That was quite hard to cope with. It also brought us closer"* (P5, lines 163 - 168).

> *"It's brought me and my uncle closer because he donated a kidney in order for me to receive one"* (P5, lines 186 - 187).

The participant describes how the relationship with their father took on a new dynamic, one of gratitude toward him for saving their life. This then meant that the participant felt guilty for experiencing emotions such as irritation toward their father. This created an internal conflict for the participant, and it was difficult for them to navigate and manage. However, in another sense, the donations from the participant's father and uncle, brought them closer together, strengthening the bonds of their relationship. This participant also spoke about the negative impact this had on the relationships they held with those of whom they had asked to be potential donors:

> *"There was that element in there of, it was potentially that element in there of, do I matter enough to you to give me a kidney or are you going to walk away from me? Although I absolutely, completely understood if they didn't want to because it's such a massive thing. It's the people that didn't respond at all that hurt a little bit, but I can understand that as well. I didn't want to have to ask in the first place, but I was, I had*

> *two young children, and I wanted to carry on living. It was really, really difficult"* (P5, lines 77 - 82).

The participant acknowledges that they placed a sense of worth on whether people decided to agree to donation or not. If they did not, the participant felt that they could not have valued them or their relationship enough to save their life. The decision was a matter of life and death for the participant, and this decision lay in the hands of others.

Having undergone the transplant successfully, participant four discussed how they would like to build a relationship of some kind with the deceased donor's family:

> *"I'd love to hear back from his family. I'd love to know whether he had kids, or he was somebody's son. I hate to think I was doing them a disservice, is what I mean. I'd like him or his family to know that I appreciate them and that I'm not taking advantage of them. I'm using them what they were used for"* (P4, lines 218 - 220).

Participant four wishes to convey their gratitude and appreciation to the donor's family. However, it also appears that in forming a relationship with them, the participant is able to form a relationship with their donor vicariously. Due to the donor being deceased, the participant may have to consider other ways of fulfilling their desire for a relationship with them.

In the case of deceased donation, the recipients would not have met the person who will become their donor. Despite not having had a prior relationship, some of the participants felt that the donor had become a part of them:

> *"One thing I've gone off beer. Now, I used to be a big beer drinker, drank beer, used to loved it. Used to love a pint, can't stand the smell or taste of it now, so we joke that my donor was-wasn't a beer drinker"* (P3, lines 172 - 174).

> *"I ordered a turkey casserole thing, which I'd have thrown it at anybody that offered me that before the transplant. Where things like that, my tastes developed. I don't know if*

> *it's because it was a fresh new pair of lungs and tubes. I discovered things that I liked that I didn't like before and I'd love to know what found out, like did he like these things and what was he like, what did he do? Was he healthy? That's my biggest thing is my curiosity; I'd love to know about my donor"* (P4, lines 225 - 229).

> *"He's a part of me now, I think. He's a part of me now, that's now me, that's my new lungs. I think I've only got them on loan, maybe that's what it is. I think that's it. I'm not guaranteed, I might get five years, I might get 50 years, we don't know. I'm down as a donor; hopefully they'll be able to be used again. I just want them to know I'm looking after them till they maybe go to the next person. [laughs] I wish I could talk to him, that's what I'm missing"* (P4, lines 231 - 235).

The participants discussed the emergence of the donor intertwined with themselves, made possible through organ transplantation. The participants express a change in personality and attribute this to the taking on of the donor's characteristics through the organ they have received from them. Therefore, the relationship they hold with the donor is entwined with the relationship they hold with themselves.

In relation to receiving the donated organ, participant three explicitly expressed their gratitude to the donor and the donor's family for making this decision:

> *"Oh yeah gratitude, yeah, yeah. I mean it's erm as I say, it's the gift of life, and I shall be eternally grateful to err, you know, to the erm, to the family of the, of the donor, who I erm yeah, I don't particularly, I suppose I would like to have known, but then I don't know, I mean it's probably better to, to keep it anonymous. Yes, its gratitude, I suppose"* (P3, lines 228 – 231).

The participant describes the donor's family's decision to donate the organ as the gift of life, which they will be eternally grateful for receiving. This decision has allowed the participant to continue to live on and therefore saved their life. Within their gratitude, the participant plays with the idea of wanting to know about the donor; however, this does not seem to be something they have arrived at a definite answer to. This could be a wish to express the gratitude they are experiencing about their life being saved.

5.5 Temporality theme

5.5.1 Waiting for the transplant

This theme relates to the participants' experiences of waiting for their transplant. All of the participants discussed experiences that fell into this theme.

Following being assessed as suitable for an organ transplant, the individual will be placed on a register to wait for a suitable organ to be sourced. This register acts as a waiting list, and therefore more urgent cases will be offered transplantation sooner than those considered less urgent. One participant in this study shared how their transplant was considered to be an emergency, and they received this very shortly after being placed on the list:

> *"Initially said that I was too ill to be transplanted, but then thought about it for a couple of nights and said, alright we'll give it a go. I was put up on the emergency list immediately, and I actually received my transplant about a day later"* (P2, lines 9 - 11).

This participant was given very little time to get their head around needing a transplant; from the point of the decision being made to the operation going ahead, was a matter of 24 hours. Other participants shared how their wait for a suitable organ was considerably longer than this:

> *"Well I was trying to remember actually how, how long I'd been on the waiting list; I think it was probably three, four years before I had the transplant"* (P3, lines 2 - 3).

> *"We spent about two and a half years just waiting on the phone call, just to see, "Right, we've got your lungs"* (P4, lines 34 - 35).

These participants spent years waiting for their transplant to occur, which can sometimes be the case if new patients are added to the list who are deemed more of an emergency. The participants went on to share what impact the long wait had on their conceptualisation of the organ transplant procedure:

> *"After a couple of months you sort of think, oh well it's not going to happen, and you don't sort of think about it so much"* (P1, lines 81 - 82).

> *"Mixture of sort of excitement and trepidation, a bit worried but then I knew it was some time way in the future. But I didn't know how far it was, so you sort of put it to the back of your mind"* (P3, lines 83 - 85).

> *"The first couple of months, it was maybe scary because you've got to have bag on standby, but I think the longer it went on, we had 13 calls before I got my transplant. We made that journey 13 times, and I think by that time, I've always said, I don't mean to sound blasé about it, but you get used to it. It's a way of life; it's a way of living. We never had any choice really; we just had to wait"* (P4, lines 37 - 40).

> *"It was a way of life, yes. Everything was on standby every time the phone went. To be honest, near the end, when the phone went, you didn't even think. If it went in the middle of the night, you were like, "Is this it? Is this it," but during the day you just, "It could be PPI." You just, aye. The longer it went on, the more acceptable it was"* (P4, lines 45 - 48).

The participants discuss how initially going onto the transplant list was unnerving for them; however, the longer that they spent on this, the more that waiting appeared to become a regular part of everyday life. The participants began to believe that the transplant would not occur due to the lengthy wait, and therefore this was put out of mind. In doing so, this could perhaps contribute to the shock the participants experienced when they eventually got the telephone call to advise them of a suitable organ. However, this way of thinking allowed the participants to get on with day to day life as much as possible, without constantly worrying about this. Participant one discussed how the organ transplant remained in their conscious thought processes, mainly when leaving home:

> *"Pretty nerve-wracking. Yeah. Yeah because you can never leave the house without your phone because that can ring at anytime, anywhere. You go to places where they say*

> *please turn off your phone and you think no I can’t my phone has to stay on”* (P1, lines 84 - 86).

The participant was always aware that the phone could go at any time advising them of a suitable organ being sourced; therefore, the waiting was in some way inescapable. The participant had to hold the idea of the transplant in mind in some way to ensure they were available for when the inevitable call would be made.

The waiting period would also involve other treatments to keep the recipients alive. These participants discussed how time-consuming the treatment was for them:

> *“With the dialysis, I live in St Albans, and there was no space for me to have dialysis in St Albans. I'd have two, three times a week, go to the Hammersmith from St Albans which is about an hour. That would involve leaving the house about 4:00, going to the Hammersmith, waiting up to three hours to get on to a machine, three or four hours on the machine, and then an hour back again three times a week. As you can imagine, it changed my life a lot, so that put everything would hold”* (P5, lines 232 - 236).

> *“You don't realize you spend most of your time backwards and forwards to hospital. At one time, we were going every two weeks to Leeds, which was tiring, draining, and hanging about and things. When I look back now, it had to be that way”* (P6, lines 188 - 190).

The participants reflect on how much of their time was given to treatment and that this almost placed their life on hold. This treatment was keeping them alive; therefore, it was unavoidable; however, this was also stealing their life in some way. The participants’ treatment governed their lives, and therefore their time could not be given freely.

5.5.2 Things happening quickly

This theme relates to the experience of things happening abruptly during the organ transplantation process. Five of the participants discussed experiences that fell into this theme.

Having been placed on the organ transplantation list, the recipient then waits to receive a call advising them that a suitable organ has been sourced. In the case of donations originating from a deceased donor, there is only a short period in which the organ remains viable following the donor's death and retrieval of the organ. Therefore, the call to inform the recipient of the sourced organ can happen at any time of day. Upon receiving the call, the recipient then must immediately make their way to the hospital. All the participants who received this type of donation discussed what getting this call was like for them:

> *"I got a phone call at 4 o'clock in the morning, and they just said we've got a liver for you can you be making your way down to the hospital. Erm, so we quickly wrote a note for my daughter and got in the car and drive down to the hospital"* (P1, lines 121 - 123).

> *"I was put up on the emergency list immediately, and I actually received my transplant about a day later"* (P2, lines 10 - 11).

> *"About 4 o'clock in the morning I get a phone call saying, err get yourself into Nottingham which was the transplant centre. Err, looks like we've got a kidney for you. So that was a bit of a shock. You've been waiting for this moment"* (P3, lines 23 - 25).

> *"That was quick, and I still can't remember a lot about it. We got the call, and we went down"* (P4, lines 55).

> *"When I got the phone call, it was 7 o'clock in the morning, and you can't register it. I was shocked, and so they asked to talk to my husband"* (P6, lines 28 - 29).

The participants discuss the abruptness of the call and how this was quite a shock to the system for them. No one can predict when they will receive the call; therefore this unpredictability along with the hastiness in which they are expected to attend the hospital is more than likely to add to the feeling of shock and abruptness of this situation. Some of the participants discussed how this type of energy continued once they arrived at the hospital:

> *"This was my one and only call, and I was straight in the operation and yeah. That was pretty traumatic"* (P1, lines 161 - 162).

> *"You get prepped because you've got to get prepped every time in case the lungs are any good. We got prepped, but then we were just thinking, "No. You know what, it'll not be, it'll not be this time", but as my husband says, I think we knew that if it hadn't been then, I wouldn't have been coming home. That would have been me, I think. Then they came in and told us everything was good, and I think it was within about 20 minutes, half an hour, I wasn't awake. I was off, [laughs] and I can't really remember much else after that"* (P4, lines 57 - 62).

> *"When I got to the hospital, it was all systems go. You have to have a shower and disinfect and even wash your hair, which I thought was a bit weird. You're not allowed to dry your hair either, so that was weird as well. I couldn't even comb it; I didn't have time. I had to put this gown on, and they whisked me off down there to theatre straight away, so I didn't have time to be frightened"* (P6, lines 41 - 44).

From the moment of receiving the call to advise them that there is potentially a suitable organ, the participant is thrown into the process with very little time to orientate themselves or come to terms with what is about to happen to them. The endpoint following the call is waking up having undergone the procedure, so long as this was successful, and the organ was a match. Therefore, time appears to speed up for the participant, and a lot occurs within a small window. Participant one discussed how this affected their emotional wellbeing and responses:

> *"I think there was a lot of crying that went on in those first couple of days as well from me. I think because of the shock of everything that had just suddenly happened because that's not like when you have a routine operation when you know about it for weeks beforehand, and you can get yourself all prepared, this is suddenly a phone call at 4 o'clock go"* (P1, lines 154 - 157).

The participant shared that this was a challenging time for them emotionally due to the suddenness of the transplant occurring. They discuss how potentially being given a date and time like a routine operation, would have allowed them to come to terms with this. However, due to the unpredictability of the organ transplant procedure, the participant felt they could not come to terms with this entirely. However, they were able to recognise that this was not a wholly negative aspect of the experience and that being given a short time frame could also be regarded as a positive thing:

> *"I think maybe if I'd had more time to think I might have got even more worried and even more stressed out. Whereas things happen quickly you don't have time to sort of ponder on"* (P1, lines 175 - 176).

The participant shared that because the transplant happened so abruptly, they were not afforded time to ruminate over this. When undergoing a transplant, the success of this is not guaranteed; neither is the survival of the patient. Therefore, this is not a procedure to be taken lightly. If the recipient had been provided with more time to reflect on the procedure, they possibly would have experienced a heightened sense of anxiety and stress. This participant acknowledges that the abruptness of this was therefore not necessarily a wholly negative thing, freeing them from the worry that may come with rumination.

5.5.3 Life after transplant

This theme relates to the participants' experiences of time following the transplant. Five of the participants discussed experiences that fell into this theme.

Having undergone successful organ transplantation, the recipient can now recover from this and return to their life without the overt concern that this is coming to an imminent end. Having lived beyond their death, some of the participants discussed their experience of life following this. They highlight the notion that they are now living on extra time, time that would not have existed without the transplant. This means that this phase of their life can be considered as new due to this not originally being intended for them:

> *"Well, you can only sort of think that I'm living on extra time"* (P1, lines 309).

> *"If the worst happened tomorrow, I'll look at it that I've had an extra three years now, and I'm thankful for that"* (P4, lines 164 - 165).

> *"To me, now having this liver, I'm just thankful that I've had these extra years. I may have been dead had I not have it"* (P6, lines 159 - 160).

The participants are left to contemplate how the life they now have is time that is an addition to their lifespan, having survived the surgery and no longer being considered terminal. This is something that the participants would not have had if they had not survived their brush with death. The participants express their gratitude at this extra lease of life they have been gifted. Whilst there may be gratitude experienced toward an extended life span, this does not take away the fact that the participant's life may have been disrupted due to their illness. Participant two discusses how their life was put on hold due to becoming unwell and the extensive recovery period following transplantation:

> *"I was in the middle of doing my A levels. I was planning on having a riotous summer as an 18-year old going to Ibiza and all that kind of thing. Obviously, that never happened. I was planning on going to university that September or October. That didn't happen. I did go to university eventually, but not that year. Obviously, I didn't get my A levels because I didn't finish any of the exams. That's where I was, really. Just life completely on hold, while the medical things went on around me"* (P2, lines 61 - 65).

The plans the participant held for their life had to be put to one side whilst their physical health needs were managed. The participant felt as though their life, as they had envisaged, was placed on hold. This leads to a way of considering time within their life as almost suspended, with the participant frozen in a time that is represented by ill health. The participant then experienced a period of waiting for the moment their medical issues were resolved for them to be able to re-engage with their life autonomously. They were then able to return to a life in which their time could be spent however they wished.

The transplant also appeared to transform how the participants experience time. Some of the participants discussed how they have learned to be more present in their life and to not necessarily revisit the past or project into the future too much:

> *"Just register the fact that you are here, carry on. I'm a very day to day person, I never worry about the past, well I try not to worry about the future. So, yeah, yeah, I just register that, carry on. Get on with your life"* (P3, lines 85 - 87).

> *"Yes, and it's more living for the day now. I don't get stressed out about what's going to happen next week or next month. Now it's very much on the day, and we'll worry about tomorrow tomorrow or like, "That's not happening until next week", so I very much think, "I'll worry about that next week". I'm going to worry about it but just put it off and spend a couple of hours worrying about it rather than a couple of days, so I don't waste as much mental energy I don't think now"* (P4, lines 123 - 127).

> *"I think it's a lesson I've learned that just live in the moment, very much so, you don't know what's going to happen. I've had a couple of scares since then, been in a coma, been on life support, and the last one was just six months ago. Again, I bounced back. My sisters say I'm a rubber ball. When they all pulled to come to the hospital it was no hope, I'm still there in the morning, and then I think, "Oh well, you know, it's for a reason, I've got a new day, let's concentrate on today and we'll worry about tomorrow tomorrow."* (P4, lines 129 - 133).

The participants share how they have endured the unpredictability and fragility of life through the organ transplantation procedure. This has taught them to focus their energy on the present as this is the only aspect of time that they feel is entirely within grasp and within their control to some extent. Therefore, it appears as though the participants have realised that the present is where their energy is most well spent. By also living presently, the participants can avoid to some extent ruminating over what has happened in the past and what is to come in their future.

5.6 The Psychological

5.6.1 The Unknown

This theme relates to the participants' experiences of not knowing throughout their organ transplantation journey. This may relate to not knowing what to expect from the procedure, not knowing about life expectancy, the uncertainty around complications, and not knowing the cause of their illness. All of the participants discussed experiences that fell into this theme.

Life holds uncertainty for everyone; however, when the individual is suffering from a serious illness, this uncertainty appears to be heightened and more pronounced. This appears to be the case in relation to undergoing organ transplantation. Some of the participants discussed facing the unknown concerning the transplant procedure itself and what to expect from this:

> *"They can't prepare you for, because it doesn't happen to everybody. Everybody's transplant is different, everybody reacts differently to things. Mine was just pretty traumatic"* (P1, lines 266 - 267).

> *"I think the worst aspect was the not knowing what was happening, or not understanding what was happening. They did their best to explain to you everything that was happening, but you-- when you're 18, you just do not have the life experience or the knowledge to understand what is going on at all. Well, I didn't"* (P2, lines 151 - 153).

> *"On the second one, I was really worried for a while until I knew that it had settled, and I was functioning properly, because there's every chance obviously, that it doesn't take. The second one, I was a lot more scared than the first one"* (P5, lines 127 - 129).

Participant one highlighted how everyone's transplant journey is entirely different, and therefore the medical teams cannot prepare people fully for what to expect. With this in mind, the participants had to go into this procedure with a level of not knowing. Participant two shared how difficult not knowing was for them, mainly as they were at an age where they did not feel they were fully capable of understanding and appreciating what was going on. Participant five expressed how they were worried about the outcome of the transplant and that it is impossible to predict whether it will be a definite success or not. The participant describes worrying about this until they were deemed as stable, and the organ was considered to be functioning as intended. These concerns did not stop there for some of the participants who continue to worry about the uncertainty of the complications they have experienced or not knowing what complications could arise in the future:

> *"Even now I went to Addenbrookes a couple of weeks ago, and I sat there the next day waiting for a phone call because there's something wrong. And until I get my blood results back, then I can look through them all and say yeah that's fine, that's fine. You can't relax because you're constantly waiting for a phone call"* (P1, lines 392 - 395).

> *"I've had fluid and things on them which is why they were talking about the double pneumonia, but it comes and goes. They can't explain it; I'm a weird set up apparently, I'm very weird, they don't know. It's just all guesswork I think for them"* (P4, lines 141 - 143).

> *"What was the cause there I'm not sure. When they did scans, and they scanned my brain, and they said there was activity in the brain. What sort of activity I don't know. They never really said, but I think because they changed the drugs that I was on, then it settled down at last"* (P6, lines 219 - 221).

Complications are unforeseen and are unknown at the time of transplant; these occur in the time afterwards. Participant six discusses how medical professionals are still unsure as to why the participant experienced the issues they did immediately following the transplant. Participant four describes how the complications continue to this day, and that the reasons for these reoccurring are unknown. Finally, participant one describes how this unsettling feeling of not knowing never goes away and that they are always in a pre-emptive state that something is going to go wrong for them. The participant shares that they cannot relax or settle until they get definitive answers to confirm that they are still healthy.

Organ transplantation is not a cure; instead, this is a treatment for end-stage organ failure. The transplanted organ does not have the same life span as the original organ would have had; therefore the life expectancy for an organ recipient is less than that of the life span estimated for the general population. Some of the participants shared how the unknown about their life expectancy is unsettling for them and that they are unable to know what the future has in store for them regarding the viability of the organ:

> *"It's permanent not knowing obviously because I was told when-- once I had recovered from the initial transplant, say two years after, I was told that I would probably have a life expectancy of around five years from there, so seven years altogether. Then once I got to seven years, they said, "Well, probably 15." Then, since then, they don't say it, they just say, "We don't know, we can't say." I'm now the longest, as far as I'm aware, the longest surviving heart transplant in the UK. They really do not have any idea of the future after that. That's also worrying"* (P2, lines 182 - 187).

> *"I'm not guaranteed, I might get five years, I might get 50 years, we don't know"* (P4, lines 232 - 233).

> *"I don't know; they can't tell you how long the transplant will last. Maybe two years usually. They've told me it could last me life now. How long that is, I don't know. I'll be 70 this year, so I've had quite a good life"* (P6, lines 176 - 178).

No one in life can know for certain how long they will live; however, for the case of organ recipients, this is brought into their conscious awareness. Participant two describes how they are the oldest living heart transplant recipient in the UK; therefore, the medical profession has no idea what is to come for them. The participant is almost breaking new ground, and as such is having to carry a great sense of not knowing about their lifespan. Both participants four and six also discuss the uncertainty around how long they have left regarding the transplanted organ remaining functioning and viable. The life span of the general population no longer applies to organ recipients; therefore, their very existence is in a constant state of unknown.

Concerning what caused their end-stage organ failure to begin with, some participants discussed how this remains uncertain:

> *"Still don't really know the reasons why I had a problem, although they say it can be blood pressure and even stress-related and I'd gone through a lot of stress"* (P3, lines 54 - 55).

> *"They're not sure, actually, about me. It's quite complicated because my mum and my grandparents and all my aunts have died of emphysema. They thought it was in my genes, that's a gene, a special gene or something, an E whatever it's called. You can see I listen to a lot ay? They have checked me for it several times, but apparently, I don't have it. They can't see what caused it so young because this gene isn't there. I don't know; they can't explain why it was so quick"* (P4, lines 7 - 11).

Both of the participants are left with unanswered questions regarding what went wrong for them. They are having to live with the unknown about their illness and appear to be continuing to question what the catalyst may have been. They are searching for answers, potentially to make sense of this experience and what they had to go through to continue living.

5.6.2 Coping

This theme relates to the participants' experiences of coping emotionally and psychologically with the organ transplantation process. This encompasses their views on how well they feel they coped and what mechanisms they may have utilised to aid them in doing so. All of the participants discussed experiences that fell into this theme.

Upon being advised that they were in end-stage organ failure and would require organ transplantation, some of the participants shared how they responded to receiving this news:

> *"When I was originally in for my transplant, they did send a psychiatrist to see me because they realised I was in a bit of a state of shock"* (P1, lines 319 - 320).

> *"Just accepted the fact that, yeah, you've got a problem and we're going to fix it. Engineer you see, engineer brain"* (P3, lines 206 - 207).

Participant one shared that they were referred for professional support to aid them in coping with their current situation as this news came as quite a shock for them. Participant three shared that they accepted the news well and conceptualised the transplant as a solution to a problem they currently had. In doing so, the participant felt they coped well with this stage of the treatment journey.

Once agreeing to the transplant, some of the participants shared how they coped during the lead up to the procedure:

> *"It was like, you've got to get through this to survive. Yes, it was hard, very hard, obviously. No, I didn't have any time to wallow or think of depression, or why is this happening to me or anything like that? That didn't enter into my thinking at the time"* (P2, lines 115 - 117).

> *"I was very laid back. Yeah but then, you know. Think back, think well if something had gone wrong, you know? I might not be here talking about it, but you know. You just put your, your life in their hands you know? They're the experts; they know what they're doing"* (P3, lines 111 - 113).

> *"They did prepare us for a tough time so, I knew what was going to happen, and I just dealt with that as I've always and got ready again and bash on. So, mentally, physically, everything, they prepared me so well"* (P4, lines 294 - 296).

> *"I belong to a church and knew that, and different people rang around and said I was going in so they all said they would pray for me"* (P6, lines 45 - 46).

Participant two discusses how they did not have time to reflect on the situation thoroughly and their conscious thought processes at this time were centred around surviving and the need to get through this treatment successfully. This could have been a way of channelling their energy and thought processes in one direction, so these did not wander off to places the participant did not wish them to. Participant three coped by placing faith into the hands of the medical professionals that would be performing the transplant and caring for them following this. In doing so, the participant felt they could take a more laid-back approach to contemplating the procedure due to having confidence in the experts prevailing. Participant four shares that psychological preparation for how challenging the procedure and aftercare would be was vital for them, and how integrating this into their sense of self allowed them to cope reasonably well throughout the process. In doing so, perhaps aspects of this treatment were not so much of a shock for them, and they had developed the tolerance for what would arise during this journey. Participant six shared how religion helped them in the lead up to the transplant and knowing that others were praying for their recovery aided them in coping with the psychological demands of the situation. Having faith in a higher power than the situation the participant found themselves in, gave them a sense of meaning and purpose within this.

Having undergone the transplant, some of the participants reflected on how well they had coped and how the experience of undergoing the transplant had affected them:

> *"I was diagnosed with PTSD and had some treatment for that for about six months, which gradually got better"* (P2, lines 140 - 141).

> *"Considering everything I've been through; I think I've coped remarkably well. Yes, it's been hard; it still is hard at times, but yes. It would have been easy to give up on many, many, many occasions, but I never have"* (P2, lines 277 - 278).

> *"I'm not going to make it in vain. They were saved. Had I been saved," so kind of spiritual, I'm looking at it, "Had I been saved because my daughter needed me, my family needed me, or do you know?" I asked myself all these things. That's what I tell myself, that's what the minister told me to tell myself that I was needed for my daughter"* (P4, lines 177 - 180).

> *"The second time, because of the story I told you about being in my gown and everything and then being cancelled, going on to dialysis and everything, I still hurt a bit but less*

> *well. I think I coped with it less well mentally because it was a much harder journey"* (P5, lines 217 - 220).

Participant two disclosed that they developed post-traumatic stress disorder following undergoing the transplant due to how traumatic this was for them. Despite this, the participant remarks on how well they feel they have coped with their brush with death. They highlight that this has not been an easy journey for them and that it may have been easier to give up, but through a determination to survive, the participant was able to weather the storm. Participant four shared that they found meaning in suffering when their grandchild sadly passed away. The participant developed a sense of purpose in that they had been saved to help their loved ones cope with this loss. Participant five shared that the second transplant procedure they underwent was more stressful than the first due to complications with the donors, and the procedure did not initially go ahead. As a result of this, the participant felt they did not cope as well as they did during the first procedure they underwent.

5.6.3 Choice and control

This theme relates to the amount of choice and control the participants felt they possessed throughout undergoing the organ transplantation journey. Four of the participants discussed experiences that fell into this theme.

Having been considered as a suitable candidate for organ transplantation, the recipients are faced with their first decision of many to make; this being whether or not they will consent to undergo the procedure and therefore placing themselves onto the waitlist for this. Participant one shared that they initially did not agree to transplantation:

> *"With their agreement, I didn't sign the papers. They were happy as long as I kept going in for blood tests and that if anything did dramatically change I would sign the papers there and then"* (P1, lines 33 - 35)

The participant made this choice in collaboration with the medical staff and that it was safe for them to do so at the time. They did not wish to engage with the process until it was necessary for them. Participant two shared that in their case, the decision to undergo transplant had to be made very quickly due to it being considered an emergency:

> *"I didn't feel like I had much control over any of it. It just happened. I was taken from hospital to hospital and saw a different doctor and different doctors after a different doctor, all of whom had different views on things and whether I might survive or might not survive"* (P2, lines 65 - 68).

> *"I think it just meant life or death. It was a life that I chose. Death was the other option, which was not to have a transplant"* (P2, lines 266 - 267).

Whilst the participant felt powerless in some ways, such as being cared for and a prognosis being achieved, they acknowledged that they had some choice and control in amongst this. The participant highlights that the decision to undergo the transplant was still theirs to make, and they had autonomy over whether they would agree to this or not.

Participant five shared that because they received a live donation, they were provided with a date the procedure was going to be performed on, and therefore they felt they possessed a greater degree of control over this process:

> *"I had a given date, and it was a direct transplant from my own father. I knew exactly when it was going to happen. I knew that I had a donor and it was all-- we were able to control when we went in et cetera. In that respect, it was good"* (P5, lines 26 - 28).

This participant appears to relate control to predictability, in that the more they are aware of what is to come, the more in control they feel within the situation. Because the transplant was predictable to a certain degree, this eased the anxieties of the participant awaiting this. Whereas those who are receiving donations from deceased donors have less control as this can occur at any time of day, without any predictability.

In the lead up to receiving the transplant, participant three shared how they were given choices about the treatment they were receiving:

> *“I didn’t fancy that, because they told me three days a week going in hospital for about three hours at a time, so I opted for the err peritoneal so I could do it at home, it went well”* (P3, lines 17 - 19).

The participant discussed how they chose the treatment option that most appealed to them, which had the least impact on their life. In making this decision, the participant was exerting some control over their treatment pathway.

Having received the transplant, some of the participants discussed their experience of the recovery period and how much choice and control they had within this:

> *“I think because I was so ill at the time, you can’t think; you don’t really think about being ill. It’s just a matter of lying there and letting doctors pump stuff into you”* (P1, lines 214 - 216).

> *“I guess it was such a time where I was just of the thought, "You had to get on with it" I guess. There was nothing you could do. You're in hospital. It wasn't pleasant. It was horrendous. They were sticking stuff in you, pulling stuff out of you, doing all sorts of procedures which were painful. But it was either that or die”* (P2, lines 72 - 74).

Both participants discuss how they assumed the role of passivity concerning their aftercare in the initial recovery phase following transplantation. They share that during that time, their health needs were quite significant, and if they wished to survive, they had to allow the medical staff to do what needed to be done. However, it could be said that to take on the role of patient, one must first have to choose this.

Being post-transplant, participant two shared their thoughts on whether or not they would make the same choices again, regarding undergoing transplantation, if they were faced with this sometime in the future:

> *“If I was to become ill now, and need another transplant, I don't know whether I would put myself through it all again or not because it was such a horrendous experience at*

> *the time. That I might well not now because obviously, I'm a lot older now. I've had a good life. If my heart does go wrong, the only cure for a heart transplant patient is re-transplantation. Whether I'd go for that or not, I don't really know"* (P2, lines 319 - 322).

The participant shares how they are undecided as to whether they would agree once again to undergo organ transplantation if they became unwell again in the future. The participant discussed how they are more aware of what this choice would entail due to their past lived experience of this. Therefore, this may not seem as appealing to the participant as it once was.

The findings from this research project have been outlined in detail above in a way that allows the reader to observe how these themes have emerged from the data. The subsequent chapter will move on to discuss these findings in light of the research presented in the literature review, along with further literature sourced in light of these findings. The consecutive chapter aims to explain what these findings mean from a psychological perspective and highlight the implications these have for the field of Counselling Psychology and Psychotherapy.

6. Discussion

6.1 Introduction

This research explored the lived experience of undergoing the organ transplantation procedure and how this may have affected the lives of those who have journeyed this. The study aimed to gain an understanding of what it is like to live through this process and how people are affected by this. Six participants were recruited and interviewed using a semi-structured approach, exploring their lived experience of undergoing a solid organ transplant. The Interpretative Phenomenological Analysis research method was then utilised to analyse the data from these interviews. From doing so, five superordinate themes were identified; these were Embodied Experience, Life & Death, Relationships, Temporality, and The Psychological. This section of the study will now discuss the findings presented above in light of pre-existing research and literature held on organ transplantation. Aspects of existential philosophy will also be interwoven within this to enhance the understanding of the findings from this particular philosophical perspective. From doing so, it is hoped that further meaning can be derived from the findings, which will ultimately aid professionals working with the organ transplantation population.

6.2 Embodied experience theme

This theme captured the physical aspects of the participants' experiences when undergoing the organ transplantation process. As previously mentioned within the literature review, for many years, the westernised way of conceptualising embodiment was informed by the Cartesian dualism notion. However, a revolution in consideration of embodiment has occurred within the past few years, leading the census on this to a materialism notion that mind and body are one entity (Quiroga, 2020). Existential philosophy highlights that physical existence is only made possible through being in the body. Subsequently, how this is experienced holds important considerations (Merleau-Ponty, 1962). Whilst this theme relates to physical experiences, the focus of this discussion is on the psychological implications that manifest as a result. Accepting that mind and body are indeed one entity, then it is inconceivable that an individual could undergo the organ transplantation process without this affecting their psychological domain (Mehta, 2011).

6.2.1 Illness and Wellness

The participants within this study spoke of experiencing states of illness and wellness, at differing times throughout their organ transplantation journey. These two states were often presented to them as dichotomous positions, namely that of illness in the lead up to the transplant and wellness following this occurring. This polarised view of illness and wellness has been held by many and continues to pervade the conceptualisation of both physical and mental health (Mackey, 2009). However, this was not reflective of the participants' experiential sense of being in the world throughout the transplantation treatment. Many of them shared that whilst they may have been considered as 'physically unwell' they did not feel this way and described their lived experience as one of wellness. Studies have shown that illness and wellness should be considered as one in the same process as opposed to contradictory states (Jensen & Allen, 1993). Those with chronic illness are described as living in "*the dual kingdoms of the well and the sick*" (Donelly, 1993, p. 6), meaning that the individual experiences themselves as both ill and well at the same time. The shifting perspectives model sets forth a notion of illness and wellness existing in unison and that in any given moment the individual experiences a state in the foreground, whilst the other assumes the background (Paterson, 2001). This ever-changing perspective about their health allows those suffering from chronic illness to make sense of their experience. This also holds important implications for professionals working with and supporting those who are undergoing the organ transplant process. In possessing an increased understanding and knowledge regarding this, it will aid practitioners to support the patient in adapting to their illness (Moreno-Lacalle, 2015).

The experience of pain was a pertinent aspect of the participants' experiences of undergoing organ transplantation treatment. Pain was seen to arise as a result of being chronically ill and directly as a result of the medical procedures. Being in pain is a subjective experience and has emotional and behavioural consequences for the individual concerned. How the individual responds to their pain has been shown to influence their experience of this, particularly concerning chronicity and intensity (Linton, 2004). Benedetti et al. (2013) found that reframing the experience of pain was particularly beneficial for those suffering from this. Post-operative pain could be considered as part of the healing process, meaning a move toward life and away from death. Another study conducted by Graham et al. (2008) found that those suffering from pain due to chronic illness reported improvement in the control of the pain, mood state, and pain severity when afforded the opportunity to express their emotional responses. It was felt that this facilitated the participants in making meaning of their pain which eased the burden this may have imposed. Therefore, it is of importance for practitioners working with organ transplantation recipients to be alive to the individual's experience of pain and consider how they may integrate both physical and psychological therapies into the management of this (Linton & Shaw, 2011).

The experience of post-operative and medically induced complications was another critical aspect of the participant's experience of undergoing organ transplantation. The participants highlighted how this was another hurdle for them to overcome amongst many other significant issues they were facing. Pinto et al. (2016) found that complications following surgery affected patients psychologically due to prolonged recovery periods or lasting disabilities/limitations. In turn, the psychological distress experienced by patients was seen to further delay recovery due to the effects of stress on physical healing and immunity. Therefore, this further highlights the importance of attending to the psychological needs of organ transplantation patients post-surgery to support effective and timely recovery (Mavros et al., 2011).

6.2.2 Being in the world

The hospital environment itself was something that several of the participants found distressing and challenging. Adjusting to this environment was reported as stressful and tiring by some, and that they felt this prolonged their recovery period. Dijkstra et al. (2006) conducted a study exploring how healthcare environments influenced the recovery of the patients housed within these. They found that the individual's environment directly affected their wellbeing. Therefore, it raises the question as to whether the psychological healing process is slightly delayed in relation to the physical healing process due to hospitals being predominantly orientated toward catering to physical health needs. This is important for professionals to bear in mind as the environment in which the individual recovers may adversely affect their wellbeing, further adding to the challenges they have to overcome.

Some of the participants in this study discussed how they found it unsettling that their perception and experience of the world became distorted and altered following the organ transplant surgery. This could have occurred due to receiving medication for pain relief and sedation or because of an occurrence of postoperative delirium. There is significant research conducted into post-operative care and how attending to its psychological impacts is crucial to the patient's recovery (Koster et al., 2009). However, there is little in the way of how these experiences can be worked with from a psychotherapeutic perspective. Drawing on Existential philosophy can offer professionals insight into how they can address the issues of distorted world experience. Existential psychotherapy places the individual's experience of the world at the centre of any psychotherapeutic interaction. Laing (1969) felt that instead of dismissing people's experiences as 'delusional' we should explore these for what meaning they may hold for the individual. Existential psychotherapy achieves this by asking the client to discuss their experience in a phenomenological manner, aiming to help the individual understand their experiences (Cohn, 2000). It may have aided the participants in this study to discuss their experiences more openly with others and doing so may have helped them ease the sense of shame surrounding this.

6.2.3 Change to the Physical Self

Having undergone the organ transplantation procedure, some of the participants discussed a change in the way they related to themselves physically. Baines and Jindal (2003) urge professionals to conceptualise this change as an alteration to the self-image of the individual as opposed to limiting this shift to their physicality alone. Barsky et al. (1998) highlighted that this change could occur for the individual as soon as they are made aware of their organ failure. They are met with a heightened sense of their physicality, which they may have previously overlooked. Merleau-Ponty (1962) coined the term 'lived body' to capture the experience of our embodied existence and suggested that such exploration should be afforded to everyone. In the case of organ transplant recipients, professionals must be alive to changes in the way in which recipients may relate to their physicality, or it could be argued that they are overlooking a significant and wide-reaching aspect of the individual’s existence (Deurzen, 2010). It has also been found to increase the likelihood of ‘psychological disturbance’ if this shift in self-image is left unattended (Sadeghian et al., 2016).

Due to postoperative scarring or side effects from the immunosuppressive medication, the recipient may have an altered sense of appearance. Tierney (as cited by bethematch.org, 2018) encourages professionals and recipients to bring the topic of conversation around to that of altered appearance with which the individual may be struggling with. From doing so, this may reveal a host of issues that the change in self-image has brought about for the individual. Such changes may also influence how the person relates to others. Some of the participants in this study highlighted that their sexual function was affected as a result of their chronic illness and noted changes to their physicality being a factor within this. Studies have shown that up to 30% of organ transplant recipients have experienced sexual fears and dysfunction (Mordkin, 1999). Therefore, the alteration to self-image not only impacts the individual’s relationship with themselves but how they engage with others. Professionals working with this population should be aiding recipients in adjusting to change brought about as a result of their chronic illness and organ transplantation treatment.

6.2.4 The Organ

The relationship that is developed with the new organ was something that several of the participants discussed in this study. Receiving an organ transplant changes the dynamic of how the inside of the body is arranged. There is a loss experienced concerning the failing organ and a strangeness experienced regarding introducing something new into the body. Castelnuovo-Tedesco (1973) discusses different phases of integration recipients may experience with their new organs. The ‘foreign body’ phase relates to the organ being conceptualised as a stranger to the recipient’s body. The ‘partial incorporation’ phase is when the individual begins to accept and integrate the organ into their sense of self. Finally, the ‘total incorporation’ phase is where the organ is fully integrated with the recipient’s sense of self, and there is no longer a conscious awareness of its presence. It is generally considered that until the organ is fully integrated into the individual’s sense of self, anxiety about the organ will remain (Muslin, 1971). Therefore, this has important implications for the psychotherapeutic work conducted with this population. The aim of the psychotherapist here would be to aid the individual in integrating the organ fully or managing the anxieties that may arise as a result of non-integration. Within Existential philosophy, the self is considered to be a dynamic construct, created by the individual and their mode of being in the world (Deurzen, 2015). With this in mind, perhaps organ recipients can be supported in finding their idiosyncratic sense of self and in turn, construct a relationship with the transplanted organ that is meaningful and functional for them. This would help to overcome flaws in prescribed ways of relating to the new organ and would give space for practitioners to be responsive to the individual's needs.

Barsky et al. (1998) highlighted how organ transplantation recipients might experience a heightened sense of the new organ following transplantation and continuous conscious consideration of how this is functioning. An example of this is following a heart transplant; the individual may begin to pay attention to the heart beating which is ordinarily overlooked unless there is an issue that draws a sense of consciousness in this direction. This is something that several of the participants discussed how awareness of the functioning of the organ creates a source of anxiety for them. Gaining a new body part, this inadvertently altered the dynamic of their embodied experience of being in the body. This change may be anxiety-provoking until this is accommodated and accepted. Therefore, professionals working with this population should be devoting time and space to helping the individual explore their new sense of self and what issues the relationship with their new organ may bring forth for them.

In addition, how the individual conceptualises the organ is something that emerged from this study. This ranged from the organ being considered as a spare part that has been utilised to fix a problem, to that of the organ being a gift. Both of these metaphors are drawn upon by professionals to facilitate the relationship between the recipient and the organ (Fox & Swazey, 1978). However, as discussed within the literature review, these metaphors have been criticised for contributing to further anxiety experienced by the recipient (Fox & Swazey, 2013). To overcome this, it is recommended that practitioners should be encouraging the individual to derive meaning from the experience and their own way of conceptualising the organ that works for them.

6.3 Life and death theme

This theme captured the participants' experiences of existence and mortality throughout the organ transplantation process. Various aspects of this emerged within this study such as the quality of life for the organ recipient, what it was like to face their death, how is it to have lived beyond their death, and their feelings towards the donor's death. Despite death being an ontological concern everyone must grapple with, as highlighted in the literature review, the topic has received little attention in general psychotherapeutic literature (Barnett, 2009). However, within Existential philosophy, death has been afforded a prominent place as this is considered to underpin the very facticity of existence (Macquarrie, 1972). Death is something that comes to all, however for the participants in this study they possess a very tangible experiential knowledge of what it is like to be dying and how this may influence the way in which they engage with their life following the transplant.

6.3.1 Quality of Life

Quality of life both before, during, and after the transplantation procedure is something that emerged from the participants' accounts in this study. Several of them discussed how, before receiving the transplant, their quality of life significantly deteriorated, with one participant describing this as existing as opposed to living. This could be likened to the phrase Sartre (1943, pt1, p13) coined of "Being presupposes Essence" to describe the process of physically existing before carving out the individual quality to our lives. Perhaps the participants felt so limited by their physical health needs that they felt they were no longer able to author their own lives and that this then became reduced to mere physical presence in the world. This could have led to a feeling that life was no longer meaningful for them, and therefore they had lost their essence. This is something that should be kept in mind for psychotherapeutic work in helping this population become creative with their existence when this has been imposed upon by their physical health needs.

Transplantation hopes not only to extend the life of those undergoing this but also to improve the quality of life experienced (Burra & De Bona, 2007). This is something that several of the participants reported to have occurred for them following receiving their transplant. However, this did not mitigate the death of certain possibilities the participants had to face in their life, such as going to university, pursuing a particular career, having children. The quality of their lives had deteriorated so significantly that this had almost ‘stolen’ from them certain possibilities for their life that they had previously envisaged. This may bring forth existential guilt which represents the struggle in the individual’s life to make meaning following a loss (Stephenson & Murphy, 1986). Whilst nothing is guaranteed about the future, the possibilities that people project themselves toward exist in some way in their psyche. Therefore, the implications this holds for psychotherapeutic work with this population is to help them come to terms with and overcome the death of possibilities and a loss of a fantasised future they may have held for themselves.

Quality of life is very much a subjective experience for the individual; therefore, what effects this is also subjective (Pinson et al., 2000). Turning the attention toward those participants who expressed that their quality of life was not affected prior to undergoing transplantation, raises the question as to why this was the case. Frankl (1967) felt that meaning could be discovered in any situation encountered, even one of suffering. He felt that if the individual actively examined their situation to establish what meaning they can derive, then this alone would aid the individual in continuing with a purposeful life. Therefore, perhaps those who felt their quality of life did not deteriorate were able to find a sense of meaning and purpose in their circumstances.

6.3.2 Facing Death

To be found suitable for organ transplantation, the individual will have been diagnosed with end-stage organ failure, and without the transplant, their death would be imminent. Therefore, facing death is something that the organ transplantation population will have encountered. Some of the participants acknowledged this and spoke openly about it. Death is usually something that is stretched out far into the future for most, and these thoughts are pushed out of consciousness. However, for the participants, the notion of death was brought about abruptly and prematurely for them. Death was no longer something reserved for the elderly and a natural part of their life span, this was now looming and in turn disrupted the ‘natural’ course of life (Lynn et al., 2011).

Having been presented with the possibility of impending mortality, the participants on some level had to accept this in order to make decisions about their treatment. Accepting death allows for a greater degree of management over the feelings this evokes and the circumstances regarding how this will happen (Kyota & Kanda, 2019). However, it does not diminish the feelings of grief that one may experience when acknowledging their finality. Grief can permeate the individual's experience of being in its totality. It may be felt as a physical sensation in their body, it may be present in the interactions they have with others, and it may influence the relationship they hold with themselves (Mannix, 2020). Mannix (2020) highlights the importance of offering psychotherapy during this challenging time to support the individual with moving toward their death in a purposeful and fulfilling manner.

Some of the participants in this study spoke of their 'survival instinct' kicking in which meant they began fighting for the preservation of their life. The decision to agree to the transplant despite the odds not being great at times was part of this process for them. A study conducted by Daneault et al. (2016) found that the experience of hope in terminally ill patients was something that aided them in continuing their life despite their prognosis. Nietzsche (1895/1962, p. 468) spoke of this continued hope possessing the ability to carry anyone through the most challenging of times "*If we have our own why in life, we shall get along with almost any how*". Therefore, if the individual were aided to establish a sense of hope, this could, in turn, ease the burden of facing death.

Organ transplantation treatment does not 'secure' survival for the recipient, and when agreeing to undergo this, they must accept the risk this poses. Some of the participants in this study spoke about this decision-making process and how they weighed up the odds that were at stake. The participants shared that it was worth taking a gamble on getting an extra lease of life if the transplant was successful, against the knowledge that without this, they would ultimately die. This could be likened to Kierkegaard's (1844) 'leap of faith' in that one can never be sure if the choice they are making will pay off for them, requiring the individual to have a 'blind faith' in whatever decision they make. To achieve this, there requires an 'abandoning' of a previous state or way of being and a 'leap' with both feet into another. Therefore, each organ recipient took a leap of faith into the unknown when agreeing to undergo this risky treatment.

6.3.3 Life beyond Death

Having faced their death and narrowly escaped this through successful organ transplantation, some of the participants discussed how life changed for them having remained alive. A newfound sense of appreciation for life was experienced, and their existence took on an altered sense of purpose and meaning. Yalom (2008) asserts that in grappling with the notion of death and its inevitability, we can truly savour and embrace life. Atwater (1988) refers to a 'coming back to life' following a near-death experience, in that the individual is brought back to the living in not only a physical sense but also psychologically and spiritually. Therefore, it is essential for organ recipients to be supported in not only making sense of their experience but in adjusting to a new way of being.

A new lease of life for the participants brought with it the opportunity to accomplish possibilities that would have been extinguished at death. This experience is paradoxical as through their illness; the participants expressed the death of certain possibilities; however, through their treatment and the extended life this gave to them, there was the birth of new possibilities. Therefore, the participants would have experienced a sense of both losses and gains within their circumstances (Lange, 1992). This is important for professionals to bear in mind so they can attend to the internal conflict that may arise for the recipient. Psychotherapy and other caring professions can, at times, pay attention to the perceived negative experiences of the individual and overlook the positive. Professionals need to consider both sides of this potential conflict in order to support the individual in resolving this. Following the phenomenological principles of horizontalization and equalisation will allow for all aspects of the clients' experience to be attended to and will prevent the imposition of the practitioner's hierarchal approach (Adams, 2001).

Having faced their death, some of the participants shared how they continue to live in its shadow. The participants highlighted how they have a new profound sense of the fragility of life, which is anxiety-provoking for them. Their brush with death has left them with a taste of this and a knowledge that this could be waiting for them at any moment. The conceptualisation of death inevitably brings a sense of anxiety about one's mortality (Langs, 2004). Therefore, for organ recipients who have experienced a brush with death and continue to live in the face of this, psychological support to aid them in doing so would be incredibly beneficial.

6.3.4 The Donors' Death

The death of the donor was an aspect of the organ transplantation process that some of the participants in this study found challenging to deal with. The participants shared that they experienced a sense of grief and guilt about the donor dying and that they had benefitted from this. In the lead up to transplantation, the prospective recipients would be aware that their organ would be sourced from a deceased donor, and therefore, someone will have to die for them to receive this. However, at that point, the donor’s death is hypothetical and has not yet occurred. Once the recipient is made aware that a suitable organ has been sourced, the donor’s death suddenly becomes very real (Kandel & Merrick, 2007). The recipient is then faced with the fact that someone has died for them to live. This sense of guilt and grief is something that has been found to be a shared experience amongst organ recipients concerning not only their donor but their donor’s family (Zimmerman et al., 2016). Professionals working within the transplant population need to be aware of the fact that the recipient may well be grieving for the death of their donor and experiencing guilt as a result of their new lease of life being at their expense.

With the donor’s death in mind, some of the participants shared how this encouraged them to find a new sense of purpose and meaning in their life. Fox and Swazey (2002) stated that organ donation and transplantation is similar to the construct of gift-giving in that this process involves giving, receiving, and reciprocity. This, in turn, may lead the recipients to feel as though they are indebted to the donor, and to repay them, they strive to ‘make the most’ of their lives. Whilst this may help the recipient to find meaning within these difficult circumstances, Fox and Swazey (2002) contemplate whether this could also exacerbate the levels of guilt and stress they may experience. Therefore, this is a dynamic that professionals working with the organ transplant population need to be mindful of and where appropriate support the recipient in achieving balance with this.

6.4 Relationships Theme

This theme captured the participant's experiences of the relationships they held throughout the organ transplantation process and how undergoing this treatment may have affected these. Various aspects of the participants' relationships were highlighted including their experience of receiving care and support, engaging with other organ recipients going through similar circumstances, how the roles and responsibilities of the participant changed as a result of their illness/recovery, the experience of being isolated from others, and how the participants related to their donors. Within Existential philosophy, the social world is considered to be an unavoidable aspect of the human condition and constitutes the Mitwelt dimension of existence (Binswanger, 1958). This, in turn, means that one cannot exist without always being in relation to the other in some way, shape or form. Therefore, to not attend to the participants' experiences of their social dimension would be limiting and neglectful of their being in the world in its totality.

6.4.1 Care & Support

The organ transplantation procedure is considered to be an invasive treatment that brings inevitable hospital stays and significant physical health needs. Some of the participants in this study discussed their experience of what it was like to be cared for and receive support from others throughout this process. Relationships with staff were the primary source of care and support for the participants in the early days following the transplant surgery. There were mixed responses regarding the experiences of this with some of the participants stating that organ transplant staff focused on their physical health needs but neglected the psychological ramifications of undergoing the treatment. Various research findings stress the importance of transplant teams' understanding, acknowledging, and working with the psychological needs of recipients (Amerena & Wallace, 2009). Therefore, this is potentially an area that requires further development and implementation regarding the care and support organ recipients receive.

Some participants shared how the staff cared for them in more of a holistic manner, offering not only physical care but also psychological support. Whilst the medical profession is a caring role, as discussed in the literature review clinicians are often encouraged to form a clinical detachment to allow them to cope emotionally with the demands of their role (Austen, 2016). This can sometimes get in the way of developing connections with those they are caring for, which is required for the clinician to be alive to the emotional needs of the patient. Buber (1923) developed the concept of the I-Thou mode of relating, which involves the individual giving themselves entirely to the encounter to experience the other and their position in the world. The I-Thou mode of relating allows for one to be touched by the other's life struggles and experiences. Jaspers (1951) emphasised the concept of empathy in relating to others and how this allows for one to participate in the other's experience. He felt that by doing so, this would allow for the person's suffering or struggles to be illuminated and understood subjectively. Therefore, the staff who were alive to the emotional struggles of the participants were perhaps relating to them in a more I-Thou empathic mode. This was felt by the participants and considered by them to be a valuable part of their recovery journey.

Family members were also recognised as taking on care and support roles by the participants in this study. Focusing on how this may have affected the relationships, the participants shared that they felt this brought them closer. Assuming this unofficial caring role appeared to positively impact the quality of the relationships the family members held with the participants. Research by Reinhard et al. (2008) into family members taking on informal caregiver roles states that this is often a full-time commitment and involves significant levels of stress for the individual concerned. Whilst this proximity of care may bring people closer together; there is also recognition of the support that these informal caregivers should be afforded. Therefore, organ transplant teams should also be considering how they can best support those who will be taking on caregiving roles.

6.4.2 A Shared Experience

Sharing the experience of undergoing the organ transplantation procedure with fellow organ recipients was something that several of the participants in this study found meaningful. These participants spoke about feeling a sense of solidarity and togetherness in connecting with others who were also experiencing similar challenges. Scott et al. (2011) emphasise the importance of developing social support mechanisms for those undergoing the organ transplantation process to help them navigate and adjust to issues they may face. Support groups for organ transplant patients and their families are available through charities such as The British Liver Trust, Kidney Care UK, and the British Heart Foundation. Brennan (2016) reported that from a survey of over 800 organ transplant recipients 75% of them reported feeling more confident when speaking to medical professionals after using online peer support, and a third said they see their GP less since having access to this. Therefore, peer support and group work should also be drawn upon by professionals working with this population.

Connecting with others who are going through the organ transplantation process is not only centred around receiving support but also allows the individual to offer this. Some of the participants spoke of how they found offering support to fellow organ transplant recipients meaningful and allowed them to experience a sense of giving back. As discussed within the literature review, the gift metaphor regarding the donated organ has received criticism that this creates a sense of uncomfortableness for the recipient due to being unable to fulfil the reciprocity role in gift-giving (Campion-Vincent, 2002). Therefore, it appears that the participants have come some way toward resolution by giving back to fellow recipients in place of the donor. This strategy could be utilised by professionals working with those who are struggling with the sense of indebtedness to their donor in which they are encouraged to consider an alternative way of fulfilling their role in the gift-giving construct.

6.4.3 Roles and Responsibilities

The change to roles and responsibilities as a result of the presenting physical health needs that the organ transplantation treatment imposes was something that was highlighted as challenging for some of the participants in this study. The expectations held by the individual to fulfil certain roles and responsibilities they previously held brushed up against the reality of what their physical health needs allowed them to do. Encountering these newly found limitations in their life felt jarring, dislocating, and uncomfortable. A study conducted by Frazier et al. (1995) found that organ transplant recipients displayed higher levels of stress during the period of readjustment into family roles than other members. This may have been owed to the fact that the recipient possessed expectations for themselves in returning to previous roles and responsibilities that may not necessarily be an option for them at that time in their recovery period or may no longer be a possibility at all (Christopherson, 1987). Therefore, psychotherapeutic work should include an aspect of offering support to organ transplant recipients in readjusting to their roles and responsibilities.

The period of readjustment does not lie solely with the recipient but also with others that are implicated in these changing roles and responsibilities. In a study conducted by Shapiro & Kornfeld (1989) they found that organ recipients returning to the family can cause conflict and dysfunction with how this operates, whilst Grundbock et al. (1992) found that families functioned reasonably well following the patient undergoing the transplant procedure. This disparity in findings shows that families cope with issues such as the organ transplantation process in a fairly idiosyncratic way. Professionals working with this population need to be alive to how the patients' chronic illness and organ transplant treatment may affect the social systems they exist within, and the role in which the recipient is able/desires to fulfil (Paris & White-Williams, 2005).

6.4.4 Isolation

Due to the transplantation procedure involving hospital stays, some of the participants discussed how they were isolated from their friends and families during this phase and disclosed that it was emotionally challenging for them. Within Existential literature Yalom (1980) refers to this as interpersonal isolation when an individual is separated from others. People are inherently relational beings, making existence impossible without this dynamic. This, in turn, means that people live in a constant state of tension between togetherness and isolation. When any one of these positions is neglected, the individual will find themselves craving this in order to restore balance (Deurzen, 2010). Therefore, isolation becomes an uncomfortable experience, and the desire for togetherness grows in intensity, creating a source of discomfort for the individual until this is resolved. Research conducted by Abad et al. (2010) into the adverse effects of isolation in hospitalised patients, found that these periods of isolation significantly impacted the individuals' emotional well-being. There was also a higher prevalence of depression, anxiety, and anger experienced among patients who were isolated. Professionals who have access to organ recipients during these periods of isolation should bear this in mind and support the recipient in managing the impacts of being away from their homes, families, and friends.

Isolation was reported to not only occur in the hospital setting but also when the recipient returned home. Some of the participants discussed how they initially became housebound due to their physical health needs and recovery period. This resulted in them feeling a sense of detachment and isolation from the rest of the world. In a study conducted by Bedard-Thomas et al. (2019) exploring the perspectives and experiences of social isolation in housebound patients, it was found that this distancing from the social dimension led to feelings of loneliness. This was in turn exacerbated by factors such as a loss of friends, inability to socialize in person, a lack of family support, and fewer human interactions. It is important for the field of psychotherapy to consider creative ways of reaching those who are not able to leave their house potentially and for this support to be made accessible to those who find themselves in this position. This may particularly relate to organ recipients prior to undergoing transplantation when their physical health has deteriorated significantly and following transplantation surgery during their recovery period.

6.4.5 The Donor

In the case of live donation, the donor is usually known by the recipient and will be someone with whom they are emotionally involved (Randhawa, 2012). This subsequently will mean that the recipient possesses a relationship with their donor prior to this occurring and throughout undergoing this procedure together. One of the participants in this study shared how their relationship with their donor was, at times, quite challenging to navigate due to the fact this person had saved their life. They described how they initially experienced guilt in relation to 'normal' feelings of irritation or frustration in this relationship and that this new dynamic took time to adjust to. Research conducted by Santos & Massarollo (2005) found that live donation under these circumstances can create ambivalent and contradictory feelings in both the recipient and the donor due to the expectations that are generated by both parties. Therefore, it is recommended that in live donation cases that involve this relational quality, that awareness of the potential impacts this may have on the donor-recipient relationship are noted, and appropriate psychosocial interventions are offered to manage/limit these.

In the case of a donation from deceased donors, some of the participants within this study discussed how they had formed a relationship with their donor that exists solely in their psychological domain. The participants embarked on this by reaching out to the donors' families, to express gratitude and in the hope to elicit information about their donor. This almost served as a means of forming a relationship with the donor in a vicarious manner. Research conducted by Annema et al. (2013) found that many organ recipients wish to gain knowledge of their donor due to this being the person who is responsible for their new lease of life. However, this may not always be the wish of the donor's family, and the recipient may be left with the feeling of curiosity and uncertainty regarding who their donor was and what they were like. Therefore, therapeutic work conducted with the recipient may involve coming to terms with the donor being a mystery and how the recipient can reconcile their desire to have some form of relationship with them.

Finally, the recipient may begin to relate to the donor as being on the same continuum as their own sense of self. Some of the participants in this study spoke about their donor becoming a part of them and that they live on within the recipient. This particularly appeared to be the case when the participant reported changes in their characteristics that they attributed to the imagined characteristics of their donor. As discussed in the literature review, transplant patients often project their post-transplant characteristics onto their representation of the donor, thus attributing changes within themselves to the result of inherited characteristics (Sanner, 2001). However, Pearsall et al. (2002) and Wright (2008) argue that heart transplant recipients can change as a result of transplantation due to memory being stored in cells of the body and that these memories could be incorporated into the recipient's personality and sense of self. Bunzel et al. (1992) attribute these changes within the recipient to experiencing a life-threatening event, and it is living through this that created a shift in how the person relates to themselves. This study wishes to highlight that regardless of whether the recipient has indeed subsumed memories and characteristics from the donor, or whether this is as a result of change within themselves, the recipient needs to be offered adequate support from professionals to adapt to this change in self-concept.

6.5 Temporality theme

This theme captured the participants' experiences of time throughout the organ transplantation process. Three distinct experiences of time emerged from the participants' accounts, these being waiting for the transplant, things happening quickly, and life after transplant. As discussed in the literature review, time is an intrinsic aspect of the human condition so much so that existence itself could be considered to constitute the stretch of time between birth and death (Cohn, 2000). Heidegger (1962) stated that temporality and the experience of time is the horizon against which all aspects of being can be understood. Man is essentially time itself as opposed to being situated within this. We are projected through time and are relatively unaware of this until moments occur that draw our attention to this. Therefore, we cannot consider existence without turning our attention toward the experience of time. It is worth noting that in relation to literature held on organ transplantation from the perspective of the recipient, temporality and the relationship with time throughout this treatment appears to be the least researched of all the themes that emerged from this study.

6.5.1 Waiting for the transplant

Having been found suitable for transplantation and consenting to undergo this, the prospective organ recipient is then placed on the waiting list. From this point onward the time which it will take to source a suitable organ is unknown; therefore, the time spent on the waiting list cannot be predicted. For several of the participants in this study, their wait was a significant time, which they found challenging to manage. Being on the waiting list has been described as a time of tremendous uncertainty and vulnerability, posing unique challenges and stressors for all those involved in the organ transplantation process (Anthony et al., 2014). Many factors are at play in exacerbating this, such as living with end-stage organ failure and uncertainty about the future (Transplant living, 2020). Not only does longer waiting time affect the recipient psychologically, but it has also been shown to adversely impact the chances of the patient and post-transplant graft survival (Meier-Kriesche et al., 2000). Not much can be done in regard to shortening time spent on waiting lists as available organs arise spontaneously. However, professionals are able to invest time and space in psychologically caring for recipients during this challenging period.

In a study conducted by Brown et al. (2006) exploring the experience of waiting for a liver transplant, it was found that a new perspective on time emerged for the recipient upon being placed on the waiting list. They found that the patient began consciously considering time in a multitude of ways, such as the amount of time they imagined until transplantation and the time they imagined after transplantation. Being on the waiting list also became a way of life for some, and this experiential sense of waiting became habitual for them. Professionals working with this population should be aware of the stressors involved in waiting for a suitable organ to be sourced. Psychotherapeutic work in this phase could help the recipient bear the burden of waiting and help them prepare for when that time eventually comes.

Being on the waiting list for some of the participants in this study was akin to putting their life on hold and became time-consuming for them. Several of the participants discussed how they were unable to spend their time freely as they had to be in a constant state of readiness for when they received the call notifying them of the sourced organ. The participants also discussed how they were trapped in a paradoxical situation in that they wanted to put the waiting out of mind, so they were able to continue with their lives; however, this always had to be kept in mind, so they were available for the surgery. Support should be afforded to helping the recipient find a way of living in the face of this and adapting to the challenges that this phase of the organ transplantation process inherently brings. The individual should be aided in finding a way of being that is meaningful for them, with the least amount of disruption to their life as possible (Offer et al., 2007).

6.5.2 Things happening quickly

Once a suitable organ is sourced the candidate who this has been matched to will receive a call advising them to make their way immediately to the appropriate hospital site. Several of the participants discussed how they found this process extraordinarily abrupt, and that time appeared to speed along from the moment they got their call. This is necessary due to the short shelf life of harvested organs; however, it does not mean that the recipient avoids the emotional impact of this abrupt process. The unpredictability of the timescales involved in waiting for the organ transplant to occur coupled with the hastiness in which the recipient is expected to attend the hospital is more than likely to add to the feeling of shock and abruptness of this situation. A study conducted by Davydow et al. (2015) recognised that the shorter the length of time between waiting for the transplant and undergoing surgery is a factor for the development of post-traumatic stress disorder in organ recipients. Therefore, the abruptness with which this procedure can occur for some has been observed to contribute to significant psychological distress.

From the moment the recipient receives the call advising them of a suitable sourced organ, the organ transplantation procedure is set into motion, and this does not pause until after the surgery has been conducted. Some of the participants in this study discussed a sense of getting swept up by this passing of time, and in turn, they felt launched towards a significant event (the surgery) within a small window of time. The participants felt that this did not allow them to come to terms with what was going to happen to them or orientate themselves during the process. Proper and adequate preparation prior to this process occurring would greatly benefit the recipient in managing this occurrence (Vitin, 2019).

The abruptness of the surgery was not wholly negative in the eyes of some of the participants. They discussed how not getting time to process things also meant they did not have time to ruminate on the situation. Wolfradt et al. (2014) have observed a relationship between health anxiety and rumination, which is frequently detected by professionals working within health care settings. Zhang et al. (2019) found that depressive symptoms are common among kidney transplantation recipients and that rumination is one of the contributing factors. Therefore, the immediacy of the organ transplantation process could also prevent the individual from having time to ruminate and in turn help to mitigate the influence this style of thinking has over the psychological domain of the recipient. It is recommended that professionals working with the organ transplantation population are open to exploring the idiosyncratic relationship the recipient has developed with time during the lead up to undergoing their surgery. Professionals should also be exploring what meaning this relationship with time holds for the individual and what repercussions have occurred as a result of this.

6.5.3 Life after transplant

Having undergone the organ transplant surgery, and it is deemed as a success, the organ recipient is now considered to be medically stable, and their end-stage organ failure is being managed. Several of the participants shared how they developed a new relationship with time and subsequently, how they engaged with their life. The participants spoke of conceiving their new lease of life as extra time on the clock for them that they would not have had if it were not for the transplant. Organ donation and transplantation provides the opportunity for those with end-stage organ failure to live beyond their death by providing a new vitality to their physiological self (Moritsugu, 2013). How the recipient experiences this 'extra time' should be considered within the support professionals provide to them.

Having received a new lease of life, some of the participants spoke about how they felt their life was able to 'resume' or 'recommence'. A study by Hricik et al. (2001) exploring life satisfaction in renal transplant patients post-surgery found that as a result of physical health needs being less demanding and the anxiety concerning a terminal prognosis being taken off the table, recipients were able to 'get back' to purposefully living their life. Satisfaction with life was found to be most predominately associated with the feeling of being in control over physical health needs and the ability to engage in a 'normal' active life. Therefore, post-transplant recipients may feel as though they are in a position to resume life, and subsequently, their relationship with time takes on a new presentation. Coping with life being put on hold and resuming this as soon as possible following transplantation should be considered by all staff working to support this population.

Finally, having undergone successful transplantation treatment and having faced their death, some of the participants shared how they live more presently than they have previously. They discussed how they no longer ruminate over past events or contemplate what the future has in store for them as much as they may have done prior to their transplant experience. The participants appear to have concluded that the past cannot be changed, and the future is not promised; therefore, the present is the only time the participants can directly access and control in some manner. Research conducted by Årestedt et al. (2014) exploring living with chronic illness found that those suffering from this find a new rhythm to their life. Their life may move at a slower pace or may involve scheduling more time for things than before. This new rhythm also embraces a change towards being more focused on the present. Therefore, psychotherapeutic work with this population should explore the recipients' new rhythm to living and how this manifests itself for the individual.

6.6 The Psychological theme

This theme captured the participants' experiences of their inner world and how they relate to themselves throughout the organ transplantation process. Several aspects emerged for the participants: facing the unknown, choice and control, and coping. Within Existential philosophy, the personal dimension, otherwise known as the Eigenwelt, relates to the relationship one has with themselves. It encompasses the private inner world people possess and create through self-reflection. Through exploring the personal dimension, it is hoped that the individual's strengths and weaknesses will be illuminated, allowing them to proceed with their being in the world in a way that is meaningful for them (Deurzen, 2010). Therefore, to fully explore the experience of undergoing the organ transplantation procedure and how this may affect the recipient's life, we must consider the individual's private inner world.

6.6.1 The Unknown

Kidd and Hayden (2015) describe the human tendency towards understanding and knowledge as an insatiable demand for knowledge pervading our everyday existence. When this is applied to our conceptualisation of human existence, more specifically our own 'fate', we are met with an overwhelming sense of existential anxiety (Hersch, 2015). Not knowing what the future holds or how things will unfold for us is an ontological concern presented to us all. Uncertainty appears to be more prominent when an individual brushes up against other ontological concerns such as sickness, health, and mortality. The organ transplantation process held great uncertainty and was something that several of the participants highlighted as being quite challenging for them. Martin et al. (2010) conducted a study identifying sources of uncertainty for the organ recipient across the transplantation process and found these to relate to insufficient information about the diagnosis, complex decisions about transplantation, unknown/unknowable organ availability, unclear expectations about medical procedures/outcomes, ambiguity in the meaning of life, complex role and identity challenges, unclear financial consequences, questioning from others, and unclear relational implications. Therefore, where possible professionals should be clearly articulating information about the transplantation treatment in order to attempt to alleviate some of the concerns recipients may have around not knowing.

The unknown continues to hold a presence in the recipient's life beyond that of the initial transplantation procedure. Having undergone successful surgery, the participants discussed how they continue to worry about things such as how long the organ will function and how much longer they have in life. Stone et al. (2013) urge professionals to support individuals with the uncertainty undergoing the organ transplantation process holds and that a 'one size fits all' approach cannot be adopted. Idiosyncratic issues that arise for the individual when facing the unknown should be explored within psychotherapy to aid the recipient in bearing this burden and to feel resilient in the face of unavoidable uncertainty.

6.6.2 Choice and Control

The ability to have choice and control over certain aspects of being in the world is an important plight for everyone (Sartre, 1943). Specifically relating this to health care, research by Auerbach (2001) has shown that patients want control over their care when they feel this would be beneficial for them. Several of the participants discussed how much control they felt they had during the organ transplantation process and the choices with which they were faced with. The initial choice presented to the participants was whether or not to undergo the transplant treatment, which has serious risks and chances of complications, such as the death of the graft or patient. Following this, the recipient is faced with many choices to make about their treatment journey and recovery period. A study by Kennedy et al. (2007) highlights the importance of involving those with chronic illness in making informed decisions about their treatment and reveals how doing so helps the individual to manage this process as best as they can. Involving organ recipients in making choices concerning their healthcare should be the standard concerning the care provided. Psychotherapy can help the individual to process these often-difficult decisions. Allowing the individual to remain autonomous throughout their chronic illness is key to them finding meaning in this respect.

Another aspect of choice that was highlighted in this study was in regard to accepting care from medical staff. Some of the participants described this in a passive manner stating that they had to abandon their control over the situation to allow the transplant team to look after their significant physical health needs. Sartre (1943) purports that every stance or position taken in the world is done so through choice; therefore, not making a choice is still a choice. With this in mind revisiting the participants' accounts of taking a passive stance to be cared for was still a way in which they exercised autonomy. Lack of choice becomes an illusion, which may prove helpful for the individuals who felt 'out of control' during this process. Research conducted by Michael (1996) into integrating chronic illness into the individual's life found that helping the recipient to gain a feeling of control over their altered life course was important to the individual's wellbeing. Psychotherapy could aid the organ recipient in identifying the choices they made throughout this process, helping them to feel a sense of control in a situation that previously may have felt haphazard and unpredictable.

6.6.3 Coping

The organ transplantation process brings substantial demands on the person both physically and psychologically. The recognition of the need to support the individual in developing ways to cope with these demands is growing (Collins & Labott, 2007). Several of the participants discussed how they coped throughout this challenging and life-changing process. An aspect of this was how they coped with receiving the news of their illness and the need for transplantation. Some of the participants experienced difficulty in accepting this news and integrating this into their sense of self. Research conducted by Bombardier et al. (1990) found evidence that adaption to chronic illness could be influenced by psychological factors such as how the individual appraises their illness and how able they are to cope with the stressors this inherently brings. This holds important implications for psychotherapeutic work with the organ transplant population in that there should be support afforded in helping those adapt to and accept the status of their physical health (Burker et al., 2005).

The participants that felt they coped well undergoing the organ transplantation process drew on strategies such as spirituality, relationships, maintaining control over their lives, and ways of conceptualising the transplant itself. A study conducted by Lindqvist et al. (2004) highlighted the importance of aiding organ recipients in developing their own adaptive ways of coping with this highly stressful treatment. They purport that staff working with this population should assess the individual's coping strategies, so they can support the development of those that are likely to be useful and discourage maladaptive strategies.

An important factor in coping with the organ transplantation process was the faith that the participants placed in the medical profession to treat their illness successfully and essentially save their life. Science and medicine have proven effective over the years in saving those with chronic and terminal illnesses such as end-stage organ failure. Therefore, society places faith in medicine and this profession to sustain their life and health (Nolte & McKee, 2004). However, as previously discussed, this still requires the individual to take a leap of faith in trusting that the option they have chosen will prove best for them.

6.7 Contribution of this research

This discussion chapter will now outline what I believe to be the original contribution of this research to the existing literature and knowledge held on the lived experience of undergoing solid organ transplantation. In order for research to be considered as contributing something original, the findings need to be a meaningful extension of the boundary of knowledge held regarding the phenomenon under investigation (Might, 2010). I believe this research accomplished this in two ways. By approaching the organ transplant population as homogenous, which has previously not been the case; it aimed to create a synthesis of the existing knowledge concerning this lived experience. Secondly, this research has 'tested' existing knowledge in an original manner by approaching this from an Existential Phenomenological perspective. I have considered the findings from this research within this philosophical perspective and have also offered ways in which the organ recipient's struggles could be conceptualised and navigated within the psychotherapeutic space.

I will now outline some of the observations this study has made which appear to be original in relation to what we already know about the lived experience of organ transplantation. The subsequent sections within this discussion chapter will build on this further by discussing ways in which this research study's findings may implicit psychotherapeutic work from an Existential Phenomenological perspective.

Embodied experience

- Disorientation from felt sense to fact.

Some of the participants in this study reported a sense of shock or disbelief upon being told they had organ failure and required transplantation. This was due to the fact they did not experience symptoms of sickness and therefore assumed they were in good health. Upon learning that this was not the case, they experienced disorientation in relation to their felt sense no longer reliably guiding them through life and the world. The process of homeostasis is a regulatory mechanism in physiology, responsible for maintaining the complex internal environment of all living things upon exposure to different environments encountered (Modell et al., 2015). What happens if this mechanism 'fails' and does not alert us to something 'wrong' and the exact method we intrinsically use to maintain life no longer becomes reliable. This appeared to be very unsettling for the participants in this study and made accepting the reality of the situation a more arduous task for them. Felt sense and fact become alienated from each other, and the individual appears torn between which position to 'trust' and assume. This feeling of disorientation from the felt sense to fact appears to have not been highlighted within the organ transplantation population. It, therefore, should be awarded further consideration in order for us to illuminate the essence of this lived experience in its entirety. It is also worth noting that this may be contributing to the psychological distress experienced in organ transplant recipients and therefore holds implications for psychotherapeutic work.

- Hospital environments – healing or hindering?

The environments in which the transplantation takes place and initial aftercare is conducted in were raised as a significant factor in some of the participants lived experienced of this treatment. The participants felt that the hospital environment took ample care of their physical needs but neglected the healing nature of psychological needs. Acknowledging that hospitals are geared around physical healthcare, this finding raises the question as to whether there is anything that can be done about the provision of physical health, so this is more therapeutically orientated. Research by Huisman et al. (2012) explored the impact of physical environments on the healing process and patient wellbeing. It was found that health care facilitates play a significant role in either promoting or hindering recovery and wellbeing. This finding appears to apply to the organ transplantation population, evidenced by the accounts provided in this study. Therefore, this has important implications for hospital transplant teams and how they can limit the detrimental impact of this environment on the recipients' recovery.

- The Organ - to integrate or to not integrate?

Previous research has purported to the importance of integration regarding the recipient’s transplanted organ (Latos et al., 2015). Integration of the new organ is considered to be essential to the psychological wellbeing of the individual concerned (Consoli, 2012). The process of integration involves the recipient subsuming the organ into their sense of self and in turn, making the organ a ‘part’ in their ‘whole’ (Achille et al. 2006). However, some of the participants in this study suggested that they have been able to coexist with their new organ without this necessarily being accepted into their sense of self. Could it be the case that recipients may be able to live alongside their organ, accepting that this is not a part of them but simultaneously becoming at ease and comfortable with the organ’s presence in their life? This may fit with the proposition that I have raised within this research that organ recipients should be supported in developing idiosyncratic ways of managing this treatment process, their sense of self, and conceptualising their new organ. Further research into this type of relationship with the transplanted organ could offer insights as to whether this is a possibility, without being a factor that contributes towards psychological distress encountered. If this is the case, then perhaps metaphors around ‘gift-giving’ and ‘spare parts’ may not be the standard way forward in helping organ recipients come to terms with transplantation.

Life & Death

- Organ transplantation - The Birth of Possibilities.

Organ transplantation treatment is a life-saving procedure for those who are considered to be in end-stage organ failure (Grinyó, 2013). In being given a new lease of life, the recipient is provided with opportunities that would not have been available to them without this treatment. The birth of possibility is an aspect of organ transplantation that the participants in this study highlighted as an important facet of their lived experience. All of the participants discussed the possibilities they have been able to achieve through undergoing the transplant procedure, whether this is concerning their careers, family, or social domains. One participant highlighted the notion that through their life being saved by transplantation, the donor inadvertently saved the potentiality of their children's lives. At the time of the participant's first transplant, they did not have children; however, as a result of this occurring and being a success, they now have a family. I feel this can be likened to that of the butterfly effect in chaos theory, in that a small change in one state can result in a large difference in a later state. Changes in initial conditions can create significantly different outcomes (Shenker & Stanford, 2014). This is a powerful notion when related to organ donation, and the potentiality lay ahead of this decision. One cannot fathom the degrees to which they have created change in the universe from deciding to donate, giving rise to an infinite number of possibilities. This very compelling argument could be of use to the campaign led around increasing donor rates and also supporting organ recipients in the process of actualisation for the life lay ahead of them.

- The Donor's death – how to grieve for a stranger.

Previous research has discussed how organ recipients can experience feelings of grief about their donor and that this grief can play a part in the psychological distress recipients may face throughout the transplantation process (Poole et al., 2016). Whilst previous research has recognised this bereavement process; not many have considered the nature of this fully. Some of the participants in this study expressed grief for their donor and that this went beyond the recognition that someone had died, such as acknowledging the anniversary of their donor's death in the years that have followed transplantation. This raises the question as to how the recipient navigates the bereavement process for someone who they never knew and someone who remains a relative stranger to them. Does grief become more complicated because the subject of loss is not necessarily tangible to the recipient? The grief experienced for the donor's death is also intertwined with the recipient's survival, so this adds a further dynamic to this experience. Complicated grief is a recognised mental health condition which has been seen to affect around seven per cent of bereaved people (Shear, 2012). Does the nature of the donor's death make organ recipients more susceptible to experiencing complicated grief? I believe that this deserves further consideration in order to allow professionals to better understand the nature of the organ recipient's grief and in turn, how to work with this psychotherapeutically.

Relationships

- Giving back to fellow recipients – a way of overcoming reciprocity issues.

As discussed within the literature review, the gift metaphor regarding the donated organ has received criticism that this creates a sense of uncomfortableness for the recipient due to them being unable to fulfil the reciprocity role in gift-giving (Campion-Vincent, 2002). Despite this, transplant teams continue to use this metaphor, along with the 'spare part' to help organ recipients come to terms with their new organ. If this metaphor is going to continue in use, then ways of overcoming its limitations must be considered. The participants in this study appear to have come some way toward the resolution of this conflict by giving back to fellow recipients in place of the donor. Many of the participants discussed how helping others to get through this challenging treatment journey provided them with a sense of purpose and meaning about what they had experienced. They discussed how this also allowed them to feel a sense of 'giving back' following receiving their gift of life. This strategy could be utilised by professionals working with those who are struggling with the sense of indebtedness to their donor in which they are encouraged to consider an alternative way of fulfilling their role in the gift-giving construct. Engaging in peer support could be a practical and feasible method of resolution for the recipient.

Temporality

- Time flies – from sourced organ to surgery.

Upon being found suitable for transplantation, the recipient is placed on a waiting list to await a call to advise them that an organ has been sourced. The time spent on this waiting list is unknown to all, and subsequently, previous research has defined this stage of organ transplantation as highly stressful and fraught with uncertainty (Brown et al., 2006). Once a suitable organ has been sourced, due to the short shelf life of harvested organ viability, the recipient is expected to attend the hospital site to undergo the procedure in a brief period of time. A heart or lung can be kept viable for transplantation for only six hours; this gives the reader some indication as to how quickly this procedure has to occur. Whilst this hastiness is unavoidable, research into the experience of this, along with the ramifications of this window of time is limited. Some of the participants in this study spoke of how this expediency from the point of receiving the call to going into the operating theatre was a shock to the system, leaving lasting impacts upon them. Research into PTSD in the organ transplant population has shown that this is more prevalent in those who experience shorter waiting times between assessment for transplantation and the procedure occurring (Davydow, Lease, & Reyes, 2015). Therefore, further research into the lived experience of the organ recipient during this window of time from call to surgery would help to illuminate the challenges they face with this and how professionals can best support them in managing this.

The Psychological

- A different approach to conceptualising Anxiety.

Undergoing the organ transplantation treatment journey is ridden with anxiety for the recipients in relation to a multitude of factors across the bio-psycho-social-spiritual dimensions (Gross et al., 2010). Many of the participants in this study reported that they experienced anxiety concerning the transplantation treatment process at some point within this, with a few participants reporting to continue to experience this in some manner. Whilst many studies surrounding anxiety experienced by organ transplant recipients pertain to the state or trait anxiety model (Spielberger et al., 1999), this research project moves towards the conceptualisation of anxiety from an Existential perspective. State or trait anxiety allows for the appreciation to the origin of the anxiety or what may be a causal factor in the experience of this; however, it does not attempt to delve into the nature of this in the same way existential anxiety does. State anxiety is considered to constitute as anxiety that is induced by a particular circumstance, whereas trait anxiety is considered to be underlying anxiety experienced as a result of the individual's characteristics and cognitions (Leal et al., 2017). Existential anxiety is considered to occur as a result of the acknowledgement that life is unpredictable, fragile, and uncertain (Deurzen, 2010). Whilst it may be helpful to ascertain to what degree the organ recipient is anxious as a result of their treatment or their personality, it feels more appropriate to acknowledge the magnitude of their anxiety from an existential perspective. The accounts from the participants in this study appeared to fit more comfortably with existential anxiety caused as a result of them having to contemplate their own mortality and how their life is hanging in the balance. Therefore, in the way of anxiety, this research offers the notion that an Existential perspective feels like a more appropriate fit for the organ recipient's experiences of this.

6.8 Particularities of solid organ transplants revisited

This section of the discussion chapter will now move from a general consideration of the findings in relation to the literature held across organ transplantation types, to reflect on these findings in comparison to the particularities of organ-specific literature. I will revisit the information presented on specific organ particularities in the literature review chapter of this dissertation to establish what we can learn from this research project's findings. Having approached organ transplantation as a homogenous population, considering this in light of organ-specific research findings will help to highlight similarities and convergences across this body of knowledge.

Psychological distress has been shown to occur more frequently in heart transplant recipients with up to 60% developing anxiety disorders within the first year following transplantation, in comparison to 20% of kidney and 30% of liver (Favaro et al., 2011). Whilst this may be the case, psychological distress in other organ types must not be overlooked. The participants in this study reported experiencing distress concerning the organ transplant treatment process from a variety of organ types. This finding, therefore, supports the notion that psychological distress can occur across the organ types considered within this research piece. In turn, professionals working to support this population need to be alive to the recipient's experience of distress irrespective of organ type.

Research has shown that organ recipients can report changes to their characteristics and sense of self post-transplant. It has been shown that this most often occurs in heart transplant patients, potentially due to the concept that memory is capable of being stored in cells of the body and that these memories could be incorporated into the recipient's personality and sense of self (Pearsall et al., 2002; Wright, 2008). How the heart is culturally conceptualised as the locus to the soul also adds to this dynamic (Svenaeus, 2012). Regardless of the origin of these changes, within this study, participants from across the organ types, more specifically kidney and lung, discussed the notion of inheriting characteristics from their donors. Whilst the participants in this study did not report any distress originating from this experience, many recipients have found this shift in the sense of self unsettling. This is an important implication for professionals working with this population, one of which they need to be aware of in order to provide support where necessary. Other organ types can facilitate a change in how the recipient relates to themselves, and therefore the nature of these changes should be considered further.

Within the literature held on heart transplantation, recipients have reported to experience a sense of loss and grief in relation to the donor’s death. This may relate to how the heart is conceptualised as the boundary between life and death, therefore emphasising the fact that someone has died in order for the transplantation to be possible (Rauch & Kneen, 1989; Kaba et al., 2005). Within this study, participants from a range of organ types expressed a sense of loss and grief for their donor’s, meaning that this experience does not belong solely to heart transplant recipients. Where there is a loss, grief is always possible; therefore, transplant teams need to be alive to the recipient's experience of this, understanding that this can occur across a range of organ transplant types in which donation from a deceased donor has occurred.

An aspect of heart transplantations that has been considered to not necessarily relate to other organ transplants is the felt sense of the heart functioning on a constant basis. The recipient experiences the heart beating, with this speeding up during times of exertion, and slowing down during periods of rest and recovery. The sensation of the heart is a constant, relentless reminder of its presence (Svenaeus, 2012). Within this study, a participant who had received a lung transplant reported the same felt sense of the functioning of their lungs, the sensation of breathing is a constant and this changes with activity. To make this point further, lung transplant recipients almost possess a heightened felt sense of organ function than heart transplant recipients do due to fluctuations in the experience of lung function both before and after transplantation. Heart transplant recipients experience their heart beating but may not necessarily experience a felt sense of this failing as much as lung transplant recipients do. This finding, therefore, supports the notion that literature held around the experiential sense of an organ functioning also relates to lung transplantation, not just heart transplantation.

Quality of life is considered as a goal of treatment when undergoing organ transplantation, with research showing that this increases across all organ types in some way shape or form (Burra & De Bona, 2007). Literature held surrounding this suggests that quality of life may improve more imminently for lung transplant recipients due to the immediate gain in physical function (Gross et al., 1995). Within this study, participants who received other organs, in particular kidney, discussed how their quality of life improved significantly and immediately following transplantation. The participants spoke of having to engage with time-consuming treatment prior to transplantation such as dialysis, and the symptoms of kidney failure resulting in chronic constant headaches. Having received transplantation, the participants were immediately set free from the chains of dialysis and headaches, resulting in a perception of the quality of life improving immediately. Therefore, this finding may also apply across organ types, potentially depending on the level of debilitation, and pre-transplant maintenance carried out by the recipient.

Body image concerns have been raised as a significant factor in liver transplantation due to the fact that liver recipients are most perceptible to post-operative weight gain than any other organ type (Beckmann et al., 2017). Some of the participants in this study discussed body image concerns both before and after transplantation. The participant who had received lung transplantation discussed how the weight loss associated with illness was very unsettling for them, and that post-transplant weight gain improved their relationship with their body. The participants who had received a kidney transplant spoke of surgical scarring and detrimental changes to their body as a result of the immunosuppressive medication. One of the participants who received a liver transplant did not speak of post-operative weight gain but discussed body image concerns in relation to post-operative surgical scarring. Therefore, these findings help to highlight that body image concerns can occur across the solid organ types, for several different reasons, resulting in a number of different perceptions of self.

Kidney transplants are the primary type of solid organ transplantation that can originate from a living donor. Live donation has become the preferred method of kidney transplantation due to this holding advantage over deceased donation when considering time frames of transplantation and long-term survival of graft and patient (Davis, & Delmonico, 2005). Whilst some live donations are anonymous, the most frequent source of kidney donation is made from someone known to the donor. Very few studies have explored what impact this may have on the relationship between donor and recipient. Research conducted by Simmons (1981) found that in these circumstances, the relationship between donor and recipient was reported to function more effectively following a successful outcome of transplantation. Simmons

(1981) also found that adverse post-operative outcomes impacted donor-recipient relationships. The participant in this study who had received a donation from a live donor discussed experiences that supported these findings in that they reported challenges in navigating the relationship held with their donor post-transplantation. Due to advancements in the field of organ transplantation, the possibility for live donation has been opened up to liver and lung transplants. This means that live donation is no longer reserved for kidney transplantation alone; therefore, the issues surrounding live donation recipient-donor relationships may apply across these organ types.

From revisiting the literature held on particularities around specific solid organ types, it appears as though the findings from this study support the notion that literature held on organ transplantation can be largely applied across the different organ transplantation types. This supports the notion that solid organ transplantation could be seen as a homogeneous population, with nuances in experiences 'separating' organ types as opposed to these being considered as significantly different phenomena to be explored and conceptualised independently.

6.9 The Four Dimensions – A theoretical framework

I will now turn towards considering the findings of this research project within a theoretical framework borrowed from Counselling Psychology, more specifically, Existential philosophy and psychotherapy. I chose to utilise the four dimensions of existence set forth by Emmy Van Deurzen (2010). My reasons for choosing this particular framework is as follows; firstly the four dimensions are considered to be a 'blueprint' of human existence, meaning that all aspects of being can be 'mapped' onto these (Deurzen, & Arnold-Baker, 2005). Subsequently, this provides the breadth of consideration to human experience needed in order to contain the findings from this research adequately. Secondly, the four dimensions can be used as a heuristic device within the research method Structured Existential Analysis in order to allow the researcher to understand the lived experience of a phenomenon and to systematically explore this (Deurzen, 2014). Thirdly, the four dimensions can be and have been used as a method of conceptualising, formulating, and navigating life struggles within psychotherapeutic work (Deurzen & Arnold-Baker, 2018). Therefore, I feel the four dimensions theoretical framework allows for a smooth transition from research findings to therapeutic intervention. This allows me to attempt to bridge the gap from research findings to psychotherapeutic work, something of which is required if this research is to help guide professionals in supporting the organ transplantation population.

Deurzen (2010, p135) describes the four dimensions as follows; "*Umwelt – the physical, natural, material domain. Mitwelt – the social, public, cultural domain. Eigenwelt – the personal, private, psychological domain. Uberwelt – the spiritual, interpretive, ideological domain*". A more comprehensive overview of the four dimensions has been included within the appendices (appendix 12) as I believe this is a useful illustration for practitioners wanting to understand and work with this theoretical framework (Fraser, 2020). The splitting off of human existence into the four dimensions is purely that of an intellectual task for the purpose of grappling with the totality of being. Therefore, whilst discrimination has been made between the dimensions, caution should be given regarding this being an accurate representation of human existence. The four dimensions are inextricably bound up with each other, and therefore issues will echo through them all (Deurzen, 2010). Temporality does not fall into any one dimension; instead, this is considered to be experienced in flux throughout them all (Deurzen, 2014).

This research project's findings will now be considered in light of the four dimensions of existence. The superordinate theme titles have been 'abandoned' for this consideration, and the superordinate themes have been collected into 'new' categories representing each of the four dimensions. It is worth stressing that this is my interpretation of how these research findings can be considered within the theoretical framework of the four dimensions of existence; therefore, this is open to further interpretation.

Physical dimension (Umwelt)

Illness and Wellness - This theme relates to the participants' physical experiences of being ill and well throughout the organ transplantation process. The theme considers the experience of pain, medical procedures and practices, complications, and the recovery period.

Being in the world - This theme relates to the participants’ experiences of being in the world. The prominent features highlighted within this theme were uncertainty about the world, changes in physical states brought about by medication, and the environments participants experienced when undergoing the organ transplantation procedure.

Change to the physical self - This theme relates to the participants’ experiences of their physicality changing in some way as a result of the organ transplantation process, encompassing physical changes to the body itself, body image, limitations, and gains to physical function.

The Organ - This theme relates to the participants' experience of receiving a new organ and their relationship with this.

Facing death - This theme relates to the participants’ experience of facing their death. This encompasses the experience of being told they were terminal, considering the transplant treatment, how they coped with facing death, and what meaning this held for them.

Things happening quickly - This theme relates to the experience of time passing quickly during the organ transplantation process.

The findings that have been ‘sorted’ into this dimension all represent the physical domain of the organ recipient, such as a change to their body, the environments they encountered, and facing death. It feels quite evident that change occurs concerning the recipient's physicality when undergoing transplantation; however, the psychological ramifications of this may not necessarily be afforded time and space in recipients engagement with professionals. Therefore, professionals working with this population need to be alive to the issues that may be faced relating to the recipients physical and material domain, paying attention to how this manifests for the individual concerned.

Social dimension (Mitwelt)

The Donor's death - This theme relates to the death of the organ donor from the perspective of the participant. This theme encompasses the grief participants felt about the death of the donor, how they coped with this grief, and the meaning they have attributed to the donor's death.

Care and Support - This theme relates to the participants' experiences of receiving care and support during the organ transplantation process, both physically and psychologically.

A Shared Experience - This theme relates to the participants' feeling of connectedness to others who share the experience of organ transplantation.

Isolation - This theme relates to the participants' experiences of feeling isolated during the organ transplantation process; this may relate to physical isolation, such as being hospitalised or psychological isolation, such as missing certain relationships.

The Donor - This theme relates to the participants' relationship with the donor. This encompasses a physical relationship experienced in the case of a live donor, and a felt sense of a relationship in the cases of deceased donors.

The findings that have been 'sorted' into this dimension all focus on how the organ recipient relates to others throughout this treatment journey, whether that be friends, family, or the donor. This highlights that the transplantation treatment not only affects the individual concerned but impacts how they connect with others, both in positive and negative ways. Therefore, professionals need to be aware of how this lived experience can impact the individual's mode of relating to others and provide space for this to be discussed should the recipient require support with the alteration to their social domain.

Psychological dimension (Eigenwelt)

Roles and responsibilities - This theme relates to the participants' experiences of changing roles and responsibilities as a result of undergoing the organ transplantation process.

Coping - This theme relates to the participants' experiences of coping emotionally and psychologically with the organ transplantation process. This encompasses their views on how well they feel they coped and what mechanisms they may have utilised to aid them in doing so.

Choice and control - This theme relates to the amount of choice and control the participants felt they possessed throughout undergoing the organ transplantation journey.

Whilst there appears only to be three themes that have been 'sorted' onto this category, it is essential to note that all the other themes from this research project will present some change to the psychological dimension for the recipient, as discussed in the introduction above. The themes that have been collated here relate solely to the organ recipients inner private world such as the roles and responsibilities the recipient embodies within their life, how they coped throughout the transplantation treatment process, and how they were able to exercise agency regarding their health care. Psychological and psychotherapeutic intervention can sometimes find itself 'favouring' the psychological domain of the individual and neglecting others (Deurzen, 2010). It is vital for professionals working with the organ transplantation population to be alive to the psychological domain of the recipient; however, this needs to be in balance with the other dimensions so that an 'overshadowing' does not occur.

Spiritual dimension (Uberwelt)

Quality of life - This theme relates to the quality of life the participants experienced both before and after the transplant. For the purpose of this theme, quality of life is judged by the participant regarding how fulfilling and purposeful they found this to be.

Life beyond death - This theme relates to the participants' experiences of living beyond their death and subsequently, life after this for them. This theme encompasses the participants' reflections on how living beyond death continues to affect them, the opportunities they have been afforded through their gift of life, and ways in which their perspectives may have changed about life having faced death and escaped this.

Waiting for the transplant - This theme relates to the participants’ experiences of waiting for their transplant. All of the participants discussed experiences that fell into this theme.

Life after transplant - This theme relates to the participants’ experiences of time following the transplant.

The Unknown - This theme relates to the participants’ experiences of not knowing throughout their organ transplantation journey. This may relate to not knowing what to expect from the procedure, not knowing about life expectancy, the uncertainty around complications, and not knowing the cause of their illness.

The themes that have been ‘sorted’ into this category all relate to the recipient's ideological and meaning-making domain such as how purposeful the participant found their lives to be, the notion of living on extra time, how this affects the conceptualisation of life, and what it is like to sit with the unknown. Professionals working with this population must be alive to how the organ transplantation procedure can impact the individual's sense of meaning and purpose and whether this holds issues for them. Issues that relate to spirituality or meaning are essential to the individual's understanding of being as this is what human existence inherently grapples with (Frankl, 1967).

From considering this research project’s findings in the theoretical framework of the four dimensions of existence, it has further highlighted and supported the notion that organ transplantation treatment presents a host of bio-psycho-social-spiritual issues that the recipient has to navigate. The four dimensions have served to aid practitioners in understanding the breadth of issues the organ transplant recipient may face and how to begin working with these therapeutically. The subsequent section will move on to specifically discuss how some of the most pertinent issues can be worked with in the therapeutic space by explicitly considering what implications this research holds for the field of Counselling Psychology and Psychotherapy.

6.10 Implications for Counselling Psychology

Throughout the first segment of this discussion chapter, each theme has been individually considered in light of the literature presented in the review, with further literature being drawn on to breathe life into the findings from this research. Suggestions for those working with the organ transplantation population have been made within this discussion, and specific aspects of the findings have been highlighted for further consideration by those delivering therapeutic interventions. This section will now devote time to the most pertinent findings and the implications these may hold for the field of Counselling Psychology and Psychotherapy. Ways in which these findings could be conceptualised and worked with therapeutically, specifically from an Existential psychotherapeutic perspective, have been presented. These suggestions are unique in that they depart from the existing literature on organ transplantation and offer alternative ways of conceptualising and navigating these issues within the therapeutic space.

Embodied experience theme

- Working with ‘unusual’ experiences

As previously discussed, the prevalence of postoperative delirium in the organ transplantation population is high, considered to be as a result of the stress the body has been placed under and the medications the patient receives. This leads the patient to experience hallucinations which can be considerably distressing for the individual concerned and their loved ones. Drawing on Existential philosophy in these circumstances can offer professionals insight into how they are able to address the issue of the distorted world experience. Existential psychotherapy places the individual’s experience of the world at the centre of any psychotherapeutic interaction. Laing (1969) felt that instead of dismissing people’s experiences as ‘delusional’ or ‘illogical’ we should explore these for what meaning they may hold for the individual. Existential psychotherapy achieves this by asking the client to describe their experience in a phenomenological manner, free from judgement or challenge. Having done so, the client is then encouraged to consider what meaning this experience held for them in the hope they are able to achieve an understanding of their being (Cohn, 1997). The therapist does not confront, challenge, or dismiss any aspect of the client’s experience and instead positions themselves as a companion on this journey of self-discovery (Deurzen, 2012). This approach may aid organ recipients in discussing unusual experiences they have endured, and in doing so, this may lessen the shame, embarrassment, or distress experienced in relation to these.

- Changes to the physical self and integrating the new organ

Undergoing the organ transplantation treatment brings about an inevitable change to the physical self, such as surgical scarring and alternated physical functioning and the awareness that one now has someone else's organ inside their body. As previously discussed in the literature presented, there remain issues surrounding the current methods of aiding organ recipients in coming to terms with these physical changes and integration of the new organ (Siminoff & Chillag, 1999; Mauthner et al., 2015). Research has shown that adapting to the physical changes and new organ is crucially important in relation to limiting psychological distress and none compliance with medical regimes (Goetzmann et al., 2009). Therefore, it is a worthwhile endeavour to consider how to support the recipient in achieving these goals and overcoming the issues that the current methods of integration inherently bring. Existential psychotherapy promotes idiosyncratic meaning-making for the client, from the client (Cooper, 2016). Therefore, practitioners could embrace this and encourage the recipient to find their idiosyncratic way of achieving integration and assimilation, without imposing predefined theoretical frameworks onto the individual's lived experience. Psychologists and psychotherapists are invited to abandon approaches in which a 'one size fits all' is taken and instead find the courage to allow the client to move towards their own understanding of being.

Life & Death theme

- The birth and death of possibility

Those found suitable for organ transplantation treatment will be considered as being in end-stage organ failure and subsequently at the end of their life. On the majority of occasions, this status will be accompanied by chronic illness caused by organ failure and a significant deterioration in physical function. The recipient's illness becomes life-limiting for them, meaning they are no longer able to engage with their existence in the ways they may wish to (Chan, Cardoso, & Chronister, 2009). This may result in the individual experiencing a sense of loss in relation to the life they had wanted for themselves. This grief over the death of possibility holds important implications for the psychotherapeutic work and professionals delivering interventions to this population need to be alive to this. However, with the death of imagined possibility through their illness, comes the birth of new possibilities through treatment and recovery. Within Existential philosophy, possibilities for self-expression and being are endless (Frankl, 1966). Whilst certain aspects of existence may be fixed, paradoxically there exists an infinite amount of possibilities within these boundaries. Therefore, it is the job of the therapist to aid the individual in imagining what possibility is within their reach. In acknowledging their loss and aiding the organ recipient in imagining and carving out new possibilities, professionals can help lessen the impact the individuals' illness may have on their quality of life.

- Quality of life – deriving meaning from suffering.

This research project, along with many others, has set forth the bio-psycho-social-spiritual issues organ recipients face undergoing transplantation treatment. Whilst these challenges can adversely impact the recipient's quality of life, adequate support from professionals can help to limit the extent to which this occurs. Turning our attention towards the role of psychologists and psychotherapists in this treatment process, it is worth suggesting a way in which the suffering of the client can be approached in a meaningful manner. Frankl (1967) felt that meaning could be discovered in any situation encountered, even one of suffering. He felt that if the individual actively examined their situation to establish what meaning they can derive from this, then this alone would aid the individual in continuing with a purposeful life. Therefore, rather than conceptualising suffering as something of a wholly negative experience, practitioners are encouraged to embrace the search for meaning within this. Approaching the client's life struggles from this perspective, not only helps to instil hope but allows the client to reframe their circumstances towards one of purpose.

Relationships theme

- The self in relation to the donor

Many transplant patients will report a change to their sense of self following transplantation, such as an alteration to their characteristics. The origin of these changes can be often projected onto the recipient's representation of the donor, thus attributing changes within themselves to the result of inherited characteristics (Sanner, 2001). Bunzel et al. (1992) attribute these changes within the recipient to experiencing a life-threatening event, and it is living through this that created a shift in how the person relates to themselves. However, Pearsall et al. (2002) and Wright (2008) argue that heart transplant recipients can change as a result of transplantation due to memory being stored in cells of the body and that these memories could be incorporated into the recipient's personality and sense of self. The role of psychology and psychotherapy in amongst this particular phenomenon is not to ascertain why this may be occurring but rather to support the recipient in their experience of this. Within Existential philosophy, the nature of being is subjective, and therefore how this manifests holds truth for the individual concerned (Crowell, 2012). How the individual experiences being in the world should be awarded credence by the therapist, not confronted or challenged. Therefore, in relation to this specific issue psychologists and psychotherapists are encouraged to accept the client's experience of altered characteristics and whatever meaning they have attributed to this. I raise the question as to the value of 'objective truth-seeking' in relation to people's experiences and instead invite therapists to meet the client where they are.

Temporality theme

- Thrownness – a window of time

From the moment of receiving the call to advise them that there is potentially a suitable organ, the recipient is launched into the transplantation process with very little time to orientate themselves or come to terms with what is about to happen to them. As previously discussed, this is unavoidable due to the short shelf life of harvested organs. Time appears to speed up for the recipient with a considerable amount occurring within a small window of time. Some of the participants in this study described this process as quite traumatising and that they were 'swept' up in the process of undergoing organ transplantation. We cannot change how the organ transplantation procedure occurs; however, we can support the recipient in preparing for this and dealing with this post-transplant. The Existential philosopher Heidegger (1962) discusses a concept known as Thrownness in that we are 'delivered over to' aspects of being that is already determined (Withy, 2014). This may be a useful notion for psychologists and psychotherapists to reflect on and bring to the client work in an attempt to prepare the recipient for the experience of the organ transplantation procedure or to contextualise their experience post-surgery. The recipient can potentially approach and navigate this Thrownness and window of time in a way that lessens the psychological impact on them.

The Psychological

- The Unknown – Existential Anxiety

The experience of anxiety is something of which the organ transplantation population frequently reports, with the cause of this being for many different reasons (Favaro et al., 2011). Anxiety can be often pathologised and conceptualised as a neurosis of which the individual requires freeing from. However, this may not always be helpful, and therefore approaching the experience of anxiety from an Existential perspective may well be useful for working with this population. From this theoretical perspective, anxiety is seen as an inevitable aspect of existence itself as opposed to the result of a psychological mechanism (Tillich, 1999). The origins of anxiety are threefold (i) anxiety is rooted in our thrownness, (ii) anxiety is rooted in the necessity to make choices of which outcomes are never certain, (iii) anxiety is rooted in the realisation that life will inevitably come to an end (Cohn, 2000). In turn, anxiety cannot be judged as either good or bad, it is what it is, and its presence is pervasive and unavoidable. Applying this to the therapeutic work with the organ transplantation population, practitioners could abandon the hunt for the eradication of anxiety and help the client sit with this. If existence itself constitutes anxiety, then embarking on the deconstruction of anxiety is a pointless endeavour. Perhaps the needs of the client would be better served if the practitioner supported them in bearing anxiety and therefore equipping them to live their lives with courage in the face of the unknown.

- Choice and control

The perception of choice and control over organ transplantation treatment is something that arose for the participants in this research project. At some point or another, the recipients were faced with difficult choices to make, opportunities to exert control, and on other occasions observed how choice appeared to diminish along with their ability to control their circumstances. Upon closer inspection, choice and control may not be as dichotomous as the participants perceived this to be. The Existential philosopher Jean-Paul Sartre (1943) purports that every stance or position taken in the world is done so through choice, therefore in not exercising autonomy, the individual is still making a choice. The experience of being is considered to possess both aspects of facticity and transcendence (Capelle, 1998). This means that there are aspects of our existence that are fixed or determined and aspects of existence that can be transcended and changed. Both of these aspects exist in each moment and permeate our being in the world. Not acknowledging this tension is what Betty Cannon (1991, p46) describes as bad faith; “I fall into bad faith if I take one or both of the two dishonest positions about reality: If I pretend either to be free in a world without facts or to be a fact in a world without freedom”. Within the organ transplantation process, there are aspects of this the recipient is unable to change or control, such as the availability of a suitable organ. However, within this circumstance, the recipient has a choice over the stance and attitude they take towards these fixed circumstances, representing the transcendental aspect of being (Frankl, 1985). This can be a useful insight to both the client and the therapist in that within limitations and boundaries we still possess choice. This allows the individual to seize their agency and maintain a sense of authorship throughout their lives.

6.11 Psychological assessments in organ transplantation

The criteria surrounding medical selection for transplantation suitability is comprehensive and well defined, in turn, adequately guiding physicians in identifying those who will most benefit from undergoing this treatment. However, to date, there exist no guidelines for pre-transplant psychological and behavioural screening (Calia et al., 2011). Psychological evaluation prior to transplantation allows for professionals to identify potential risk factors such as compliance issues, psychopathology, and substance misuse that may influence the rate of noncompliance and morbidity. Psychological evaluations can also help to inform post-treatment planning for individuals who have been identified as ‘high risk’ in relation to the issues discussed above (Dew et al., 2000). Research has helped to highlight these issues, and subsequently, there is an ever-growing awareness that pre-transplant psychological factors can help predict post-transplant clinical outcomes (Dobbels et al., 2009). These factors not only affect compliance to medical regimes; they also concern patient mortality, graft rejection rates, and quality of life experienced by the recipient (Grady et al., 2007). Exploring these issues further to become more aware of the relationship between adverse clinical outcomes and psychological factors could help clinicians to develop therapeutic plans to support those who may require intervention to mitigate these concerns. Therefore, psychological evaluation and intervention could improve the survival rates of both the patient and the graft, and the quality of life experienced by the recipient. With this in mind, it is argued that the psychological domain of the recipient is afforded equal space and importance in consideration of transplant treatment suitability that the physical domain is provided. Psychological evaluation is also necessary post-transplantation treatment in order to ascertain what support the recipient requires from a psychological perspective, such as in caring for their new organ and integrating this successfully into their sense of self (Germani et al., 2011).

At present, there remains a significant variance in whether transplant teams undergo a psychological evaluation as part of their pre-transplant investigation/post-transplant aftercare and if so, how these assessments are navigated. As previously mentioned, this is due to there being no existing set standard pertaining to how this should be done. There have been several brief instruments designed to aid in the psychological assessment of transplant patients, such as the Psychosocial Assessment of Candidates for Transplantation (Olbrisch, Levenson, & Hamer, 1989) and the Transplant Evaluation Rating Scale (Twillman, Manetto, Wellisch, & Wolcott, 1993). A study conducted by Calia et al. (2011) utilised a batch assessment approach of the Cognitive Behavioural Assessment (CBA-2.0). This included an assessment of fears, personality, obsessive-compulsive symptoms, state and trait anxiety, psychological reactions, and depression. This was found to be an effective approach to predicting postoperative outcome issues; therefore, this may be a suitable method of proceeding with the pre-transplantation psychological evaluation of organ recipients. This could also be applied postoperatively in order to establish what issues the recipient may be facing having undergone the transplantation treatment. Further research is needed in order to develop a cohesive, standardised approach to pre-transplant/post-transplant psychological evaluation in order to overcome the issues discussed here. It also raises the question as to whether the reason why psychological evaluation is not afforded the space and importance that is required is due to the fact that a valid and reliable approach to doing this has not yet been established.

Having discussed the findings of this study in light of the literature held on organ transplantation, with elements of Existential philosophy interwoven within this, the next chapter will summarise and conclude this research project. It will restate the research aims and briefly discuss how these were addressed, moving on to outline the themes that emerged from the data. Finally, this dissertation will conclude by highlighting the limitations of this study and offer ideas for future research in this area.

7. Conclusion

7.1 Summary of research

This study aimed to explore the experience of undergoing lifesaving organ transplantation treatment and how this may affect life subsequently. Six participants were interviewed using semi-structured interviews focusing on the experience of undergoing the transplantation procedure and how this affected their life following this. The data in the form of the participants' accounts were analysed using Interpretative Phenomenological Analysis - IPA. Five superordinate themes were identified with 19 subordinate themes falling within these. The superordinate themes were; Embodied Experience, Life & Death, Relationships, Temporality, and The Psychological.

The Embodied Experience theme related to the physical aspects of undergoing the organ transplantation process such as; the participants' experiences of being ill and well, how they related to their environment, changes to the physical self, and how they related to the organ. The Life & Death theme captured the participants' experiences of life and death throughout the transplantation process such as; their quality of life before and after, facing their death, and life beyond death. The Relationships theme captured the participants' experience of relating to others throughout the organ transplantation treatment such as; what it was like to receive care and support from others, sharing the experience of transplantation with fellow recipients, changes to the roles and responsibilities in their lives, being isolated from others during this treatment, and how they related physically or spiritually to the donor. The Temporality theme captured the participants' experiences of time throughout their transplantation treatment such as; waiting for the transplant, things happening quickly, and life after the transplant. Finally, the Psychological theme related to the participants' experiences of their inner world and how they related to themselves throughout their treatment such as; facing the unknown, coping strategies, and having choice and control over their lives, their illness, and their medical treatment.

The study concludes that organ recipients undergoing transplantation experience an array of bio-psycho-social-spiritual issues that professionals working with this population need to be aware of. It is argued that appropriate and sufficient evidence-based evaluations and interventions should be offered to all those undergoing the transplant treatment as standard in the provision of care provided to this population. Unfortunately, at present psychological support for organ recipients is only offered as and when a need 'arises'. It is hoped that this study has come some way to contributing to the body of knowledge held on the lived experience of this phenomenon and may support professionals in caring for this population. This study has highlighted throughout particular pertinent implications for Counselling Psychology and Psychotherapy, and it is hoped that these insights are drawn upon when working therapeutically with this population.

7.2 Limitations of this study

This study was executed with six participants, whilst this is an adequate sample for an IPA study, according to Smith and Shinebourne (2012), it could be proposed that this remains relatively small in size. Future studies could increase the number of participants they include within their research to overcome this. It is worth bearing in mind that introducing too many participants into qualitative research has been suggested to dilute the intimacy the researcher is able to develop with the data (Crouch & McKenzie, 2006). Therefore, balance is recommended when considering sample size in line with the chosen research method recommendations for participant pools.

This study approached the phenomenon of organ transplantation as homogenous, and as such, it did not discriminate between the type of solid organ transplants. Previous research in this area had kept to organ-specific cases, meaning that these findings can only be generalised within organ-specific cases. This research project aimed to move beyond this and in approaching organ transplantation as homogenous across solid organ types hoped to unite these findings. In doing so, it could be argued that this sample possesses less homogeneity than those kept to organ-specific cases. Therefore, further research into organ transplantation as a homogenous group will support the generalisability of this study's findings.

The participants within this study were all of a similar age and ethnic/cultural background. Due to these common characteristics, the participants were sharing their experiences of the phenomenon under investigation from a similar stance within the world. Whilst this is positive in terms of seeking homogeneity, this sample could be said to lack diversity in regard to factors such as cultural values and how these may influence the interpretation of their experience. Therefore, to broaden this perspective, it may be useful to recruit participants with more diverse characteristics.

This study employed a qualitative research methodology that possesses limitations much the same as other research methodologies. Qualitative research aims to generate knowledge in relation to the human experience and as such, produces data that requires interpretation on behalf of the researcher (Sandelowski, 2004). As such the trustworthiness of the data and findings from this approach has come under scrutiny from the research field and researchers are increasingly expected to 'evidence' their processes of data collection and analysis (Nowell et al., 2017). This research project has made every attempt to clearly and transparently discuss the research process from beginning to end, explicitly referencing Yardley's (2000) four principles in which the validity of a research study can be assessed; these being sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. A more detailed discussion around the trustworthiness of this research project's findings can be found in the Methodology chapter of this dissertation. However, further considering practices that could be introduced in the future in order to continue to improve the credibility of this research could be returning to participants to ensure the analyse is grounded in their experience and working with an independent researcher to compare the analysis of the findings. These strategies could illuminate some interesting lines of enquiry and will be considered in light of the intended dissemination and publication of this research.

7.3 Suggestions for future research

Having completed this study, several suggestions for future research emerged from this. Not only is it encouraged that further research is conducted into the phenomenon of organ transplantation, but there also appears to be several 'angles' in which this is particularly pertinent. Research with Black, Asian, Minority Ethnic (BAME) groups concerning organ donation and transplantation is needed as statistics show that there continues to remain an inequality with these groups and organ donation rates/organ transplantation rates (NHS Blood and Transplant, 2019). This also applies to different age groups such as paediatric as donation and transplantation are also not as prevalent within this population (Brierley, 2010).

This study focused on the experience of undergoing solid organ transplants, these being heart, liver, lung, and kidney. As previously discussed in the literature review, organ transplantation is a reasonably under-researched phenomenon, with the pre-existing research findings being in relation to solid organ transplants as these are vital for life. Subsequently, there is extremely little research conducted on the lived experience of other types of transplants, such as bone marrow, pancreatic, and corneal. Exploring these different types of transplants may produce some interesting findings and insights that have not yet been gained due to not considering these.

Further research is needed in order to develop a cohesive, standardised approach to pre-transplant/post-transplant psychological evaluation in order to overcome the issues discussed in this study. Psychological evaluation prior to transplantation allows for professionals to identify potential risk factors such as compliance issues, psychopathology, and substance misuse that may influence the rate of noncompliance and morbidity. Psychological evaluations can also help to inform post-treatment planning for individuals who have been identified as 'high risk' in relation to these issues (Dew et al., 2000).

The research project had an Existential leaning, and therefore, this was the only psychotherapeutic and philosophical influence that was drawn upon in this study. Consequently approaching the phenomenon of organ transplantation from a different psychotherapeutic position may reveal a differing perspective on this lived experience.

Finally focusing in more depth on issues such as temporality throughout the organ transplantation treatment would be beneficial as this appears to be underrepresented in the body of knowledge held. Further exploration into any of the issues and themes highlighted within this study would be fruitful as this is an area of physical health that we possess very little psychological understanding of. Therefore, research from a bio-psycho-social-spiritual perspective is encouraged and welcomed to allow for the development of evidence-based interventions that can be utilised to support the transplant population adequately.

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9. Appendices

- 1 - Survival rates for recipient and graft
- 2 - Researcher’s interview matrix
- 3 - Research advert
- 4 - Participant information sheet
- 5 - Participant consent form
- 6 - Participant emergency contact form
- 7 - Participant demographic information form
- 8 - Participant support networks information sheet
- 9 - Participant debrief information sheet
- 10 - Table of themes
- 11 - Participant one transcribed interview
- 12 - The Blueprint of Existential Dimensions

Appendix 1 – survival rates for recipient and graft

Kidney

Table 1.1 Survival rates of the patient

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	95 – 99%	93 – 98%	86 – 96%	72 – 91%
2007 - 2009	96 – 99%	94 – 98%	88 – 95%	-
2010 - 2012	95 – 99%	93 – 98%	85 – 94%	-
2013 – 2016	97 – 99%	-	-	-

Table 1.2 Survival rates of the graft

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	93 – 96%	91 – 95%	85 – 92%	76 – 82%
2007 - 2009	91 – 96%	90 – 95%	85 – 91%	-
2010 - 2012	93 – 97%	91 – 96%	86 – 92%	-
2013 – 2016	94 – 98%	-	-	-

Heart

Table 1.3 Survival rates of the patient

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	82%	80%	72%	60%
2007 - 2009	82%	80%	75%	-
2010 - 2012	80%	78%	68%	-
2013 – 2016	84%	-	-	-

Heart & lung

Table 1.4 Survival rates of the patient

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	67%	62%	62%	46%
2007 - 2009	92%	92%	92%	-
2010 - 2012	91%	82%	73%	-
2013 – 2016	75%	-	-	-

Lung

Table 1.5 Survival rates of the patient

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	77%	70%	53%	34%
2007 - 2009	81%	73%	58%	-
2010 - 2012	81 – 82%	73 – 74%	56%	-
2013 – 2016	78 – 81%	-	-	-

Liver

Table 1.6 Survival rates of the patient

Year of transplant	One year	Two year	Five year	Ten year
2004 - 2006	90%	87%	77%	63%
2007 - 2009	89 – 92%	82 – 90%	73 – 82%	-
2010 - 2012	89 – 93%	86 – 90%	77 – 81%	-
2013 – 2016	94 – 95%	-	-	-

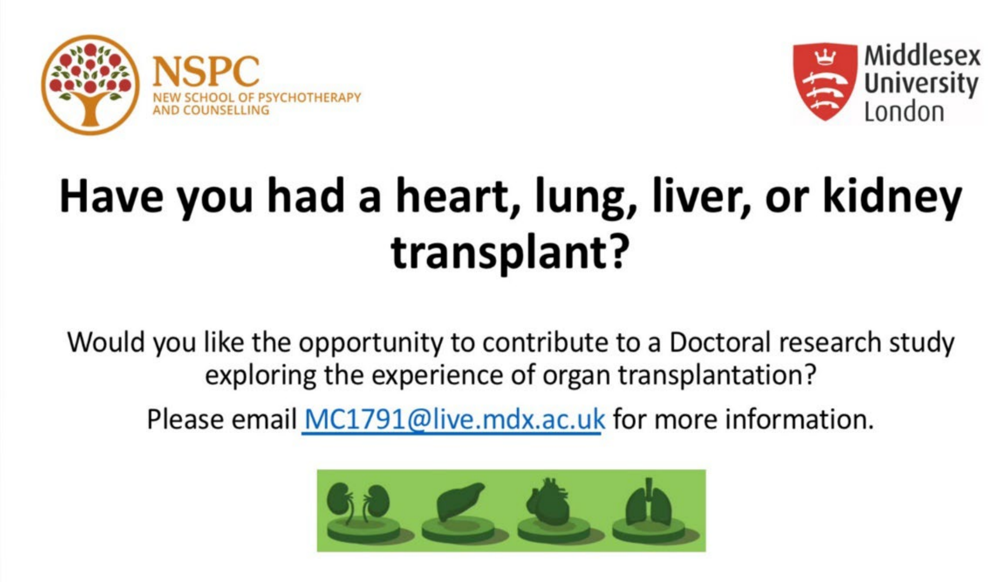
Appendix 2 – interview matrix

The three temporal phases of the organ transplantation process

(Rainer, Thompson & Lambros, 2010)

		Pre-transplant	Preoperative	Post-transplant
Types of experience	Physical dimension			
	Social dimension			
	Psychological dimension			
	Spiritual dimension			

Appendix 3 – advert placed on social media



NSPC
NEW SCHOOL OF PSYCHOTHERAPY AND COUNSELLING

Middlesex University London

Have you had a heart, lung, liver, or kidney transplant?

Would you like the opportunity to contribute to a Doctoral research study exploring the experience of organ transplantation?

Please email MC1791@live.mdx.ac.uk for more information.

Appendix 4 – participant information sheet

New School of Psychotherapy &
Counselling
Existential Academy
61-63 Fortune Green Road
London
NW6 1DR

The Department of Health
and Social Sciences
Middlesex University
London NW4 4BT

Middlesex
University
London

The Gift of Life: An Existential Phenomenological exploration of receiving a lifesaving organ transplant and how this affects life subsequently.

My name is Melissa Crutchley and I am currently undertaking a Doctorate in Counselling Psychology & Psychotherapy by Professional Studies with the New School of Psychotherapy & Counselling, in partnership with Middlesex University. As part of my qualification, I am required to undertake an original piece of research that will contribute to my field.

What is the purpose of the research?

I am conducting research into the experience of life after receiving a vital organ transplant, these being heart, lung, liver, and kidney. I am looking to recruit individuals who have undergone one of these procedures, who are willing to discuss their experience of this. The purpose of this research is to better understand how this procedure impacts individuals undergoing it.

Why have I been chosen?

You have been identified as a potential participant because of the following criteria:

- You are over the age of 18.
- Have had a heart, lung, liver, or kidney transplant.
- It has been at least 18 months since you had the surgery.
- Are medically stable - this meaning the organ is functioning as intended.
- Speak English fluently.
- Can legally provide consent to engage in the study.
- Underwent the procedure in the UK.

Do I have to take part?

No, participation in this research is on a voluntary basis.

What will happen to me if I take part?

If you wish to take part in this research, you will firstly be asked to sign a consent form. Once this has been done, we will arrange a suitable time and place for you to take part in an interview with myself. This may be in person or if our geographical location cannot facilitate this then the interview may take place via Skype. This interview should last for approximately 60 – 90 minutes and will be audio recorded with a Dictaphone. In this interview I will ask you questions about what the experience was like for you, how it has affected you and areas of your life, and how you view the procedure now. You do not have to answer any questions you do not want to. The audio recordings will only be accessible to the researcher and these will be deleted as soon as the interview has been transcribed. The interview will be transcribed and assigned a number, meaning that none of your personal details will be on this document.

Consent

You are free to withdraw your consent without consequences up until the data analysis when your data can no longer be identifiable as yours. You do not need to provide an explanation for withdrawing your consent.

What will happen to the data?

Audio recordings of your interview will be transcribed by myself the researcher. I will use these to explore if there are any patterns between the experiences of the participants, to allow me to highlight important aspects of your experiences. I will anonymise the interviews so you cannot be identified from these. I will store these on my personal laptop computer and password protect all documentation relating to you. No one other than myself will have access to your information and your transcribed interview. The audio recordings will be deleted upon the research project being examined and passed by the supervising institutes. The findings of the research may be published in psychology and psychotherapy journals and/or may be presented at conferences/workshops.

What are the possible disadvantages to taking part?

As this research involves discussing potentially sensitive and emotive experiences for you, some upsetting feelings and memories could emerge as part of this. You are able to stop the interview at any time, without question, and should you wish to continue with this we would ensure that you were comfortable to do so. You will have the opportunity to discuss your experience of the research with the researcher at the end of the interview, you will also be provided with the details of the supervising institutes should you wish to raise an issue or share your concerns. If you feel that you require further support as a result of engaging in this research, the researcher will provide you with contact details of agencies where you can access this. You will also be asked to provide the contact details of a nominated person, this could be your next of kin or your GP, who the researcher is able to contact to advise of any concerns about you, should any arise throughout this research. Please note that this will only be the case if you advise of any risk of harm to yourself or others.

What are the possible advantages of taking part?

An advantage to taking part in this research is that you can talk about how this procedure has impacted your life, something you may not have had the chance to do in the same way before. Your experience of this procedure and engagement in this study will also go some way in helping professionals understand how to best support other organ transplant recipients. The experience of receiving an organ transplant is a very under researched area at present, therefore you will also be contributing to how we understand this procedure.

Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC Ethics Committee and Middlesex's department of science and technology, Hendon campus, have reviewed and agreed this proposal.

Who is organising and funding the research?

I am funding and organising this research project as part of my Doctoral studies.

If you wish to take part in this study or if you have any questions as a result of reading this information sheet, then please contact me at MC1791@live.mdx.ac.uk where I will be available to answer any further questions you may have.

Researcher: Melissa Crutchley MC1791@live.mdx.ac.uk

Supervisors: Dr Pamela James & Dr Susan Iacovou – contactable via NSPC

Supervising Institutes:

NSPC
61-63 Fortune Green Road
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Tel: +44 (0) 207 435 8067 / 0203 515 0223
Email: office@nspc.org.uk

The Department of Science and Technology
Hendon Campus
Middlesex University
London
NW4 4BT

Appendix 5 – informed consent form

New School of Psychotherapy &
Counselling
Existential Academy
61-63 Fortune Green Road
London
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The Department of Health and Social
Sciences
Middlesex University
London NW4 4BT

Title of study:	The Gift of Life; an existential phenomenological exploration of receiving a lifesaving organ transplant and how this affects life subsequently.
Academic year:	18/19 & 19/20
Researcher's name:	Melissa Crutchley MC1791@live.mdx.ac.uk
Supervisor's names:	Dr Pamela James & Dr Susan Iacovou – contactable at NSPC.
Supervising institutes:	New School of Psychotherapy and Counselling – London, NW6 1DR Middlesex University – London, NW4 4BT

☐ I have understood the details of the research as explained to me by the researcher and confirm that I have consented to be a participant.

☐ I can confirm that I am over the age of 18.

☐ I can confirm that I have had an organ transplant of either heart, lung, kidney, or liver.

☐ I can confirm that it has been at least 18 months since I underwent this procedure.

☐ I can confirm that this procedure was conducted in the UK.

☐ I can confirm that I am medically stable in that the organ is functioning as intended.

☐ I can confirm that I speak English fluently.

☐ I can confirm that I am able to legally provide my consent to engage in this study.

☐ I have been given contact details for the researcher in the information sheet.

☐ I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project, up until the data analysis stage starts, without any obligation to explain my reasons for doing so.

☐ I understand that I can ask for my research data to be withdrawn from the project until data analysis begins. I also understand that my personal details will be stored in a secure place, separate from my interview data and that my personal details will be deleted once interview has been transcribed so that your confidentiality is protected.

☐ I further understand that the data I provide may be used for analysis and subsequent publication in psychology and psychotherapy journals, and I provide my consent that this may occur.

Print name: Sign: Date:

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University/New School of Psychotherapy & Counselling, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ___________

Appendix 6 – emergency contact details

New School of Psychotherapy &
Counselling
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The Department of Health and Social
Sciences
Middlesex University
London NW4 4BT

Emergency contact details

Can you please provide the name and number of a nominated person, this could be your next of kin or your GP, who I am able to contact to advise of any concerns about yourself, should these arise. This will only happen if you tell me about a risk of harm to yourself or others.

Participant name:
……………………………………………………………………………………………………..

Name of nominated contact:
…………………………………………………………………………………………

Number of nominated contact:
………………………………………………………………………………………

Date:

Researcher: Melissa Crutchley MC1791@live.mdx.ac.uk

Supervisors: Dr Pamela James & Dr Susan Iacovou – contactable via NSPC

Supervising Institutes:

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Appendix 7 – participant demographic information form

New School of Psychotherapy &
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The Department of Health and Social
Sciences
Middlesex University
London NW4 4BT

Name:				
D.O.B:				
Gender:				
Organ transplant received:	☐ Heart	☐ Lung	☐ Liver	☐ Kidney
Date transplant received:				
Hospital transplant was completed at:				

Researcher: Melissa Crutchley MC1791@live.mdx.ac.uk

Supervisors: Dr Pamela James & Dr Susan Iacovou – contactable via NSPC

Supervising Institutes:

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Appendix 8 – support networks information sheet

New School of Psychotherapy &
Counselling
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London
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The Department of Health and Social
Sciences
Middlesex University
London NW4 4BT

Further Support Contact Details

Thank you for taking part in this research project, your engagement has been greatly appreciated. Below is a list of organisations that are able to offer you further support should you need this.

Samaritans
Phone: 116 123
Email: jo@samaritans.org

British Heart Foundation
Phone: 0300 330 3311

British Lung Foundation
Phone: 03000 030 555

Kidney Care UK
Phone: 01420 541424

British Liver Trust
Phone: 0800 652 7330

You can also contact your GP who will be able to refer you to services such as IAPT who specialise in mental health.

If you have any concerns about the project, then you can contact the supervising institutes directly to express these at:

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Middlesex University London
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London
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Tel: +44 (0)20 8411 6060

Appendix 9 – Participant debrief sheet.

New School of Psychotherapy &
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Middlesex University
London NW4 4BT

Participant Debrief Form

Thank you for taking part in this research project, your engagement has been greatly appreciated.

Study title: The Gift of Life; an existential phenomenological exploration of receiving a lifesaving organ transplant and how this affects life subsequently.

Researcher: Melissa Crutchley MC1791@live.mdx.ac.uk

Supervisors: Dr Pamela James & Dr Susan Iacovou – contactable at NSPC

Study details: This study is interested in people's experiences of receiving a life-saving organ transplant. These verbal accounts will be transcribed and from these the researcher will look for themes and patterns that have arisen across the participants accounts. It is thought that these patterns will reveal insights into what the procedure is like to experience. The study's aim was therefore to attempt to understand what it is like to live through this experience and how this impacts people's lives. This information will help inform professionals how to best support individuals going through this process.

The study's theoretical approach: Existentialism is the study of human existence and what this is concerned with. Phenomenology is the study of how people experience things. Therefore this study was concerned with the experience of receiving a lifesaving organ transplant and what this was like for the individuals undergoing this.

What happens now? If you would like either a summary of this research project or a copy of the finalised piece, then you are able to request an electronic version of this at the above email address upon completion of this study.

If you feel that the study has raised personal issues for you then please ask the researcher for contact details of networks and agencies that are able to offer you support with these issues. If you have any concerns about the project, then you can contact the supervising institutes directly to express these at:

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Appendix 10 – Theme table

Superordinate theme	Subordinate theme	Theme applicable to participant
Embodied Experience	Illness & Wellness	P1, P2, P3, P4, P5, P6
	Being in the world	P1, P2, P3, P6
	Change to the physical self	P1, P2, P3, P4, P5, P6
	The Organ	P1, P2, P3, P4, P5
Life & Death	Quality of life	P1, P2, P4, P5, P6
	Facing death	P1, P2, P4, P5, P6
	Life beyond death	P1, P2, P3, P4, P5, P6
	The donor's death	P1, P2, P6
Relationships	Care & Support	P1, P2, P3, P4, P5, P6
	A shared experience	P1, P2, P3, P4, P5, P6
	Roles & Responsibilities	P1, P2, P4, P5, P6
	Isolation	P1, P2, P4, P5, P6
	The Donor	P1, P2, P3, P4, P5
Temporality	Waiting for the transplant	P1, P2, P3, P4, P5, P6
	Things happening quickly	P1, P2, P3, P4, P6
	Life after transplant	P1, P2, P3, P4, P6
The Psychological	The Unknown	P1, P2, P3, P4, P5, P6
	Coping	P1, P2, P3, P4, P5, P6
	Choice & Control	P1, P2, P3, P5

Appendix 11 – Participant one transcribed interview

R: Can you tell me what it was like for you leading up to and before the transplant?

P: Well I was never ill, I never felt ill before I had my transplant. Erm, ten years ago 28th December 2008 I took my kids swimming, got out the swimming pool and felt really really faint and dizzy, and just went in the toilet and vomited up blood. I just vomited up a whole sink full of blood everywhere, up the walls. I rang my husband to pick me up because I didn't think I could drive, and erm we got home, and I phoned the doctors and the doctor came out with a paramedic and an ambulance and took me straight into hospital. They thought I had a bleeding ulcer, so they left it to the next day, and then they put a camera down and found out I had all these bleeding varices, erm and banded them all. I woke up 3 days later to be told I'd had a stroke and that erm I nearly didn't make it.

R: When was it they told you that you would need the transplant?

P: Oh, not till about Christmas 2015.

R: Ok, can you tell me about that?

P: Erm, well it was a bit of a shock, I didn't feel ill, apart from twice I vomited up blood. Erm, I never felt ill so when the doctor suddenly turns around and said has anyone ever talked to you about having a transplant, I told him not to be so stupid, I wasn't ill. Erm that was just a registrar and he didn't know what to say so he left it to the next time I saw my consultant and he said yes we do need to start thinking about a transplant because your blood results are terrible.

R: How were you feeling at that point?

P: Erm, that was a bit of a shock, like I said I never felt ill and I just carried on with my life as normal and looked after my kids and done all the things I've always done.

R: What were you diagnosed with that required you to have the transplant?

P: Erm, non-alcohol steatohepatitis. That's what had caused all the vomiting up of the blood.

R: How long was it between receiving the diagnosis and having the transplant?

P: Erm, they first sort of said about it in February 2016 and wanted me to meet the transplant team which I did in the march. I went in in May and had my 3-day assessment, erm and they would have put me on the transplant list there and then but I told them I was too busy to sit about and wait for a phone call, so I didn't sign the paperwork until the September.

R: What was it that made you sign the paperwork?
P: Well, the doctors told me I would be dead within a matter of months if I didn't, and that I really was ill. And erm yeah I didn't sign them for several months because my son was taking his A levels and wanted to get into university, there was just so much going on at the time, they needed me at home not in hospital.

R: So, it was when the doctors told you it was life threatening?
P: Yeah well they said that in the May, but then with their agreement I didn't sign the papers. They were happy as long as I kept going in for blood tests and that if anything did dramatically change I would sign the papers there and then.

R: What was that like for you at that time then?
P: Well I never really sort of thought about it much. I never really felt ill so it's not as if I couldn't do anything or was sick. That was, yeah, it was very strange. Once I signed the papers, I posted them on the Monday, and I had a phone call on the Tuesday to say I was on the transplant list. That's when you sit and wait for a phone call.

R: So pre transplant you didn't feel unwell and you said it was quite a shock to you, so had you ever thought about transplants before?
P: Well it's something I've always known about ever since I was at school, but happening to me, no.

R: How did you feel about the prospect of having the transplant?
P: Well once they actually said yes I definitely needed one, I just sort of accepted it and got on with it. Yeah, that's very difficult thing to think about. You just have to accept what the doctors tell you.

R: Do you think you accepted it before that point?

P: Well when I was in Addenbrookes having my 3-day assessment, I had all the tests because you have to go through loads and loads of tests to make sure your fit enough to go through with a major long operation. Erm and on the Friday morning my consultant came in and he said yes you definitely need one, you are very very ill. And I just broke down and cried and erm, he said we will wait until your husband comes this afternoon and we will talk more about it. Again, I just sat and cried all day because I think it was just the shock of knowing that I have just been told I was that ill.

R: So, what would you say the experience was like for you prior to the transplant?

P: Erm, it was a bit of a shock. I put it off a few months before I actually signed the papers, so I had a few months to get used to it before I had to sit and wait before I knew it could be anytime that the phone could ring. I had children to look after, you don't think too much about yourself. I think I was more concerned about my son passing his A levels and getting him off to uni. And my older daughter was ill at the time, she had been doing her masters and had to drop out because she was will. My younger daughter was 15/14 at the time. I was more worried about them.

R: What was it that you were worried about?

P: Well my son had failed his AS levels once and he really wanted to go to uni so that was a bit of a tense time waiting for his results to come through. I was worried about my older daughter because she was ill and. Yeah I just didn't think about myself. Then once they were all sorted out, that was time to say right I need to something about me now and that's when I signed the paperwork and got put on the transplant list.

R: So, when you were put onto the transplant list, what happened after that?

P: I just had to sit and wait for a phone call. Every month I had to go and talk to the consultant. Basically, I would walk in and they would say how are you and I would say fine nothing, wrong with me. I would have some blood tests and go home again. They were just keeping an eye. I had to have CT scans and things, cause also when I had the 3-day assessment they found out I had a blood clot in my portal vein. So, I had to take a lot of blood thinners, I had to inject myself twice a day with blood thinners which caused massive bleeding all over, so I was forever back, and forwards from the doctors because something was bleeding.

R: What was that experience like for you?
P: Erm, it was quite strange as I would wake up and suddenly my arm was bleeding, your tongue was bleeding and erm. Every time the phone rang I would jump because you sort of think could this be it. Where is my husband because I needed someone to take me to the hospital, where are the kids and, because you have to think about all these things. My two eldest children, my eldest daughter was living in Paignton at the time working, and my son had just started at uni, so it was only my youngest daughter at home. We had to have someone on standby to look after her, erm, so like I said every time the phone rung these things jump through your head, where's my husband, how quickly can he get home, who has got to be here for Beth. But then after a couple of months you sort of think, oh well it's not going to happen, and you don't sort of think about it so much.

R: What was it like to go through that experience?
P: Erm, pretty nerve wracking. Yeah. Yeah because you can never leave the house without your phone because that can ring at anytime, anywhere. You go to places where they say please turn off your phone and you think no I can't my phone has to stay on. Erm.

R: So, what was it like to live like that?
P: Erm, I'd say the first couple of months, that was pretty tense. But then after that you sort of settle down. Because I wasn't ill, or I didn't feel ill it weren't so bad because it wasn't, I weren't desperately needing or wanting a transplant. Because I didn't feel ill they could have put it off forever as far as I was concerned.

R: But that wasn't the reality in the situation?
P: No, no. and then I had a CT scan in the April and erm. Apparently my portal vein was completely blocked with this blood clot and I think I suddenly jumped up the list because I got the phone call two weeks later.

R: So, your health began to deteriorate significantly?

P: I didn't notice it; it made no difference to me. I never felt ill, erm obviously the doctors realised it because of what they saw on CT scans.

R: How did you feel being told that news?

P: Well they never really sort of said, I think they were very much didn't want to frighten me. I just got a phone call to say that, I had stopped taking the blood thinners because they were causing me so many problems. I ended up in hospital because my arm was black because that was just leaking blood everywhere and they told me to stop taking them. Then I suddenly got a phone call to say that whatever the consequences you need to take them because we have noticed that the blood clot is getting bigger. It was only afterwards that I found out that it was completely blocked.

R: What was it like to live not feeling ill but being told you were ill?

P: Erm, that's really difficult because I just got on with my life, nothing changed for me. It was just always in the back of my head the thought that I'm going to get a phone call at some time and then things are going to happen. But I was still running around after the kids, I still took my mom shopping every week and doing everything that I normally do because there was no reason not to because I didn't feel ill. It never stopped me doing anything.

R: How did it feel to be waiting on that telephone call?

P: Erm, again that's really difficult because I didn't feel ill that weren't, that never seemed desperate. You know I've talked to people since who are so ill that they know if they don't get that phone call and they don't get that transplant, they are going to die. But because I never felt ill, however many times the doctors told me that I was ill and that it was only a matter of months if I didn't get a transplant. Yeah that's very difficult to get your head around when you're feeling well but the doctors are telling you that you are actually dying.

R: How did it feel to have to tackle that?

P: Well again I just got on with my life, I didn't think about it that much apart from every month having to go to the hospital it didn't really interfere with my life. I know I'm not coming across very well.

R: You are doing really well. What was your experience of the organ transplant process?

P: Pretty traumatic (laughs) I got a phone call at 4 o'clock in the morning and they just said we've got a liver for you can you be making your way down to the hospital. Erm, so we quickly wrote a note for my daughter and got in the car and drive down to the hospital. We got there about 6, I had to have blood tests CT scans and all the general ECG's and things like that. And then I just had to sit and wait because it was up to the surgeon because of the blood clot in my portal vein, if that had gone too far then they wouldn't have been able to operate. So, we just had to sit and wait for his to say yes and erm, then he came in about midday and said yes the surgeons said it's all go, and we went straight down to the operating theatre. I said goodbye to my husband and erm, didn't know anything for a couple of days (laughs). And I just woke up screaming in pain, and erm yeah (laughs) that's the most I can remember of coming around in intensive care.

R: So, you said the experience was quite traumatic for you?

P: Yeah, because I didn't feel ill there was always this thought in the back of my mind that they had got it wrong and that I wouldn't end up having a transplant. So, when I came around in intensive care and they said right it's all over now you've got a new liver, that was a bit yeah (laughs) suddenly hit home that hang on I was ill.

R: And how did that feel?

P: Well it was a bit of a shock I think, and erm, I was quite shocked at that and the amount of pain I was in. They don't tell you how much pain you are going to be in. Apparently I had woken up a few hours beforehand and they had took the breathing tubes and everything out and they had given me the patient-controlled button thing you press for your pain killers. But because I wasn't really awake enough I hadn't has any painkillers for a few hours so I was in a lot of pain so they suddenly had to start pumping pain killers into me and there seemed a lot of people in the room there was someone trying to do an ultra sounds, and there was doctors and nurses there. And no one thought to give me my glasses and I'm as blind as a bat. So, it's very difficult to tell anyone how your feeling at that time, you know because I was in so much pain I couldn't really say oh can I have my glasses please. And erm, yeah that was very traumatic for a little while, trying to sort out the pain.

R: After the pain subsided, what was going on for you then?

P: Well you have a nurse with you all the time and it didn't seem many hours before they were like come on let's get you out of bed, I had a physio come in and I had to get out of bed and walk to a chair which I know was essential because they don't want you to get chest infections and sort of things. But again, when you've been cut in half, to have to get out of bed and walk is again very painful (laughs). But you have to do it.

R: What was it like to live with that pain initially?

P: Well they gave me a lot of pain killers so that was soon under control. So yeah (laugh) that's very hard to describe. Yeah, I think there was a lot of crying that went on in those first couple of days as well from me. I think because of the shock of everything that had just suddenly happened, because that's not like when you have a routine operation when you know about it for weeks before hand and you can get yourself all prepared, this is suddenly a phone call at 4 o'clock go.

R: How do you think that affected you?

P: Again, I think that was just the sheer shock of everything happening and happening so quickly. Because of again other people have calls and when they get there the liver is no good or they can't do it or one thing or another, whereas this was my one and only call and I was straight in the operation and yeah. That was pretty traumatic.

R: So, the process happened quite abruptly for you?

P: Yeah, yeah. I was at the hospital 6 hours before I actually went into theatre. Most of that time was having things done to me, sort of waiting for a CT scan and waiting for x rays and then being poked and prodded all the time.

R: Can you tell me what it was like sitting in the hospital waiting to hear if they could operate?

P: Erm, well as I said as soon as we got there they do some blood tests then it was like right we've got a bed for you. Then you need to go down and have a CT scan and then can you go and have an x ray. So, the first 3 hours were taken up having all these sort of things done, and erm, running back and forwards to the loo because of stress and then the nurse sort of stuck her head around the door and said the surgeon said it's all go. She had a porter with her, and we went straight down to theatre, there weren't no time, there didn't seem a lot of time to sit and think and…

R: Not being given that time, how do you think that affected you?
P: Well I think maybe if I'd had more time to think I might have got even more worried and even more stressed out. Whereas things happen quickly you don't have time to sort of ponder on and. In the car on the way down there I had been talking to my husband and said well if I don't wake up, if I die look after the kids and…

R: So, you thought about not waking up and dying?
P: Yeah that's always there isn't it. You've got to think about that sort of thing.

R: What was it like to have to contemplate that?
P: That was quite stressful, because obviously, sorry I'm getting upset (laughs). I was more worried about the kids and how would they cope without me (cries). My husband would never show his feelings or anything. He would just sit there and say don't be so stupid, you're going to be alright. How he really felt I don't know…

R: Did you think of any benefits to having the transplant?
P: Well I knew I would live; without it I wouldn't be here.

R: So, you were aware that you needed the transplant to live?
P: Yeah the doctors had made that quite clear, that I needed it and it would be a matter of months if I didn't have it.

R: So, how do you feel about having the transplant?
P: Well I'm alive (laughs) erm. I've had a lot of problems since. I was never ill beforehand but ever since it seems to be one thing after another the first 5 months I was in and out of hospital. I spent more time in hospital then I did out because everything went wrong. Nothing went wrong with my liver but everything else. I had a lot of blue light ambulance rides and things. And that was all very traumatic.

R: Can you tell me more about what was traumatic for you in that period?

P: Well I came out of hospital after 2 weeks and erm, I went back for my first check up, and I had been home for about 10 days and my eldest daughter drove home from Kent to see me and she had been home for about 10 minutes and then I just started screaming in pain. We phoned 111 and they thought I was having a heart attack and I had blue lights straight to hospital, but it actually turned out my spleen was bleeding. Then I had an ambulance blue lights down to Addenbrookes, then I was in hospital for a couple of weeks. Then I came home, and I was only home a couple of days and I was in so much pain I had to go back to my doctor who sent me straight back to hospital because I had a massive haematoma over my liver. Another couple of weeks in hospital. Then I was home for another couple of days and I just couldn't stop being sick, so I had another week in hospital erm. Then I had a couple of weeks at home and began to feel a bit better, then I ended up with sickness and diarrhoea and ended up being rushed into hospital and it turned out I had sepsis. So that was another blue light ride down to Addenbrookes. Then I had another bout of diarrhoea and sickness, then I went for a clinical visit and I had a phone call to say you need to come back in right now because your kidneys are failing. That was another 3 weeks in hospital. So that first 5 months was just constantly being ill, and everything was trauma and an emergency and. I sort of didn't really have time to recover. So, I don't feel as though I really started to get, recover from my transplant until the October when I left hospital the last time. I was very traumatically ill.

R: What was that experience like for you?

P: I'm one of these people who, things just happen, I just let them happen. I think because I was so ill at the time you can't think; you don't really think about being ill. It's just a matter of lying there and letting doctors pump stuff into you and. Let everybody else. Again, I was more worried about letting my kids down because I wasn't here for them. Erm. My youngest daughter was at high school and was just starting GCSE's, and erm, she hadn't told anybody. She hadn't told anybody that I was ill, and she suddenly broke down at school one day (cries).

R: What was that like for you?

P: I think that was worse than (cries). I think that was the worst thing, seeing how much that affected them.

R: Why do you feel that was the worst thing?

P: Because I never wanted to impact them, I never wanted them to be affected. But obviously they were, they had to be because I wasn't here. My daughter never really knew when I was going to be here. She would come home at night and her mum would be back in hospital again.

R: So, after the 6 months what was the experience like for you say up until now?

P: Erm, well again I've had lots of little things go wrong, blood work has been up and down and again I've been backwards and forwards to the hospital. To start with that was every week, then it was every 2 weeks, and now I go every 3 months. At the moment I'm fairly fine, I just get really really tired. I haven't got a lot of energy to do anything.

R: And what's that like?

P: Erm, well I look back at how I used to and all the things I used to do and all the running about after people and doing things, and you think I can't do that anymore. I try erm. I potter around the house and, as long as the kids are fed and the washing is done, and one thing and another and that's about it.

R: How does it feel to be in that position?

P: Erm (laughs) I feel as if I should be doing a lot more than I do, but as soon as I start doing anything I just have to sit down and rest. And erm, the eldest 2 kids are off, well Emily doesn't live at home anymore, my son is just home from uni, but I haven't seen him yet today. I think they just are used to me not being able to do everything I used to be able to do. And they just get on with our lives.

R: What is it like for you not being able to do everything you used to do?

P: Erm, I dunno, it's really hard to explain. I feel left out sometimes. I feel as if I should be doing more and erm. Normally we go on holiday every year, but we didn't go on holiday last year because I think my husband was just terrified to take me anywhere in case anything goes wrong (laughs).

R: How does that feel?

P: I dunno, it’s just. Sometimes it upsets me that I can’t do all these things I used to be able to do but I just do as much as I can and even if it’s just sitting here talking to my kids and erm. Again, because they are that much older they have got their own lives. Erm yeah (laughs) yeah it’s really strange.

R: Ok, so how do you feel about the transplant process now?

P: Erm, well its happened and it’s in the past now. I talk to a lot of people now who are waiting for transplants or who have had transplants and try and help them to get through it. It’s all through Facebook, I don’t meet these people face to face, but there’s several transplant groups onlines and if people ask questions you answer, tell them your experiences and erm. I try not to frighten people and I’ve also being doing work for the British liver trust and trying to spread the message about looking after your liver and not getting into this position.

R: What does it mean to you to be able to do that?

P: If I can stop one person from having to go through all this by actually thinking about what they are doing to their liver then that helps me.

R: How does it help you?

P: Just the thought that someone else hasn’t got to go through all this.

R: So, how would you describe the transplant process for you then?

P: Pretty traumatic (laughs) again because all of the things that happened afterwards. I didn’t come out of hospital and just got on with things because I ended upkeep having to go back even the doctors have said that it was a fairly traumatic time. I think if I had come home from hospital that first time and that would have bene it and I could have just got on with getting better, then that would have been a lot easier. But because I had to keep going back into hospital and all the things that happened afterwards, that was erm. They don’t, they can’t prepare you for, because it doesn’t happen to everybody. Everybody’s transplant is different, everybody reacts differently to things. Mine was just pretty traumatic.

R: Can you tell me how it feels to have had a new liver?

P: Erm, well it just comes down to the fact I'm still alive. For the first few months I couldn't even think about where that had come from or yes I knew in my mind that someone had died and that's where my liver had come from but I couldn't think of it in terms of that because I think I would have just broke down and got a bit, got really upset. Erm, so for months and months I think I was in denial of the fact that had come from another person but then I got accidently sent all the details of my donor and that really hit me hard because I was suddenly faced with the fact that where that had come from. That the person had died and all this. But now because I know so many facts about my donor I'm more at ease with it.

R: Can you explain a bit more about that?

P: Well my liver came from a 74-year-old who died having a heart operation, so that wasn't from a young person who died suddenly. That was from a person who had been ill. So, I think that, I don't know how I would have coped if that had been from a younger person. The fact it came from a 74-year old who I know had a daughter, had grandchildren, that she lived a life that wasn't suddenly cut short at a younger age. I think that's quite a reassuring thought, rather than from somebody who was young. But then again you don't know how you're going to feel if that was from different circumstances. I just had to think that was a spare part. I always knew that at some point I would have to face it and at some point I would write and thank the donor's family. That was always at the back of my mind. That was just, yeah a spare part. Then I had this letter that had all the details in and that was like being slapped around the face.

R: What was that experience like for you?

P: That was, I opened this letter which I thought was just a normal letter I got after a clinical review and erm, they had inadvertently put all the details of the donor on. Which even the doctors should be able to access.

R: How did that affect you?

P: I sat and cried for half an hour. Erm, then I got I touch with the hospital and said I don't think I should have this information should I, and they all said no and apologised. And yeah, but suddenly I knew, and you can't take that information out of your head again can you. As much as they apologised for sending that to me, they couldn't take it out again. I knew that my donor was 74 and where she died, and how she died.

R: How did it feel knowing that?

P: At first I was totally in shock, but once I had sat and thought about it you think well yeah 74. For a start I didn't think you could transplant, anybody that age could donate organs, because you always think of it from being from younger people. But the more I thought about it the more you think well yes she was 74 she had a family, she had grandchildren, in a way she had lived more of a life. Yeah that is what I think my liver is 76 years old, but it was in better condition than mine.

R: So, what does it mean for you to have had the transplant?

P: Well the bottom lines is that I'm still alive and that I would just like to use my experience to help other people, either prevent it or go through it. I've been assured that I wouldn't be here, because on the actual day of the transplant when I had to wait for the surgeon to decide whether he was going to operate due to this blood clot. And they told me afterwards another 2 weeks and I would have been inoperable because the veins wouldn't have been big enough to join up to the new liver and that I would have been dead by Christmas.

R: How does it feel to reflect on that?

P: Well you can only sort of think that I'm living on extra time, that I've got to look after my new liver as best as I can for my donor and for all the surgeons and doctors that put in all the hours of work. And are still looking after me, I've got to live the best life I can. That's why I volunteer for things like this (laughs). I only had 2 months.

R: How does it feel to be here now knowing that information?

P: Erm, it feels good really because I don't know what life would have been like for everybody else without me. Just, yeah, I don't really know, I can't really answer.

R: That's fine. What support would you have liked throughout the process?

P: Well I did have support, that's first sort of 6 months I was in hospital there was always nurses and transplant coordinators and doctors there. I don't think a single one of the doctors hadn't sat and held my hand whilst I cried or the nurses. When I was originally in for my transplant, they did send a psychiatrist to see me because they realised I was in a bit of a state of shock.

And also because of all the drugs and things I was having, you have nightmares and hallucinations and, which they don't want you about.

R: What was that like to experience?
P: That was awful. They sort of said are you having hallucinations, are you seeing people who are not there, and I said no because all these people were so real. It was so real having these people sitting on my bed and talking to me, who weren't there at all. It was because of all the painkillers that they pump into toy. And nightmares they were so bad I fell out of bed one night because I was in such a state.

R: How did going through that effect you?
P: Well that was awful, awful (laughs). A lot of the nightmares involved my brother, my elder brother. When my mom came to see me, I talked them all to her and just said go home and tell him to stop up and that seemed to stop the problem. Well the ones involving him anyway. It happened in the two weeks I was in hospital, directly after the transplant. Apparently its fairly normal but they don't want you about it. You think you're the only one and you don't want to admit to seeing all these people that aren't there because you think I'm going mad.

R: So, going through that was difficult for you?
P: Yeah, I think that you don't want to admit you're going through all this. The nightmares you have to admit because when you wake up screaming, and again I fell out the bed. But to admit that you have all these people coming to see you and sitting on your bed and talking to you, when they're not there.

R: What was it like for you to face that?
P: I think I knew that they weren't there because I couldn't possibly have all these children sitting on my bed and all these people there because I knew that was against the rules of the ward. Children weren't allowed in, so I think I knew they weren't real all along. That's only looking back on it now, you sort of think that's pretty weird. That's really weird. It wasn't something I'd ever experienced before.

R: How did it effect you going through that?

P: That was just a really strange and surreal time. You don't know what's real and what's not. Even looking back on it now you think did that really happen or was that all in my mind. You sort of have to work out what was real and what wasn't. I think if beforehand your told that you're going to be put on a lot of heavy painkillers and that you probably will have all these hallucinations and, but don't worry about it we know about it sort of thing. Which again is something I can now say to people on Facebook whose partners, mothers, fathers are in hospital and they Are sort of saying ooh they're not behaving like they normally do; they are seeing people. And you think yeah that's perfectly normal. That's fine, you can talk about it to them. You just, yeah because I've been through that I can explain to others who have gone through that that is normal.

R: Do you think it would have been less traumatic if someone had have spoken to you about that?

P: Yeah if they talk about that in the process leading up to the transplant that you will be put on a lot of painkillers and its possible you will have all these hallucinations and nightmares. That's perfectly normal, you can talk about it and we won't lock you up because your mental. You would have known that that was normal and that that wasn't you, me going mad. I think that's. the one good thing is that you're on a ward which everyone on the ward has had transplants, kidneys, or livers, so at least other people are in the same situation.

R: How do you feel you coped through the process?

P: Erm, I know they did send somebody to talk to me but because I didn't admit, I didn't say anything to him that I was having these hallucinations because I thought they would think I'm mad. And because they were so real at the time. My husband would come and see me every day, so I had somebody to talk to. I think I talked to him and mum more about it than anyone else.

R: So, family were a big source of support for you?

P: Yeah, yeah.

R: Do you think it effected your relationships in anyway having the transplant?

P: No not really, I think if anything it brought me and my husband closer together because he had to look after me for so long and. All the times he's had to run about after me and one thing or another. I think it brought up closer together.

R: How did it feel to be looked after?

P: Awful because I've always been the one looking after everybody else. I've always been the one doing everything for the family and all of a sudden I couldn't do it. Even though my husband had to do all the washing and you think ooh he's never had to do that before. That's always been my job. I should be the one doing it, and my younger daughter had a parents evening at school, and I couldn't go so my elder daughter went. And you think no that should be me talking to her teachers not her sister (laughs) and erm but I just couldn't do it.

R: Would you say there were limitations you've had to live through going through this process?

P: Yeah sort of yeah. I didn't drive for the first 9 months. Where I live is very limiting, basically we live in the middle of nowhere. If you don't drive your stuck at home. Which meant I couldn't take my daughter to all her dancing lessons. I couldn't do things when she had done things at school because I just couldn't get there. Once I started driving again, things improved a lot because I could suddenly get out and I could start the school run and doing things with her again and taking her to her dance lessons and instead of having to rely on other people to do it. It's not something I've ever really done before; it's always been me doing it. I was the one running other people's kids around and being there for them and other parents in the village would phone me up and say ooh I can't get back to the school could you pick so and so up from school and is it alright if they come round yours tonight because I can't get there. And then all of a sudden it was me in that position, asking can you take Beth to dancing tonight and can you do this, and can you do that. Which no body minded because I had done it all in the past, but I don't like asking people for help (laughs). Having to ask the elder kids to run about after their sister. You know you have to.

R: How would you say you have personally coped? Have you coped well or not so well?

P: Erm, I think it was very very stressful. Like even now I went to Addenbrookes a couple of weeks ago and I sat there the next day waiting for a phone call because there's something wrong. And until I get my blood results back then I can look through them all and say yeah that's fine, that's fine. You can't relax because you're constantly waiting for a phone call to change your drugs or. I think my life revolves around taking drugs and one thing and another (laughs).

R: And what's that like for you?

P: I hate taking drugs, I'm not very good at it (laughs) I can't swallow them. Which I know is all in my mind but again the hospital and doctors and the pharmacists, they're all brilliant and have all found ways round it so that I can take them. Yeah, you just have to live with it don't you and that just becomes part of your routine that every 12 hours I have to sit down and take loads of drugs.

R: How do you feel about having to do that?

P: Well I know if I don't do it I will possibly die, so you just get on with it don't you. There's no good moaning about it I've just got to do it (laughs).

R: Is there anything about your experience of the transplant process that we haven't discussed that you would like to tell me about or mention?

P: Erm, no I don't think so. I think we've spoke about everything. I just hope I've been able to help you.

R: Is there anything pertinent you would like to say as a leaving message?

P: Everybody thinks you have a transplant and your cured, it's not a cure it's a treatment. It's a lifetime process. It's going to affect me for the rest of my life because for the rest of my life I've got to be trailing back and to the hospital for check-ups, blood tests, taking drugs (laughs). Even the doctors think well you've had your transplant and your alive. Yeah they don't realise, every time I go to clinic I seem to take a list of moans (laughs). My doctors are absolutely brilliant, and they will sit and listen to me, but I don't think they really realise how that affects you.

R: Have you had any sort of therapy at all?

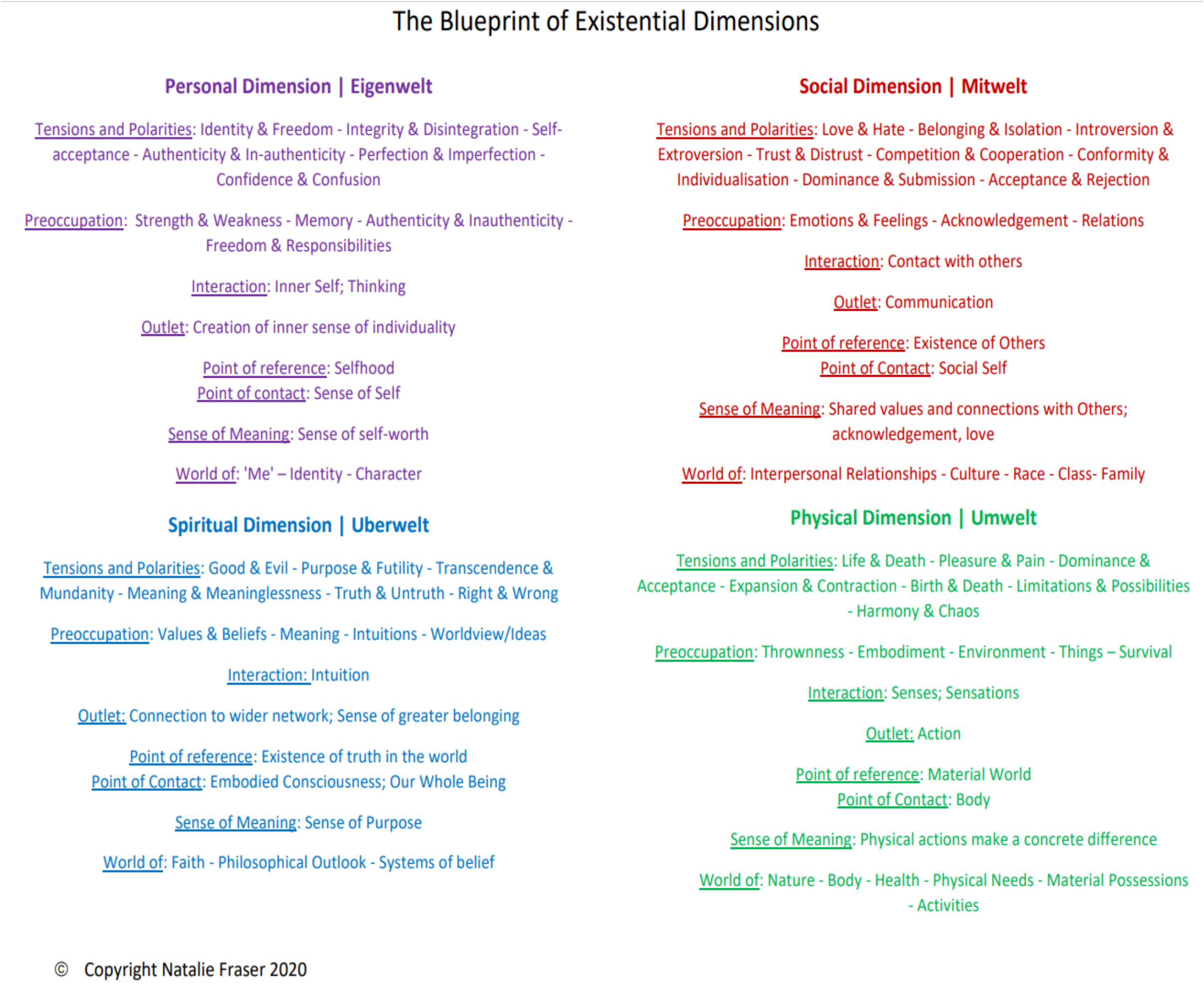
P: No, no, I think in my own mind I can sort it out. Yeah (laughs).

R: Do you think it would have been beneficial to you?

P: Not really no because I always really analyse everything I think through anyway sort of do it myself really yes. I sort of sit and think yeah that was pretty traumatic, but I've survived it and now let's just cope with the next hurdle and get over it.

R: Thank you for today. (Researcher went on to debrief participant)

Appendix 12 – The Blueprint of Existential Dimensions



The Blueprint of Existential Dimensions

Personal Dimension | Eigenwelt

Tensions and Polarities: Identity & Freedom - Integrity & Disintegration - Self-acceptance - Authenticity & In-authenticity - Perfection & Imperfection - Confidence & Confusion

Preoccupation: Strength & Weakness - Memory - Authenticity & Inauthenticity - Freedom & Responsibilities

Interaction: Inner Self; Thinking

Outlet: Creation of inner sense of individuality

Point of reference: Selfhood
Point of contact: Sense of Self

Sense of Meaning: Sense of self-worth

World of: 'Me' – Identity - Character

Spiritual Dimension | Uberwelt

Tensions and Polarities: Good & Evil - Purpose & Futility - Transcendence & Mundanity - Meaning & Meaninglessness - Truth & Untruth - Right & Wrong

Preoccupation: Values & Beliefs - Meaning - Intuitions - Worldview/Ideas

Interaction: Intuition

Outlet: Connection to wider network; Sense of greater belonging

Point of reference: Existence of truth in the world
Point of Contact: Embodied Consciousness; Our Whole Being

Sense of Meaning: Sense of Purpose

World of: Faith - Philosophical Outlook - Systems of belief

Social Dimension | Mitwelt

Tensions and Polarities: Love & Hate - Belonging & Isolation - Introversion & Extroversion - Trust & Distrust - Competition & Cooperation - Conformity & Individualisation - Dominance & Submission - Acceptance & Rejection

Preoccupation: Emotions & Feelings - Acknowledgement - Relations

Interaction: Contact with others

Outlet: Communication

Point of reference: Existence of Others
Point of Contact: Social Self

Sense of Meaning: Shared values and connections with Others; acknowledgement, love

World of: Interpersonal Relationships - Culture - Race - Class- Family

Physical Dimension | Umwelt

Tensions and Polarities: Life & Death - Pleasure & Pain - Dominance & Acceptance - Expansion & Contraction - Birth & Death - Limitations & Possibilities - Harmony & Chaos

Preoccupation: Thrownness - Embodiment - Environment - Things – Survival

Interaction: Senses; Sensations

Outlet: Action

Point of reference: Material World
Point of Contact: Body

Sense of Meaning: Physical actions make a concrete difference

World of: Nature - Body - Health - Physical Needs - Material Possessions - Activities