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MAJOR RESEARCH PROJECT

RACHEL ELIZABETH FALK BSc (Hons) MSc MSc

IDENTITY AND ADJUSTMENT: EXPERIENCES OF THE ORGAN
TRANSPLANT RECIPIENT

Section A: Identity and the organ transplant recipient: A systematic review

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Section B: *"So I am grateful to be here, very grateful"*

:A Constructed Grounded Theory of Young Adults' Adjustment Post Liver
Transplant

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Summary of MRP Portfolio

Section A: The gap between medical progression and psychological research in the area of organ transplantation is of concern. Psychological factors have been shown to impact on the outcome of these expensive and invasive medical treatments. Studies show that difficulties in incorporating the transplanted organ into one's identity may be a risk factor for non-adherence to medical advice, and therefore contribute to graft rejection. Through a systematic search of six databases, 20 relevant empirical studies were identified, which focused specifically on how receiving a whole organ transplant may impact on an individual's identity. Implications for clinical practice and future research are also discussed.

Section B: The study presents a constructed grounded theory of young adults' experiences of liver transplant. Positive health-related behaviours are beneficial and important in transplant recovery. However, evidence indicates that adolescents in particular are less likely to engage in these behaviours, putting their post-transplant health at risk. Semi-structured interviews were conducted with 12 young adult liver transplant recipients. Analysis resulted in a model constructed to capture the dynamic interactions between thirteen categories, resulting in four main themes. A deepened understanding of these processes may help improve health-related behaviours in a population that struggle with adherence.

Section C: Appendices and Supporting Material

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MAJOR RESEARCH PROJECT

RACHEL ELIZABETH FALK BSc (Hons) MSc MSc

Section A

Identity and the organ transplant recipient: A systematic review

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Abstract

Five-year graft survival rates for liver, kidney and heart transplant are now almost 80%. Advances in physical medicine raise the question regarding the long-term psychological impact of such procedures. The gap between medical progression and psychological research is of concern, as psychological factors may impact on the outcome of these expensive, time-consuming and invasive medical treatments. Studies show that difficulties in incorporating the transplanted organ into one's identity may be a risk factor for non-adherence to medical advice. Therefore if transplant recipients' psychological needs are understood, and they are supported to integrate the donated organ into their identity, they may demonstrate better adherence to their medical regime. This review will focus specifically on how receiving a whole organ transplant may impact on an individual's identity. Through a systematic search of six databases, 20 relevant empirical studies were identified. Implications for clinical practice and future research are also discussed, including whether different organ transplant recipients face different challenges in relation to identity and organ integration. Furthermore, a gap in the research literature is highlighted, as there seems to be a dearth of UK based research in the area of transplant recipients' experiences.

Keywords: Organ Transplant, Identity, Transplant Recipients

1. Introduction

1.1 Organ Transplants

The first organ transplants took place in the 1950s and since then have grown exponentially in terms of the numbers carried out, survival rates and those on waiting lists (Svenaesus, 2012; Tilney, 2003). The discovery of immunosuppressive drugs such as cyclosporine in 1969, resulted in a decrease in graft rejections post-transplant (Griffith, Hardsby & Thompson, 1983). Five-year graft survival rates for liver (Kim et al., 2012), kidney (Colvin-Adams et al., 2012) and heart (Matas et al., 2012) transplant are now almost 80%. Transplants now include kidney, liver, pancreas, heart, lung, arm, leg, hand, foot and face. High demand for these life saving organs with low, limited supply have lead to their commodification. The world's media have also recently reported that the first human head transplant could be as little as two years away (Thompson, 2015). These advances in physical medicine raise the question regarding the psychological impact of such procedures and shine the light on an area of much needed, but limited, research.

1.2 The psychological impact of receiving a donated organ

In a large-scale review that included almost 150 studies it was found that depression and anxiety related disorders were common post-transplant (Dew & DiMartini, 2005). It was also reported that these experiences are not only common in the initial post-transplant stages, but can be present at any time, particularly in the 3-5 year post-transplant period (Dew & DiMartini,

2005). Another longitudinal study with 156 heart transplant recipients, over a period of four years, found that 21% had highlighted significant levels of distress at all times (Dew et al., 2005). Pre-operatively transplant recipients may be dealing with end stage disease, chronic illness, alcohol dependence, the impact of attempted suicide or any other number of physical and emotional difficulties. They may have to face their own mortality, whilst also the reality that an anonymous donor has to die in order to save their own life. Whilst they wait for that donor to die, they may be faced with intense feelings of shame and guilt (Bunzel, Schmidl-Mohl, Grundböck & Wollenek, 1992). Post-transplant the uncertainty of graft survival, adapting to life, and coping with treatment side effects can majorly impact on transplant recipients' development and psychosocial outcomes (Tong, Morton, Howard, & Craig, 2009).

Rodgers (1984) speaks of a psychological transplant that occurs beneath the organic one. Receiving an organ from a cadaver may negatively impact on the integration of the organ, due to the recipient's psychological reaction to the lifeless state of the donor (Bash, 1973). A study found that many transplant professionals agree that physiological rejection of a transplanted heart may, at times, be associated with psychological rejection (Rauch and Kneen, 1989). Non-compliance to medication and postoperative care is one of the biggest factors leading to graft rejection post transplantation (Goetzmann et al, 2007). A study with young adult heart transplant recipients found that those who integrate their donated organ into their identity were good adherers, whilst those who continued to 'push away' their transplant

experience were poor adherers to medication, appointments, tests and engaged in more high-risk behaviours (Lawrence, Stille, Olshansky, Bender, & Webber, 2008, p.50). It therefore seems logical that a great number of graft rejections may be avoidable if transplant recipients' psychological needs are understood and they are supported to integrate the donated organ into their identity and adhere to their medical regime.

1.3 Identity

Our identity is shaped by processes that occur in our body, our mind, in our interactions, and by our society and culture (Svenaeus, 2012). As we live in a world of language it is also shaped by the stories that are told about us, and our experiences that are shared with others. Havighurt's (1972) theory on development brings together multiple aspects of development, including; physical, personality and identity and societal expectations (Lugasi et al, 2013). Havighurt (1972) proposes that developmental tasks can come from physical, identity or social sources. It seems that this is particularly relevant to transplant recipients, as development and recovery post-transplant provides challenges from each of these areas.

Erikson's theory of identity development (1959) describes eight stages, each involving a conflict that needs to be resolved before one can move onto the next stage. Mastering the fifth stage, identity achievement versus identity diffusion, which is traditionally associated with adolescence, can have positive

consequences in adulthood (Kroger, 2007). Studies show that identity status is strongly related to well-being and self-esteem (Phillips & Pittman, 2007).

The terms identity, self-concept, self, self-image or sense of self can have different meanings for many people and yet all seem to overlap and interact. They seem to be important constructs in the formation of self-esteem (Bailey, 2003). In order to operationalize the term '*identity*' for the purpose of this review the author attempted to find a clear definition; however it was clear that there are a wide variety of ways that identity is defined including individuality, sameness, personality and the act of 'being', to mention a few. This range of definitions immediately brings up interesting ideas when being considered in the context of organ transplant. Specific definitions given in papers included in this review are discussed in further detail, when considered to be relevant. However Bailey (2003) reminds us that self-identity is more of a process, "the result of a series of involved steps over a long period of time" (p.385).

1.4 Organ Transplants and Identity

In the UK, a dead person is considered to be a prospective organ donor, unless their family refuse. The fact that the donor's family are involved in this decision-making process, suggests that they too are part of the identity of that individual. It highlights that identity stretches beyond the individual (Carosella & Pradeu, 2006). Indeed, it has also been reported in the literature that integration issues are not only limited to transplant recipients, but may

also prove challenging for their family members (Frierson & Lippmann, 1987). A common belief in popular culture is that organ transplant recipients may take on the personality traits of their donors. It was found that recipients fantasied about adopting some parts of their donors' identity (Sanner, 2001).

Whilst there is a dearth of empirical research in the area of how whole organ transplant may impact on identity and vice versa, this topic has been discussed in more detail in relation to other transplants, such as face and hand transplants. This is perhaps understandable, given the impact of having such a transplant that may significantly change the way one appears, and how one is perceived. It has been noted that a graft of a visible organ (i.e. hand or face) may lead to an identity split and that if the recipient does not psychologically accept the new organ, this may lead to catastrophic consequences such as non-adherence to their medical regime, or even death (Carosella & Pradeu, 2006). However, the question must be asked if this only applies to visible organs. Perhaps as whole organ donors' scars may be hidden under clothes from mainstream society, their psychological distress relating to difficulties in integrating their new organ is also hidden.

1.5 Rationale

The gap between medical progression and psychological research is of concern, as psychological factors may impact on the outcome of expensive, time-consuming and invasive medical treatments (Collier, Nathanson & Carolyn, 1999). It therefore seems that there is a need to address this gap in

the literature and begin to answer some of the questions related to the transplant experience, and how transplant recipients adjust psychologically post-transplant. It has been highlighted that on-going psychological assessment and support is necessary for paediatric transplant recipients and their families, for example, as more than 25% of them will have emotional adjustment difficulties (DeMaso et al., 2004). We can assume that this is also the case for those undergoing other whole organ transplants, at different life stages. Without meaningful research, and a development of our understanding of the processes involved for transplant recipients, these psychological interventions may not be adequate.

This review will focus specifically on how receiving a whole organ transplant may impact on an individual's identity. It is important to focus on the impact on identity because studies show that difficulties in incorporating the transplanted organ into one's identity may be a risk factor for non-adherence to medical advice (Goetzmann et al., 2007; Lawrence, Stilley, Olshansky, Bender & Weber, 2008). It is hoped that this review will contribute to this growing area of research and help to develop understanding and practice in this field.

1.5.1 This review. Through a systematic search of the literature, this review will consider the empirical evidence relating to how receiving a whole organ transplant may impact on an individual's identity. This review will bring together, and summarise, the existing published literature in this area, highlighting the most important issues and themes. Implications for future research and clinical practice will be presented.

2. Method

2.1 Literature Search

Preliminary electronic database searches were carried out to identify appropriate terminology for the systematic search. Pertinent search terms were obtained from relevant articles obtained through these initial searches. The following databases were searched: Ovid Platform: PsycINFO, Medline, PsycARTICLES, EuropePMC Platform: PubMed Central, EBSCO Host Platform: CINAHL, Web of Knowledge: Web of Science. The searches were all conducted using the appropriate search operators for each database, up to week 4, January 2014. Please see Appendix 1 for more details.

Appropriate studies were identified through a four stage process; identification, screening, eligibility and inclusion. A flow chart, describing the process of this search, citations identified and screening procedure can be found in Appendix 2 (Moher, Liberati, Tetzlaff, Altman, The PRISMA Group, 2009). Papers were excluded following full text screening, if they did not meet the eligibility criteria. At the end of the eligibility screening stage any duplicate citations were removed (n=19), resulting in the twenty papers included in the present review, see Appendix 3 for an overview.

2.2 Study Features

2.2.1 Design. For the purpose of this review papers were only included if they were empirical studies; conceptual papers were excluded. No

limitations relating to design were applied, in order to achieve a wide range of research. The papers included in this review used a range of experimental design; longitudinal, cross-sectional, retrospective and case studies. None of the studies had a control group and studies used a mixture of quantitative and qualitative measures.

2.2.2 Exclusion criteria. Studies were excluded from the review if they;

1. Were not available in English,
2. Were conducted with a non-human sample,
3. Were not conducted with whole organ transplant recipients,
4. Were not empirical research,
5. Were conceptual papers,
6. Were not published in peer-reviewed journals.

2.3 Data Extraction and Quality Assessment

Most of the studies identified used qualitative methodologies (n=13), whilst others used a mixed method approach (n=4). The quality of the qualitative studies, and qualitative aspects of the mixed-methods studies, were assessed using guidelines for qualitative research (Elliott, Fischer & Rennie, 1999; Appendix 4). The articles that used quantitative methods (n=3), as well as those who adopted quantitative methods as part of their mixed-method approach (n=4) were assessed using an adapted Effective Public Health Practice Project (EPHPP, 2009) assessment tool for quantitative

studies, which was developed for use in public health and therefore felt especially appropriate for this study. Some of the sections, referring to confounders and blinding, were removed from the tool, making it more pertinent to the present study (Appendix 5). One paper included in the study was a case study, and was therefore assessed using Yin's (2003; Appendix 6) guidance. Meltzoff's (1998) suggestions for critically evaluating research, were also adopted in critiquing the papers. Strengths and limitations of the papers will be discussed further in the results section.

3. Results and Discussion

3. 1 Overview of selected papers

Studies were based in the United Kingdom (UK; n=1) Australia (n=2), Austria, (n=1), China (n=1), Finland (n=1), Israel (n=1), Germany (n=1), Switzerland (n=3) Sweden (n=5), Turkey (n=1) and the United States of America (USA; n=4). Authors came from a diverse range of occupational backgrounds, including nursing, occupational therapy, social work, psychiatry, cardiology, pulmonary medicine and psychology.

The studies were carried out with heart (n=6), kidney (n=7), liver (n=6) and lung (n=5) TRs, or a combination of recipients. Although not reported in two papers, the participants ranged in age from four to 68 years across the remaining studies. Although not reported in three papers, the participants' time post-transplant ranged from six weeks to 10 years across the remaining studies. Participants were undergoing transplants for a range of medical

reasons, not always reported in the literature. Participants also received their organs from living and deceased donors. A basic thematic analysis was conducted as papers were searched for common themes. They will be discussed below, according to their main themes, for ease of synthesis.

3.2 Denial of Identity

TRs' denial of the donor, or donated organ, and this potential impact on identity was discussed in a number of studies (Ådahl, 2013; Biörck & Magnusson, 1968; Bunzel et al., 1992; Jones, 2005; Kaba, Thompson, Burnard, Edwards & Theodosopoulou, 2005; Nilsson, Persson & Forsberg, 2008; Sanner, 2003; Ullrich et al., 2010; Zhang et al., 2005). It has also been reported elsewhere in the literature that transplant recipients may use a number of defence mechanisms to cope with the stress of transplant (Mai, 1986), such as depersonalization in the form of comparing the organ to a piece of machinery, or regression such as denying ever thinking about it (Bunzel et al., 1992). In a qualitative study Bunzel et al. concluded that 80% of the recipients made comments suggesting that they were in either complete or partial denial that undergoing a heart transplant may have changed their personality, for example, "I never think about it" (Bunzel et al., 1992, p.254). It was also reported that the transplant recipients knew the interviewer since their admission to the transplant waiting list. The authors felt this contributed to open and honest answers, however there is also the possibility that this introduced bias to the data. This is not considered or discussed in the article.

Zhang et al. (2005) found that Quality of Life (QoL) in post liver transplant recipients is associated with their psychological characteristics. In their quantitative, cross-sectional, study they found that psychological wellbeing is positively correlated with confrontation ($r=0.28$, $p<0.05$) and negatively correlated with acceptance ($r=-0.472$, $p<0.01$), according to the Medical Coping Modes Questionnaire (MCMQ). They highlighted the need of transplant recipients to communicate frequently with their family and medical team about the details of their illness in order to obtain relevant information, as avoiding the topic leads to a poor general QoL. As this study was conducted in China, the findings may not be generalizable to other cultures or ethnicities. The authors compare their findings to a study carried out in the United States of America (USA; Streisand et al., 1999) where lower scores of avoidance were reported.

Some interesting results were found in a qualitative study, conducted in Germany with lung transplant recipients, which analysed semi-structured interviews using content analysis and frequency distributions (Ullrich et al. 2010). Recipients were asked their views on the integration of their new organ. It was found that time since transplant was important in how transplant recipients spoke about their experiences. Recipients with a post-transplant interval below 3 years answered in a more positive or neutral manner, whereas transplant recipients with a longer interval post-transplant denied thoughts of the donor or donated organ answering with 'exclusion', which is defined in the study as denial ($p=0.07$; Ullrich et al. 2010, p.716).

Ullrich et al. (2010) also reported 7- year follow-up data, and found that eight transplant recipients had died. Interestingly, seven of these eight people had answered with 'exclusion' (Ullrich et al. 2010, p.716), denying thoughts of the donor or donated organ. If patients who had undergone a re-transplantation are included this brings the total number to 16. Of these 16, 12 transplant recipients answered with denial. These results warrant further exploration of this sensitive issue, given that transplant recipients were asked about integration of their new organ and most deaths occurred in those who expressed more denial. However, it should be noted that this finding was not statistically significant, likely due to the small number of deceased to living participants in the sample (Ullrich et al., 2010). A similar finding was presented by a study where the majority of recipients accepted the donated kidney as "their own" (Biörck & Magnusson, 1968, p.183), but for the one transplant recipients who could not accept their donated organ, it had to be removed after three years.

A longitudinal qualitative study was completed in Sweden, which interviewed lung and heart transplant recipients, who received donations from living and dead donors, on five occasions during the two years immediately post-transplant (Sanner, 2003). All deceased-donor transplant recipients were reported to have used suppression, avoidance and denial, at some point in the two year follow up. However, the authors found that these defensive strategies were used most in the six months immediately post-transplant, which was a contrary finding to the Ullrich et al. (2010) study, but seemed to be supported by Jones (2005) who found in a longitudinal study that identity

issues emerged in the first six months post-transplant. Jones (2005) reported that two years post-transplant, most of the participants were more willing to discuss some of their donor's traits. However, it was noted that for some transplant recipients, denial of their experience persisted.

It has been noted that denial may not be maladaptive but may be necessary in order to aid emotional adjustment in some transplant recipients (Mai, 1986), indeed transplant recipients who experience more emotional distress may need to use subconscious defences in order to protect themselves. One study highlighted that the transplant recipients' acceptance of their donated organ, and therefore assimilation into their identity, may be achieved through denial or suppression of feelings that may be dangerous if they came to the surface (Biörck & Magnusson, 1968). A further study discussed that transplant recipients' struggle to be regarded as healthy may act as a defence against them identifying themselves as ill (Nilsson et al., 2008), perhaps refusing this as part of their identity. In a qualitative study carried out with heart transplant recipients in the United Kingdom it was identified that denial seemed to help participants cope with their concerns about the likelihood of their personality having changed (Kaba et al., 2005).

Ådahl (2013) highlighted the role of the medical profession in denying the possible impact of having a transplanted organ on transplant recipients' identity. The objectifying and anonymising dominant discourses used by medical professionals, in order to put the recipient at ease, can deny that the organ belonged to someone else, and has its own story.

3.3 Integration and Incorporation into a new Identity

Identification is the practice in which an individual mentally assimilates aspects of another person into their own psyche (van der Velde, 1985). A number of papers talk about issues that fall under this theme (Bunzel, et al., 1992; Forsberg, Bäckman & Möller, 2000; Durst et al., 2001; Sanner, 2003; Inspector, Kutz & David, 2004; Jones, 2005; Goetzmann et al., 2007; Neukom, Corti, Boothe, Boehler, Goetzmann, 2011; Schmid-Mohler, Schäfer-Keller, Frei, Fehr & Spirig, 2014).

One idea is that the transplanted organ is incorporated into one's identity, and a new mixed version of the self is reborn. Ådahl (2013) hypothesised that this happens through a process of personification, relationality and identification. In Ådahl's ethnographic study with kidney transplant recipients, recipients seemed to personify the donated organ in order to ascribe selfhood to the transplant organ as a way of trying to mix the self of the kidney, with ones' own self, "It's my pet...I have the kidney's name day today...to my mind most [recipients] surely give it a name" (Ådahl, 2013, p.142). Interestingly Sanner (2003) highlighted that identification seemed to occur when TRs could think about their donor in a positive way. It seems that they were therefore able to move away from denial and some of these recipients also found a way to honour their donor i.e. thanking them in some way.

A mixed-method study to explore transplant recipients' perspective of self-management tasks in the early phase after kidney transplant was conducted in Switzerland (Schmid-Mohler, Schäfer-Keller, Frei, Fehr & Spirig, 2014). One of the themes identified was "Managing changes in self-perception" (p.11). This theme included the challenge to transplant recipients' identities of dealing with changes in appearance, managing reduced energy and bonding with the transplanted kidney. One transplant recipient spoke of the feeling that the graft was not his own, and struggled to form a bond with it, "is it alien, is it not alien? Is it mine? Is it not mine?" (P.12). Another study acknowledged the grief in losing an organ, albeit diseased, experienced by transplant recipients as though a loss of previous identity took place (Forsberg et al., 2000). One recipient found it hard to incorporate the new identity into their old familiar bodily shell, 'I couldn't find me. Who am I...Instead there was a new person, the whole identity, you became new, a new person' (Forsberg et al., 2000, p.331).

In a mix-methods study which looked at heart transplant recipients' psychological adaptation post-transplant, it was concluded that incorporating another's heart involved a complex and prolonged course, from despair, near death experiences to 'miraculous' recoveries (Inspector, Kutz & David, 2004, p.171). Severe difficulties were also observed in another study regarding incorporation of a transplanted heart, based on ideas about the heart housing one's feelings and personality (Bunzel et al.,1992). Inspector et al. (2004) also highlighted the tension between having a new lease of life, whilst simultaneously having an insight into fragility and unpredictability of life.

However, this theme does not seem to solely apply to heart transplants, and in their study, although 16% (n=4) found it difficult to accept the heart as their own, 84% (n=17) assumed ownership.

Durst et al. (2001) found in their qualitative study examining 19 adolescent cystic fibrosis patients' responses to lung transplantation, that all of the participants demonstrated successful psychological integration of organ. Of these 19 transplant recipients, 16 underwent living donor lobar lung transplant procedures and three received deceased donor lungs. They noted that the participants did not express guilt in relation to their donor, something that was picked up on in other studies (Neukom, Corti, Boothe, Boehler, Goetzmann, 2011; Schmid-Mohler et al., 2014). Given that this study included a specific set of recipients, that had a chronic condition before transplant, these results may not be generalizable to other transplant recipients. Furthermore, the majority of these donors were living, which may also have a positive impact in reducing feelings of guilt.

A qualitative study examining transplant recipients' fantasized recipient-donor relationships following lung transplantations considered the incorporation of a donated organ (n=6; Neukom et al., 2011). In all eight narratives, participants implicitly consider whether and how they are still connected to the deceased donor. In five narratives, they concern themselves with the person of the donor in terms of gender, age or specific personality traits. Four narratives talk about the correlation between the death of the donor and one's own life. One person mentioned the donor had not died, but

continued to live in them. This study was the only one in the current review that presented a theoretical model of organ integration. They focused on the relationship between the donor and the recipient and describe the process in three stages (see Figure 1).

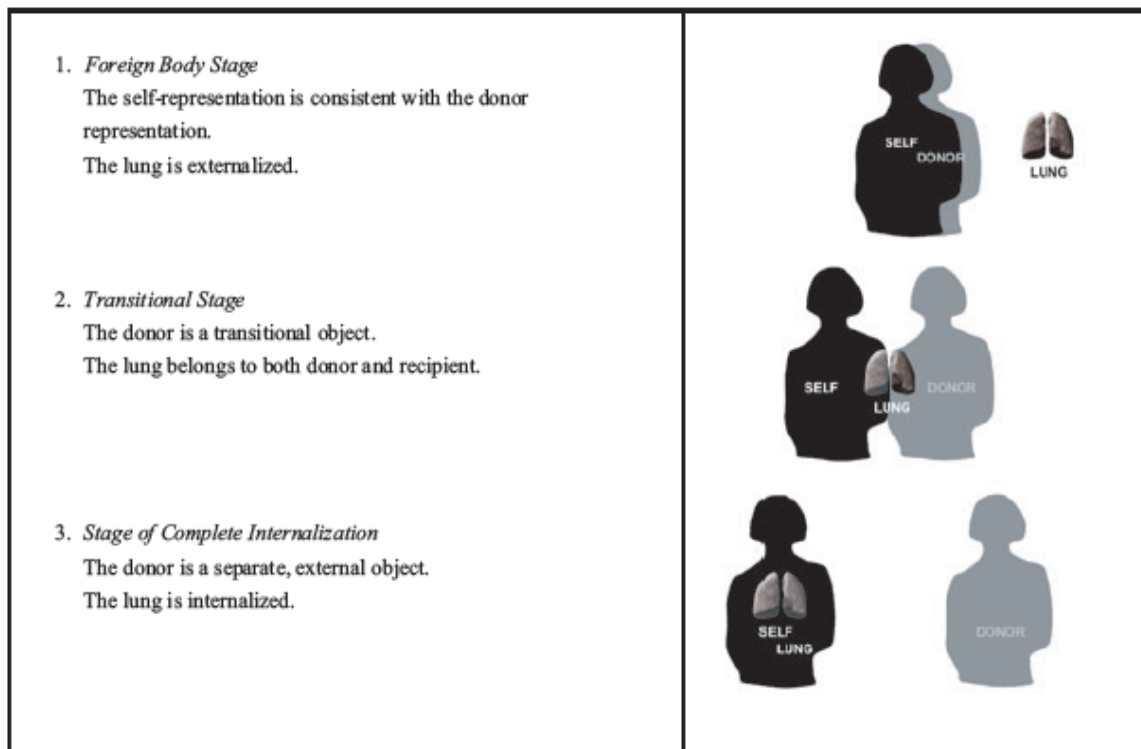


Figure 1: “Self, donor, and organ representations using the lung in a transplantation-specific model” Reprinted from Reprinted from “Fantasized recipient-donor relationships following lung transplantations: A qualitative case analysis based on patient narratives,” by Neukom, M., Corti, V., Boothe, B., Boehler, A., & Goetzmann, L. 2011. *The International Journal of Psychoanalysis*, 93(1), p.120. 117–137. Copyright 2012 by Wiley Publications. Reprinted with permission (Appendix 7).

In support of this theory, it was found that psychological processing of the transplanted organ may be successful, if firstly the new organ is integrated into the self and secondly the donor perceived as a separate person (n= 14;

Goetzmann et al., 2007). Furthermore transplant recipients in this study with poor medical adherence seem to experience their organ as a foreign object, but the donor as close at the same time. We could hypothesize that these participants are in the Foreign Body Stage of organ integration, and have not yet reached complete integration.

In a longitudinal study (Jones, 2005) integration and identity findings were consistent with, and discussed, using The Simmons and Abress (1990) 3-stage model of organ transplant recovery. This model states that the first stage of recovery can be explained by initial euphoria, as the transplant recipients survives major surgery and cheats death. However, by the 6-week interviews this has given way to fear and depression as transplant recipients realise the challenges that lie ahead of them. Identity issues emerged in the six-month interviews, where many reported an unsettled sense of self.

3.4 Adopting Donors' Traits

The theme of transplant recipients adopting the traits of their donor was widely discussed in the literature (Ådahl, 2013; Bunzel et al., 1992; Durst et al., 2001; Inspector et al., 2004; Jones, 2005; Kaba et al., 2005; Sanner, 2003). One paper found that kidney transplant recipients in Finland may anthropomorphise their transplanted organ, as they believe that personal features are carried over (Ådahl, 2013). In a grounded theory qualitative paper on heart transplant recipients' postoperative psychological difficulties one of four identified categories was presented, 'somebody else's heart inside me'

(Kaba et al., 2005, p.617). This category related to transplant recipients' concerns about the donor's heart, and how the donation might affect their own personality. The subcategory, 'Will the new heart change me?' (p.617) was fully saturated. All participants reported feeling guilty about the donor and worrying whether the new heart would change them.

In a contradictory study with adolescent cystic fibrosis patients who were lung transplant recipients, Durst et al. (2001) found that few had considered whether or not they had received donors' traits. All believed they had a stronger sense of self, post-transplant. Many also spoke of a new, inner strength and now saw themselves as healthy and normal. As discussed above, this was a very specific set of participants who suffered from a chronic condition before transplant. It should also be noted that 16 of the 19 participants received their transplanted lungs from living donors. Knowing, or possibly being related to, their donors might mean that these transplant recipients have a different response than those who receive cadaveric organs.

Similarly, in a study with heart TR and kidney transplant recipients, who had both living and necro-kidney transplants, few differences were identified between heart and necro-kidney transplant recipients; however more prominent differences were observed between living and necro transplant recipients (Sanner, 2003). This seems to challenge the belief in the literature, and indeed in society, that having a heart transplant is particularly stressful and challenging (Rodgers, 1984; Kuhn et al., 1988). No transplant recipients in the study who received a donation from a living relative, spoke about the

possibility of being influenced by the transplant. However, the fact that they were related seemed to be favourable, 'He's flesh of my flesh and blood of my blood' (Sanner, 2003, p.395). However, living-donor TRs reportedly avoided discussing the impact of the transplant on their relationship, perhaps suggesting that there was difficulty in coping with the change this gift had on their relationship.

Overall one third of the transplant recipients in this study articulated fleeting thoughts about the influence of a donor's identity. Some of these thoughts seemed to be very powerful, with one deceased-donor transplant recipient admitting that they almost did not go ahead with their operation because of this. Their concern was that the influence would be so overwhelming they would not be the same person post-transplant, and that they may lose their identity. Other transplant recipients reported incidents where they felt their behaviour was so out of character it had to be influenced by their donor. One recipient viewed the donor as kinder than them, and therefore were not worried about the possible influence they may have on their personality, stating that this impact would 'at least not be dangerous' (Sanner, 2003, p.395). However in another study, one transplant recipient described a major personality change and was convinced that as his donor was a woman this explained his personality change (Jones, 2005).

When asked about how this may happen, transplant recipients seemed to give three explanations for personality changes due to the influence of donors,

1. Related to transmission of traits, like a contagion, 'It's possible that you will be infected in some way with the donor's personality, if you get his kidney' (Sanner, 2003, p.395).
2. That 'a gene may slip over' (p.397) from the donated organ.
3. The idea that 'people are mixed' (p.397), just as two liquids may mix together to form another substance.

Sanner's (2003) study also highlighted a difference between some transplant recipients, whereby some seemed to express being 'influenced' by the donor, whereas others expressed an ability to 'identify' with the donor. Similarly different attitudes towards the donated organ were identified. As this study was undertaken in Sweden, where necro-transplant patients can obtain information about the sex and age of their donors, this difference may not be so evident in countries such as the UK, where transplant recipients do not routinely find out this information. Interestingly, in this study several transplant recipients did not obtain the information about their donor, stating it was better that they did not know too much detail as they might start 'brooding' (Sanner, 2003, p.394), and although they could not clearly explain what this meant, it seemed to relate to thinking too much about the donor, and this seemed to link to the fear that this could be damaging, and ultimately lead to transplant rejection.

Similar opinions were expressed by 57% (n=20) of transplant recipients in another study (Inspector et al., 2004), expressed clearly by one transplant recipient who explained the feeling as "a refusal to turn into a living monument

of the donor” (p.168). In further support of this finding, transplant recipients seemed to show a fear of finding out too much information about their donors, in case this would make identification issues more challenging. Stating that they may feel obliged to adopt certain traits or habits, and somehow also allow a part of the donor’s identity to live on inside them (Jones, 2005). One study questioned whether anonymous donation made it easier for transplant recipients to incorporate the donated organ into their sense of self, discussing whether reaction to donations from near relatives may be affected by their feelings towards the donor (Biörck & Magnusson, 1968).

In a mixed-methods study examining heart transplant recipients’ psychological adaptation post-transplant (Inspector et al., 2004), 8.6% (n=3) of transplant recipients admitted to thinking about the donors prior to transplant. This percentage increased six fold, to 46%, post transplantation. Half of those who had donor related thoughts either before or after transplant (n=8), had thought about adopting their donors’ traits, compared to 20% (n=4) of those with no prior fantasies about the donor. A third of the whole sample (n=12) openly expressed that they had considered transfer of characteristics from the donor to themselves via the heart, i.e. sexual potency. This study of 35 transplant recipients did not have any female participants, and as such results may not be representative of all transplant recipients. Given its retrospective design, asking participants to discuss their thoughts at undoubtedly a stressful time, there are also issues related to recall and bias.

In a study that specifically asked 47 heart transplant recipients if changing the heart meant changing personality, 79% (n=37) stated that their personality had not changed at all post-operatively (Bunzel et al., 1992). However, as discussed above, it was felt that 80% (n=28) of this cohort showed some sort of denial towards their experience. It was also reported that two transplant recipients made statements, which suggested they had thought about it; “No, of course not, I have not changed, what nonsense! I’ve also asked my wife whether I’m changed in any way, and she said no, I’m the same as before” (Bunzel et al., 1992, p.253). Interestingly, in this same study 15% (n=7) said their personality had changed, but not due to transmission of traits from the donor organ. They felt that their change in personality was due to the life-threatening experience they had undergone. However, 6% (n=3) reported a distinct change of personality due to their new hearts, ‘the new heart has changed me...’ (Bunzel et al., 1992, p.254). This finding seems to link to another more recent study, where one participant spoke about how her transplanted kidney had changed her (Ådahl, 2013). She also believed the kidney had changed her in other ways too; ‘It can also in some way change you just the happening in itself...’ (p.144-145).

3.5 Rebirth – A New Identity

The theme of being reborn, or becoming a new person, arose in a number of papers (Ådahl, 2013; Forsberg et al., 2000; Inspector et al., 2004; Ordin, Karayurt, Wellard, 2013; Sanner, 2003;). In one study 40% (n=14) of heart TRs stated they had been ‘reborn’ (Inspector et al., 2004, p.167). Some

kidney transplant recipients spoke of a re-birth into a new kind of person, not just due to physical changes but also due to the creation of a new identity (Ådahl, 2013).

One of the seven categories that emerged in a phenomenological study with liver transplant recipients included the code 'Becoming a new person' (Forsberg et al., 2000, p.330). In this study the authors used good quality assurance measures, such as bracketing interviews. They also reached saturation after 10 interviews, but carried out a further two in order to confirm their findings. Recipients spoke of the loss of independence they experienced through their illness and feeling helpless and vulnerable whilst also receiving new life, perhaps like a pregnant woman or a new mother. One recipient 'baptised' the liver and gave it a name. 'I gave this liver a name...I walked around holding it like when I was pregnant;' (p.332). Indeed many liver transplant recipients felt as if they were 'reborn' and wanted to care more for their health in response to the sacrifice made by donors (Ordin et al., 2013).

Some transplant recipients who had received a donation from the same donor, stated that 'now we are half-siblings' (Sanner, 2003, p.395), further adding to the idea that genetics may have some role impacting recipients.

3.6 Identity, support, adjustment and adaptation

Social support was discussed in a number of papers, and was seen as essential for recovery and adjustment (Forsberg et al., 2000). Meeting others

with the same experiences helped participants to deal with their identity crises, and transform into being survivors, rather than being novel or unique among the non-transplant population. Talking to staff and other recipients who had experiences of liver transplantation was of utmost importance to these transplant recipients as they adapted to life post-transplant. One participant spoke about leaving the liver transplant unit, to go back to his local hospital to be treated, and the sense of loneliness in this, 'I felt abandoned in some way...there was nobody with the same experience...I felt lonely' (p.331).

Social support was also important for how kidney, liver, heart or lung transplant recipients framed experiences such as graft rejection (Nilsson et al., 2008). Those who had met others who had overcome a graft rejection held an adaptive perception of graft rejection, as a useful experience leading to trust in one's own strategies for mastering the health situation. This enabled them to begin to adjust to this situation and build an identity whereby the graft rejection was viewed as something quite normal, a positive experience, which one can learn from.

In this study participants also spoke about 'Identity adjustment', which referred to adjusting one's self-perception in accordance with the results of tests (Nilsson et al., 2008, p. 2411). Medical staff seemed to identify transplant recipients simply according to what the tests showed. This seems to remove transplant recipients' power and role in maintaining their health, by reducing them to a label. It was found that low-compliant transplant recipients, so presumably those struggling with adjustment and therefore with worst test

results, expressed a loss of self-competence in the post-transplant period (Goetzmann et al., 2007).

In a study investigating adaptation after liver transplantation it was acknowledged that due to the often dramatic and fast change in transplant recipients' lives, their self-concept may be negatively affected (Ordin et al., 2013). This study also highlighted the importance of nursing staff to have an awareness of these issues, as they can play an important role in developing transplant recipients' self-concept and therefore their identity (Roy, 2009).

3.7 'Normal' Identity

Transplant recipients wish to be identified as 'normal', suggesting that they feel they may not be seen in this way. In a study of transplant recipients' perceptions of graft rejection, one theme related to their struggle to be regarded as healthy, and avoid burdening others with worries and/or fear of graft rejection (Nilsson et al., 2008). This seemed to be particularly important to adolescent transplant recipients, who wanted the same opportunities as their peers and identified developing their own identity as one facilitator to achieving normality, whilst one barrier was experiencing an identity crisis (Tong, Morton, Howard, McTaggart, Craig, 2011). Normality was important as those who achieved this after transplant reported more positive development, better overall well-being and social functioning. Most of the participants felt that being given a new kidney offered them a new chance of self-discovery, and to develop their own personality and values. Their self-esteem and

confidence improved and they set new long-term career and study goals, 'It gives you more confidence to think there's nothing wrong with you' (Tong et al., 2011, p.288). Self-esteem and self-concept were also rated as areas of significant concern for adolescent heart transplant recipients in the USA (Collier et al., 1999).

However, those who did not achieve a sense of normality seemed to struggle with adjusting and coping with life post-transplant. Some adolescents felt their personality and temperament had changed post-transplant. They spoke about feeling like they had lost their self-esteem, and became more socially withdrawn and isolated. They felt they did not have so much in common with their well peers and could not relate to them 'I don't really know what my personality is now...It frustrates me because I find it annoying not knowing what personality I'm going to be at a certain time. A lot of people find that a bit weird to adjust to,' (Tong et al., 2011, p.289). In this qualitative study seven of the 22 participants were interviewed with their parents present, which may have impacted on the themes and issues discussed.

Tisza, Dorsett and Morse, (1974) presented four adolescent transplant recipients case studies and concluded that despite the life-threatening experiences all four adolescents went through, they still attempted to develop their independence, self-sufficiency, peer group acceptance and sexual identification as any 'normal' adolescent would. They reported that even the sickest adolescent, resisted regression, in order to hold onto their adolescent identity. It has been found that adolescents and young adults who integrate

their transplant into a sense of self are better adherers, and similarly poor adherers tended to refuse to accept the transplant and worry that they will never be normal (Lawrence et al., 2008).

4. Discussion

4.1 Denial of Identity

Studies highlight that transplant recipients may deny thoughts of their transplant or donor, particularly in the initial six months post-transplant. This may be a coping strategy that actually helps transplant recipients to integrate their donated organ. However, some studies did highlight that those who expressed more denial may be more susceptible to graft rejection, or even death. This is a very tentative finding in small-scale studies, but it raises questions about whether psychological processes have any role in graft rejection.

It may be that objectifying transplants serves to distance professionals from the complicated, and often upsetting, questions of identity and self. Whilst it may be necessary to objectify the donated organ at times, issues arise when transplant recipients' psychological needs are not addressed and go untreated. As seen above this may, potentially, have catastrophic effects. It also seems to be important to question whether the positive outcomes reported by TRs are accurate, and due to healthy adjustment, or if it is actually the result of a more subconscious defence mechanism (Leyendecker, Bartholomew & Neuhaus, 1993).

4.2 Integration and Incorporation

Studies highlighted that participants seemed to find it easier to integrate their donated organ if they could make it their own and think about it in a positive way. Some transplant recipients had even found their own, unique ways to say thank you to their donors. This seemed to be an important strategy that could be supported by medical staff in order to help recipients process the impact of their transplant, rather than deny or avoid thoughts of their donor or the donation. This may help with integration of the organ into transplant recipients' identities. This may also help transplant recipients to see the donor as separate to themselves, and the organ as their own, which is described as the stage of complete internalization in the theoretical model of organ integration (Neukom et al., 2011).

4.3 Adopting Donors' Traits

There seemed to be a split in the literature between transplant recipients who thought that they might adopt donors' traits and others who did not. Notably, some felt so strongly they feared they would be changed post-transplant and one transplant recipient nearly didn't go ahead with their transplant because of this fear. Those who have living donors, and therefore presumably know their donor well, did not seem to express the same fears about adopting traits. An interesting point was raised in the literature about whether transplant recipients' changed personality was due to adopting donor traits, or whether a change in their personality may be explained by the extraordinary life experience they had gone through.

Discussion of practices in different countries highlighted differences in approach to sharing information about donors, i.e. UK and Sweden. This is an important difference and warrants further research, particularly as to whether it makes it easier or harder for transplant recipients to assimilate the transplanted organ into their identity if they have access to basic information, such as gender and age.

4.4 Rebirth – A New Identity

A number of studies reported that participants felt reborn, or a new person, in both a physical way and in a sense of having a new identity. Many seemed to talk about their new organ as if it was a child, almost expressing the responsibility they felt to look after the new organ. There was also a sense of a new lease of life, through the transplant community as they made new, unique connections with organ-sharing ‘siblings’.

4.5 Identity, support, adjustment and adaptation

Social support was highlighted as being an important factor in helping TRs adapt to life post-transplant. One study reported that participants had even been able to positively reframe graft rejection as an opportunity to learn about managing their condition.

Issues relating to how transplant recipients are seen by medical staff post-transplant were discussed. This highlighted the importance of nursing staff being aware that transplant recipients may be struggling with their

identity, and supporting them. These issues may be impacting on adherence and therefore are important for nursing staff to recognise.

4.6 'Normal' Identity

Retaining a sense of 'normality', and losing the 'sick identity', seemed important for participants post-transplant, and was associated with more positive outcomes and better overall wellbeing. Those who could not return to their 'normal' lives experienced a loss of self-esteem and became more socially isolated. Adolescents, regardless of severity of illness, seemed to want to retain a 'normal' adolescent identity. Those who could integrate their transplant into a sense of self were found to be better adherers.

4.7 Methodological Issues

Most studies included in the report were qualitative (n=13). Therefore they all had small sample sizes, meaning results cannot be generalised to the general transplant population. Not all studies reported robust quality assurance methods, however three studies clearly reported good quality assurance measures (Forsberg et al., 2000; Kaba et al., 2005; Tong et al., 2011). In particular Forsberg et al. (2000) reported using critical self-reflection to bracket out their own presuppositions.

Most of the studies in the review (n=16) had a cross-sectional design; therefore they had data from one point in time and no knowledge of participants' level of functioning or self-concept prior to transplant. One study had a longitudinal design, so captured a broader picture, and change over

time (Jones, 2005). Two studies used a retrospective design, which may have impacted validity, through recall bias (Inspector et al., 2004 & Ullrich et al., 2010). Two studies did not state what method of analysis was used, therefore this further limits what can be taken from findings (Bunzel et al., 1992; Sanner, 2003).

The studies were taken from around the world, sometimes with quite contradictory findings. This raises issues of how far studies from countries with very different cultures can be applicable to the UK, particularly as only one study reviewed was conducted in the UK. However, it also highlights practices that may warrant further investigation for implementation in the UK, such as providing people with the choice of knowing basic demographic information about the donor.

There was a lack of any distinct findings within the papers that related to specific circumstances such as alcohol-related liver disease and liver damage caused through suicide attempts by overdose. It is surprising that these liver transplant recipients were not represented more in the literature, as they are likely to have specific and unique issues relating to identity and transplant. This lack of representation within the studies sampled may indicate a difficulty in recruiting such patients to studies; however this important issue was not discussed within the studies sampled.

5. Clinical Implications and Future Research

The review provides initial indications around specific findings, for example it seems that there were better outcomes for those that acknowledged their donor, but that denial may still form an important part of the post-transplant process. This is a complex finding as it raises the importance of a person-centered and nuanced post-transplant care, and certainly warrants further research.

Patients may require education and social and mental health support in order to maintain a healthy identity post-transplant. The idea that transplant recipients are simply what their medical results show came across in the literature. This approach is reductionist and fails to see the person behind the transplant. Practice needs to be more holistic, monitoring transplant recipients psychologically as well as physically. This could be achieved through routine cognitive testing and psychological assessment. The findings from this review also indicate that there is a need for education with medical and nursing staff, in order to make them aware of psychological issues that may occur and impact on adherence to post-transplant care. The need for training for nursing and medical staff was also implied in the study findings, to help them to know how to speak with transplant recipients about their sense of identity and integration of donated organs.

This review indicated that transplant recipients might rely more heavily on others to guide and support them, especially in the initial stages post-

transplant. As highlighted above, the initial post-operative months seem most difficult. There seems to be a need to support transplant recipients to understand the complex psychic process that goes on post-transplant, as one would explain physical processes. Going through such an experience may be very frightening, and having an understanding of what is happening may help transplant recipients to integrate their organ into their sense of self.

When transplant recipients and medical staff are under such stress there may be a higher propensity for individuals to experience intolerable feelings and act out. There may be a role for clinical psychologists to help be a neutral member of staff, who can work with transplant recipients, medical staff and families. This may be particularly important for patients who are non-adherent to their medical regime. Indeed non-compliance may feel like their only form of control when going through a very difficult experience and when being told, from a number of different sources, what to do.

The idea of control may also explain why complex issues relating to identity, and psychological integration, are not routinely discussed. Medically trained staff, who need to hold a position of certainty, may find such abstract and uncertain themes hard to address. This also raised the ethical need to offer transplant recipients care and advice in line with their own personal view of the world. This can be done in a way to complement the biomedical model.

Other major findings from this review seem to be the significance of a living or dead transplant donor, as well as possible differences in terms of gender and age in terms of how identity changes post-transplant. Many issues

were highlighted for further investigation, such as the impact of identity on adherence to medical regime, transplant recipients' views on the role of genetics in their illness, the difference in experience between those who have received living or deceased organ donations. The question as to whether different organ transplant recipients face different challenges in relation to identity and organ integration also warrants further exploration. Furthermore, as highlighted above there seems to be a dearth of UK based research in the area of transplant recipients' experiences, given that only one UK study relating to this area could be identified.

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MAJOR RESEARCH PROJECT

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Section B

"So I am grateful to be here, very grateful"

: A Constructed Grounded Theory of Young Adults' Adjustment
Post Liver Transplant

Word Count: 8,000 (62)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2015

Names, places and other identifying material have been removed or changed
to protect participants' identity.

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Background: Positive health-related behaviour is particularly important for liver transplant recipients' recovery. However, non-adherence in adolescents post-transplant is thought to be greater than, or equal to, 50%. Literature searches have found limited research into the area of young adults' experiences of having a donated liver. Knowing more of their experience seems important to help inform practice to improve adherence and ultimately save lives.

Aim: The present study aimed to construct a grounded theory of young adults' experiences of having a liver transplant, in order to better understand how young adults may adjust following such experiences.

Method: Semi-structured interviews were conducted with twelve liver transplant recipients (five female, seven male). Data were analysed using constructivist grounded theory.

Results: A model was constructed to capture the dynamic interactions between thirteen categories, resulting in four main themes: Finding Identity Post-Transplant, Carrying Responsibility, Unseen, Unspoken or Misunderstood Challenges and Adjusting to Life After Transplant.

Conclusions: The study highlights the importance of the themes in psychological adjustment post-transplant. Understanding this process is

imperative in order to improve health-related behaviours in a cohort with traditionally poor adherence. Implications for further research and clinical practice are discussed, including educating liver transplant recipients to raise their levels of self-efficacy, which have a positive impact on adherence.

Keywords: Liver Transplant, Young Adult, Adjustment, Adherence, Identity.

1. Introduction

1.1 Liver Transplantation and Early Adulthood

Five-year graft survival rates for liver transplant are now almost 80% (Kim et al., 2012), and is a successful option for young people with end stage liver disease or acute liver failure (Sharif & Millar, 2009). This creates a need for greater understanding of life post-transplant for liver transplant recipients, whose psychological needs may have initially been eclipsed by their medical needs. Adjusting to life after such an experience seems challenging, but may be even more so for those who are also negotiating adolescence and/or early adulthood, as they face the tasks of biological, psychological and social transition (Holmbeck, 2002). Identity development remains the central task of adolescence (Erickson, 1988; Lugasi et al, 2013); therefore adolescents with a chronic illness have to negotiate both normative (i.e. identity development) and neo-normative (i.e. transplant related) tasks (Seiffge-Krenke, 2001). Crucially however, adolescence is an important time to lay the foundations for future health-related behaviour (Holmbeck, 2002).

1.2 Adherence

As many as 1 in 10 liver transplant recipients may have died from poor adherence to treatment, and poor adherence may have played a role in chronic rejection, associated with 1 in 3 retransplantations (O'Carroll, McGregor, Swanson, Masterton, & Hayes, 2006). A study with young adult heart transplant recipients found that those who integrate their donated organ

into their identity were good adherers, whilst those who continued to 'push away' their transplant experience were poor adherers to medication, appointments, tests and engaged in more high-risk behaviours (Lawrence, Stille, Olshansky, Bender, & Webber, 2008, p.50).

Positive health-related behaviour is particularly important for transplant recipients' recovery. However, one study showed that non-adherence to immunosuppressive drugs, a key aspect of post transplant health management, can be as high as 40% and non-adherence to medical appointments as high as 47% in adult liver transplant recipients (Burra et al., 2011). Similarly, non-adherence in adolescents post-transplant is thought to be greater than or equal to 50% (Dobbels et al., 2005).

Non-adherence is associated with poor clinical outcomes, contributing to 20% of late acute rejection episodes and 16% of graft losses (Denhaerynck et al., 2005). Significant decreases in adherence after transfer to adult services are often observed (Annunziato et al., 2007), making adolescents/young adults a very vulnerable population (Kiberd et al., 2011). There is an argument that complex medical care, without attention to the psychological and social impact on young adults, runs an increased risk of failure (Abbott & Gee, 1998).

1.3 Theoretical Background

Illness representations relate to individuals' beliefs and understanding of an illness, and these representations are central to Leventhal's Self-Regulation Theory (SRT; Leventhal, 1970). SRT proposes that illness representations affect related health behaviour (Leventhal, 1970), and views adherence as a dynamic interaction between individuals' experiences of, beliefs about, and emotional reaction to their illness (Home, 1998). This project considers that SRT may also apply to the representations/beliefs that an individual makes in relation to a donated organ, following a transplant operation and therefore their ability to integrate it into their sense of self. These representations/beliefs may impact on how an individual thinks about their organ, and therefore their subsequent health-related behaviour. Poor adherence was associated with liver transplant patients' belief that the transplant had a major impact on their lives, and beliefs they had been strongly affected by the experience emotionally (O'Carroll et al., 2006).

Illness centrality is a concept that relates to the degree to which someone focuses on illness as a central or peripheral part of their identity (Fredericks, Zelikovsky, Aujoulat, Hames & Wray, 2014). Studies have found that illness centrality can have a negative impact on development of self-care skills (Helgeson & Novak, 2007; Adams, Pill & Jones, 1997).

Self-Determination Theory (SDT: Deci & Ryan, 2000; Ryan & Deci, 2000) focuses on the degree to which behaviour is self-motivated and self-

determined. This may link to SRT, as individuals' illness representations/beliefs will impact on their ability to self-motivate. SDT advises clinicians to attend more carefully to patients' experience and motivation. Patients who have their needs for autonomy, competence, and relatedness supported in the process of their health care experience show more volitional engagement in treatment and better adherence (Ryan et al., 2008). In accordance with SDT, transplant patients who feel they have a sense of choice and control independently change behaviour to meet their goals (Lisson, Rodrigue, Reed, & Nelson, 2005).

1.4 Rationale and Clinical Significance

Literature searches have found limited research, and no grounded theory studies, into the area of young adults' experiences of having a donated liver. Therefore exploratory research could be beneficial in providing information about how young adults think about their donated organ. The meaning that a young person gives to their new organ is likely to impact on their psychological adjustment post-transplant, assimilation of such an experience into their identity, and medical adherence. Gaining a greater understanding into this area may inform clinical practice to support young adults and adolescents in their medical regime, and ultimately save lives.

1.5 Sensitizing Concepts and Aims

The present study aimed to construct a grounded theory of young adults' experiences of having a liver transplant, in order to better understand how young adults may adjust following such experiences. The following questions provided the foundation from which the study evolved. These questions were used as sensitizing concepts (Strauss & Corbin, 1998), to act as a point of reference from which to guide the overall research problem (Charmaz, 2003). Research that is concerned with theory generation requires sensitizing concepts rather than hypotheses (Blaikie, 2000), as this allows the analysis to remain an inductive process. Those used in this project were:

1. How do participants make sense of, or understand, the experience of having a new donated organ?

2. Do participants feel that having a donated liver has impacted on their life and/or their identity? If so, how and why do participants feel it impacted on their life?

3. How do participants think about adherence to medical care?

2. Methodology

2.1 Participants

Participants were recruited from one supra-regional specialist NHS liver transplant unit, based on a hospital site within the United Kingdom. Participants had to be liver transplant recipients between the age of 16 and 25 years, who were aware that they had received a donated liver.

Patients with a profound learning disability and those with unstable mental or physical health, as judged by their medical team, were also excluded from the study. However participants were not excluded if they had any co-existing medical conditions. As interviews were conducted in English, it was a requirement that participants were English speaking. Participant characteristics are presented in aggregated form, to help protect anonymity (Table 1).

Table 1: Aggregated Participant Characteristics

Total number of participants	n=12
Gender	Female: n= 5 Male: n=7
Age	Average: 20 years 3 months Range: 16 years 3 months–24 years 3 months Standard Deviation: 2 years 6 months
Ethnicity	White British: n=6 Black British: n=1 Black African: n=2

	<p>Black Caribbean: n=1</p> <p>African Other: n=1</p> <p>Other: n=1</p>
Number of Liver Transplants	<p>One Transplant: n=10</p> <p>Two Transplants: n=1</p> <p>Four Transplants: n=1</p>
Age at Transplant	<p>Average: 11 years 1 months</p> <p>Range: 0 years 4 months–20 years</p> <p>Standard Deviation: 7 years 9 months</p>
Time since Transplant	<p>Average: 8 years 6 months</p> <p>Range: 0 years 2 months–17 years 10 months</p> <p>Standard Deviation: 2 years 6 months</p>
Reason for Transplant	<p>Billiary Atrisia: n=7</p> <p>Billary Cirrhosis: n=1</p> <p>Langerhans' Cell Histiocytosis: n=1</p> <p>Wilson's Disease: n=1</p> <p>Primary Sclerosing Cholangitis: n=1</p> <p>Medically Unexplained: n=1</p>
Other clinical diagnoses/difficulties, identified as significant by participants	<p>Autoimmune Liver Disease: n=1</p> <p>Depression: n=1</p> <p>Anxiety: n=1</p> <p>Stoma: n=1</p>
Employment/Education Status	<p>Second Level Education: n=4</p> <p>Third Level Education: n=2</p> <p>Working (Full Time): n=1</p> <p>Working (Part Time): n=1</p> <p>Full Time Parent: n=1</p> <p>Unemployed: n=3</p>
Transplant Type	<p>Total Number of Transplants in Sample: n=16</p> <p>Number of Living-Related Transplants: n=1</p> <p>Number of Deceased Donor Transplants:</p>

2.2 Design

Grounded theory method (GTM) was used to analyse the data collected through semi-structured interviews (Charmaz, 2006). GTM was used as a constant comparative analysis, moving between data collection, analysis and theory development (Potter, 1996). GTM aims to move beyond a mere description of the data to develop a theory of social, or psychological, processes (Charmaz, 2006). A key idea of GTM, initially proposed by Glaser and Strauss (1967), is that any developing theory is 'grounded' in the data. This allows the researcher to adopt and explore ideas indicated within the data, rather than forcing the data to fit into an already existent theory, thereby creating more space for the discovery of something new (Urquhart, 2013). As the researcher can create their own theory, rather than relying on existing theory (Willig, 2001), this method is particularly useful in areas where there is a lack of existing theory.

Charmaz's (2006) social constructionist GTM approach is used in this study, thereby adopting an interpretive ontological and epistemological research philosophy (Orlikowski & Baroudi, 1991). This approach acknowledges the role that both researcher and participant bring to the study in co-creating the data through their interactions.

Charmaz (2006) encourages a flexible approach, but suggests a four stage coding procedure, which was largely followed in this study. Constant

comparison meant that emergent categories and concepts were compared within and between interviews, in order to ensure that the data from each participant fit with the developing theory, thereby testing their validity (Holton, 2007). The four stage bottom-up approach followed is summarised in Table 2.

Table 2: Four Stage Coding Procedure (Charmaz, 2006)

	Type of Coding	Procedure
1.	Initial Coding	Active line-by-line coding, staying open-minded to ideas whilst also staying close to the data, in order to develop categories of information. The first three transcripts were analysed using this form of coding, focusing on 'how' and 'why' processes within the data. For the remaining transcripts analysis began with focused coding. For an example of initial coding please see Appendix 8.
2.	Focused Coding	Examining the routine, and more dramatic incidents, within interviews and using codes to synthesize larger sections of data. This stage involved taking the line-by line coding to a higher, more selective and conceptual level.
3.	Axial Coding	Large amounts of data were sorted and synthesized to develop the characteristics of the sub-categories

		and categories, and how they relate.
4.	Theoretical Coding	Memo-writing and diagramming, an intrinsic component of GTM (Clarke, 2005), was used at every step of the analysis, but particularly at this point. Relationships between focused codes were examined, in order to raise them into conceptual categories.

2.3 Interview Schedule

In order to meet ethical approval an interview schedule (Appendix 9) was developed. Recommendations are to not have a pre-defined interview schedule (Glaser, 1998; Charmaz, 2006) in order to limit influence on the data (Holton, 2007). The researcher therefore tried to take a more bottom-up approach and “enter the participants’ world” (Charmaz, 2006, p.19), referring to the schedule if a prompt was needed.

2.4 Procedure

Participants were initially invited to opt-in to the study by letter (Appendix 10), however this yielded limited numbers (n=2). Therefore the author reapplied to the relevant NRES ethics committee and Research and Development department to make an amendment to the study (Appendix 11&12). Having received ethical approval, the author attended eight clinics within the hospital over an eight-month period and recruited the remaining

participants (n=10). In clinics, participants were provided with a brief research flyer (Appendix 13), and then provided with information sheets (Appendix 14) if interested in hearing more regarding the purpose of the study. Once recruited, a mutually convenient time was arranged to meet with the participants. Five participants were interviewed within the hospital and seven in their own homes.

Demographic information was gathered initially (Appendix 15). Participants were then invited to complete a drawing of any aspect of their transplant experience, which was significant to them (Appendix 16). Eleven participants agreed to complete this step, with one participant choosing to opt out. Non-verbal strategies have previously been used to explore children's experiences and understanding of their physical health condition (Edwards & Davis, 1997). It is thought that this approach may help to facilitate communication, especially when talking about abstract ideas (Edwards & Davis, 1997), such as organs that are not seen everyday. Following completion of their drawing, semi-structured interviews, ranging from 36 to 99 minutes, were then completed with participants.

The researcher started the interview by asking participants to talk about their drawing (n=11) or invited them to share their experience of being a liver transplant recipient (n=1). All interviews were audio recorded and transcribed verbatim. Once transcribed, the interviews were analysed as per the steps detailed above.

Recruitment continued until no new codes pertaining to the emerging categories were identified in the data. However, given the complexity of this topic, it is difficult to be certain if theoretical saturation (Strauss & Corbin, 1990) was fully established. As a minimum it seems that 'sufficient saturation' (Strauss & Corbin, 1998) was achieved.

Due to difficulties in recruitment it was not possible to use theoretical sampling, therefore an opportune sampling approach was employed. An attempt was made to recruit participants who had undergone a liver transplant due to liver failure following a suicidal overdose, in order to theoretically broaden the sample. Unfortunately recruitment of such a participant was unsuccessful. However, recruitment from multiple clinics helped to ensure that participants with a wide variety of views and experiences were included. As interviews progressed, participants were asked questions influenced by the analysis to date (Morse, 2007).

2.4 Quality Assurance Checks

Quality guidelines for qualitative research (Elliot, Fischer & Rennie, 1999) were followed throughout this study. A key aspect of social constructionist GTM is that the researcher's view can impact on the analysis (Charmaz, 2006). It therefore seems particularly pertinent to follow the guideline 'owning one's perspective' (Elliot, Fischer & Rennie, 1999). Therefore the researcher completed a bracketing interview (Rolls & Rolf, 2006) with a colleague, to identify pre-existing assumptions (Appendix 17). A

reflective research diary (Appendix 18) was also kept throughout the research process, providing an insight into the researcher's processes (Watt, 2007).

Examples of initial and focused coding were checked independently with two research supervisors and a colleague. Verbatim participant quotes were used to develop categories, ensuring results were grounded in the data (Dey, 2007). This also contributes to the validity of the resulting theory (Williams & Morrow, 2009).

Research supervisors, and two experienced clinical psychologists working in the field of organ transplants, reviewed the category and theme development and resulting model. Differences of interpretation, as well as possible oversights, were discussed and changes made where deemed necessary. Respondent validation was obtained by contacting two participants who fed back that the results seemed to fit with their experiences.

2.5 Ethical Considerations

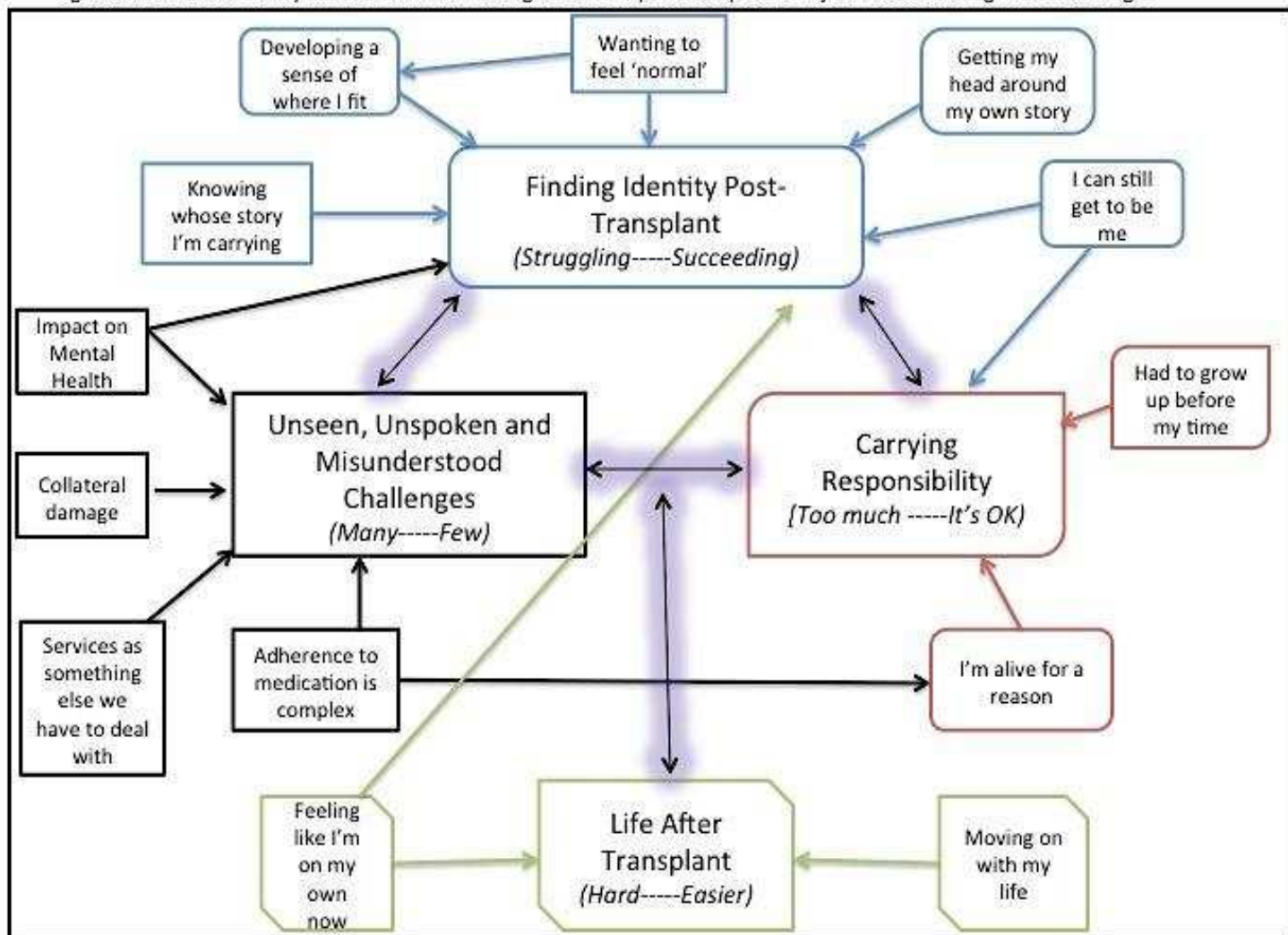
This study received NHS ethics approval by the National Research Ethics Service (NRES) Committee North West- Lancaster (Appendix 11&19). The Research and Development department of the NHS Trust attached to the recruitment site also granted permission for the study to go ahead (Appendix 12).

Participants were given a period of at least 24 hours to consider their decision, before consent was obtained (Appendix 20). When recruiting in clinics, the author initially gave prospective participants the brief research flyer. If participants were interested in finding out more they were then given the information sheet. Issues around potential participants feeling under duress, or pressure, to participate were thought about carefully, therefore participants were given at least 24 hours to consider if they wished to participate in the project, before being interviewed.

3. Results

Data analysis resulted in 81 focused codes, 21 subcategories, 13 categories and four overall themes. A table of the focused codes and categories can be found in Appendix 21. A table showing progression of the themes' development, with supporting quotes can be found in Appendix 22. The role of GTM is to create theory (Charmaz, 2006), showing how different constructs interact with and influence each other, raising analysis from a descriptive to a theoretical level (Strauss & Corbin, 1998; Urquhart, 2013). Therefore a 'bottom-up' model was developed from the data, in order to propose the dynamic relationships between the main constructs that seem to describe the range of experiences of young adult LTRs (Figure 1).

Figure 1: Grounded Theory Method Model of Young Liver Transplant Recipients' Adjustment to having a Donated Organ



3.1 Model Summary

The results can be understood as the process young adults go through when adapting to life post-transplant. It focuses on *how* they have experienced life, *why* they have experienced it in that way and the *how* and *why* of the impact upon them. This approach fits with the task of social constructionist GTM to understand the *how* and *why* individuals experience and respond to their own version of reality.

Three main themes: *Finding Identity Post-Transplant*; *Carrying Responsibility*; *Unseen, Unspoken* and *Misunderstood Challenges* seem to have a close bidirectional inter-connection with each other. The outcome of these processes, seem to impact on the fourth theme: *Life After Transplant*.

Even within the small sample of this study, there was a wide range of different experiences. This has been captured by including a spectrum of experience within each theme, as illustrated by the subtitles (i.e. Struggling – Succeeding). Similarly there was a spectrum of experiences reported within each category.

The following information summarises the key concepts that make up each category, additional information including focused codes and quotes can be found in Appendix 21&22.

3.2 Finding Identity Post-Transplant

All participants spoke about finding their identity post-transplant. Issues discussed related to the origin of their organ, the impact of their experiences on how they now see the world and where they fit within it, wanting to feel 'normal', and realising that they are strong individuals who can still live life as they choose. Some participants seemed to struggle more with coming to terms with their experiences and with accepting their donated organ as now being a part of, and belonging to, them.

3.2.1 Knowing whose story I'm carrying. Participants spoke about the concern of knowing where their donated organ came from, who owned it and its history.

With my transplant I still don't know who it came from...They were probably from the same area and I probably used to get on the bus with their parents and friends. (P10, L166 & 168-169)

There were different opinions reported as to whether knowing more about their donor would be an uncomfortable thing, *"I don't think I want to because it would probably feel like you were robbing someone. I don't think I want to know"* (P9, L737-738), or not,

I think on the whole knowing more is better. Because although it gets difficult it means that I'm not wondering. (P4, L405-406)

Some participants felt strongly about saying thank you and making a connection with their donor's family, but struggled when this was not possible, *"It was hard after the transplant, everything went so well and I wanted them [donor family] to accept the [thank you] letter and they wouldn't"* (P10, L179-180). One participant believed in a connection they had with their donor, which transcended thank you letters or details about the person's life, *"I believe that souls never die. We just reconnect. So there is obviously that connection with that person in me"* (P6, L530-531).

3.2.2 Developing a sense of where I fit. Knowing more about the origins of their organ seemed to help some participants accept it as a positive, which helped them to integrate it into their identity in a positive way. Many participants spoke very positively about their post-transplant scar, *"I love my scar, I am proud of it. I love showing my scar off"* (P10, L671-672). For some, it is almost as though it is a tribal mark showing where they belong or fit, *"I don't even want to remove it now; it's a part of me I couldn't give a shit what people think"* (P6, L452-453).

There was also a sense that the scar helped participants to tell their story. The only visible mark of having gone through serious illness, internal surgery and even facing death.

The reason why I have drawn that is because a lot of the time when people ask me especially my friends that know about my liver transplant the only real evidence I have to show them is my scar. So that kind of means a lot to me. (P8, L71-74)

There was a strong sense of family within the liver transplant community, finding somewhere where participants fit in, perhaps enforced by the close unique bonds that people share, *"I shared my first liver with a little girl and I am still in contact with her now"* (P3, L61-62), or the life and death situations they have supported each other through, *"he died on my sister's birthday so it's not a day that I can forget.... A few years later...they called*

and they were having another baby and they named it after me” (P3, L554 & 556 & 558).

However, there was a sense that more could be done to help participants connect with others who have been through similar experiences, *“before when I had my transplant there was nothing. There were no support groups or anything like that” (P3, L586-587), because, “You have got to talk to people who are going through the same thing as you. That’s the best thing” (P5, L645-646).*

Support from those who have had similar experiences is important as, despite trying, others do not seem to be able to understand in the same way, *“he’s nine thousand miles away [friend with organ transplant] and he knows exactly how I feel, and I have got my mum and dad who live two miles away and have no idea” (P3, L602-604).*

Cultural norms can make this even more difficult and add an extra layer of complexity in understanding where one fits, or with whom one can identify, *“where I come from for political reasons we don’t like British people so having a donor, a British donor...It changes things. So it’s with you all of the time that mentality” (P5, L136-137 & 139).*

The transplant experience has helped to shape participants’ personalities and world view, having a significant impact upon the success of their identity post-transplant, with some participants drawing strength, *“I*

definitely think that would be probably 60 percent of what me as an individual today is, I am quite a strong person and I can get through a lot of things just with myself will power” (P6, L392-395), whilst others feel defined by their transplant experiences, and find it difficult to adapt to ‘normality’, “I have a foreign object in my body that I am worried is going to reject” (P10, L112).

Others believed the transplant almost infiltrated their identity, bringing unanticipated changes, *“sometimes I think, this is strange but it’s not scientifically proven but my personality is affected because of my donor” (P5, L159-160), and, “Yeah. That I have got a different personality” (P7, L163).*

3.2.3 Getting my head around my own story. For all participants, understanding and coming to terms with the event around their transplant seemed to be difficult, making acceptance of the organ as their own, challenging, *“It’s weird; it was like how can I have the same organ as you?” (P12, L230-236)*

For those that were too young to remember the events, photo albums seemed important to help them come to terms with their own story.

I have a picture album of photos of when I was actually in hospital... Those sorts of photos because I was so young really matter to me, really matter to me, they especially mattered to me when I was younger

because it helped me to understand that it was me and it started the emotional development. (P4, L757-768 & 760-761)

It can be confusing as to whether the liver belongs to them or not, *"I find that really difficult to come to terms with whether it is mine because it's a part of me now or whether it's not because I wasn't born with it" (P4, L580-581)*, however others strongly believe that it does and feel a responsibility in that, *"of course it's yours now for keeps so you have to look after it "* (P9, L740). Participants made attempts to make sense of the ownership dilemma, for example,

P10: "Once it is in your body and washed with your blood it is like anything really."

Researcher: "It's yours then?"

P10: "Yeah. It's like anything, you buy something from the charity shop once you put it in the washing machine and it smells of you, it's yours." (P10, L676-680)

Telling others about their experiences was another aspect where participants differed in opinion. For one participant they wanted others to know as it fundamentally related to who they are as a person, their sense of self, *"because it is part of me and I like people to know it. If people don't understand it, it frustrates me" (P10, L487-488)*. For others, this level of personal detail made it difficult to share their story, *"for me you have to be*

really close for me to tell you that...because I feel like I'm letting you in to something pretty personal" (P12, L558 & 560).

3.2.4 I just want to feel like, and be, a 'normal' young person.

Sharing personal details may be especially difficult when it makes you different. Participants seemed to talk a great deal about feeling different from their peers, *"when you are sick and you become sick on top of being sick, that always feels different" (P5, L523-524)*. For some, being seen as different had terrible consequences, *"I was getting bullied at school people didn't understand me" (P10, L155-156)*, and clearly stated, *"I wish I was normal" (P10, L139)*. They seemed to struggle to integrate this 'difference', as a positive aspect of their identity.

For one participant who had had multiple transplants in their early teenage years, doing something 'normal' with his peers to mark the end of secondary school was very significant for him.

I went to Malaga and I drank for a week day in day out and I regret that now because it was such a stupid thing to do. But at the time it was the first time I had ever felt normal, I actually felt that I could fit in with everybody and it was great. That still is the best week of my life by far because of what it actually meant. (P3, L248-251)

Other participants spoke about how their liver disease had delayed puberty, meaning they were generally smaller and younger looking than their

peers. It felt like this issue was particularly difficult for some participants who were already struggling with their identity and fitting in, *“for someone who is going in to their teenage years to have all of that put on top of you as well, sometimes you feel like giving up”* (P10, L153-154).

Issues related to drinking alcohol were discussed by a number of participants, who felt that it seems to be a major part of being an adolescent/young adult in Britain. When you cannot partake in this ‘rite of passage’, fitting in and developing your social identity seems more challenging, *“it is difficult because I go out and have a coke and people are like oh you’re boring”* (P3, L242).

There seemed to be an internal struggle between wanting to be ‘normal’ and have a drink, and feeling a great deal of responsibility, to a number of different parties, to abstain from alcohol.

... I really want to be able to have a drink, have a good time. But I know I can’t do that because I’m not just letting myself down I’m letting this whole hospital down and my parents down and my sister down, but most of all I am letting [the surgeon] down because through [the surgeon’s] trust he has given me the chance of life. (P2, L467-471)

Another participant stated that they chose not to drink, and would if they wanted to. However, they did feel that not liking alcohol may be linked to a subconscious drive to protect themselves.

Obviously it's [alcohol] the main thing you should stay away from so subconsciously that is going to have some sort of effect. You know maybe that is why I don't like the taste. (P6, L288-289)

However, feeling well post-transplant can make it increasingly difficult to adhere to medical guidance.

That's what I struggle with when I do things like have a drink or put a cigarette in my mouth I don't feel like it's happening to me, I don't feel like that same person anymore I guess because I have not been ill for so long. I struggle with that. (P1, L630-632)

Similarly to other categories there was a spectrum of experience, with others who did not feel they were missing out at all,

When I am out with my friends and they are having a drink or whatever I don't regret it because I am blessed to be here in the first place but at the same time I think what would it be like for me to have a drink when I am out with my friends? (P8, L112 -113)

3.2.5 I still get to be me – a strong person. Holding onto the other parts of their identity, apart from being a liver transplant recipient, seemed important for participants. Those who had developed other parts of their identity, through studies or hobbies, seemed more accepting of their

transplant. For example, one participant, transplanted at four months and very well ever since, seemed to have a very well established sense of self, *"I think overall nothing has stopped me from doing anything that I want to do...so I feel normal"* (P8, L621 & 624).

One participant who had multiple transplants in adolescence and spent a lot of time in hospital and out of education, spoke about the struggle to have some control in his life and hold on to some of his identity outside of his medical illness. In recent years he had managed to find this balance, *"so I had to stop and realise you have to make the decisions because you are the one it is happening to. That's helped me a lot over the last few years."* (P3, L435-437)

Some participants dealt with the extraordinary circumstances they were going through by being strong and resilient, depending on their usual coping style, *"I just detached myself from everything the same as I do now, it was like this isn't happening to me"* (P1, L750-751). Perhaps made easier by the timing of his transplant at four months old, another participant was able to be positive and feel that he could be himself, *"I think I have had my own way of dealing with my liver transplant which is just thinking positive and feeling like I am no different from anyone else"* (P8, L669-670).

Participants' experiences were not easy at times, *"Now it's still sad I try not to cry but you get used to it"* (P7, L110). For some, coming to terms with what had happened to them had given them a sense of strength, *"like I said I*

think it made me quite a strong person. So I got through it" (P11, L622-623), and a sense of pride, "I did have problems after the transplant. The thing that makes me proud is that I really fought it like I properly wanted to get on" (P3, L59-61).

3.3 Carrying Responsibility

This theme encompassed participants' thoughts having faced their own mortality, which seemed to shape how they saw themselves. Having a donated organ came with a sense of responsibility and pressure

3.3.1 I'm alive for a reason. Participants expressed that they felt very fortunate to have been given the 'gift' of life from a donor.

For me it is one of the most beautiful gifts that any human being can give, and anyone who does get it should appreciate it from the bottom of their heart because it is another chance to live. (P2, L35-37)

There was a sense that participants felt they may have been 'picked' by a higher power, for a greater purpose.

Why did I get picked? I mean like I'm quite spiritual, and religious, and stuff so it's like, God why did you make me do this? Why out of everybody you could have picked? (P4, L354-356)

One participant also expressed that their life now seemed to have extra worth, as they now lived for two people.

I feel so special with myself. I'm not even sure if I am using the correct term but yeah I feel very expensive. So I live for the life of two people, myself and someone else. So that's not everyone else is it? (P5, L509-511)

3.3.2 Having to grow up before my time. Having been given this 'gift' many of the participants seemed to have a vivid narrative about facing their own mortality, *"they said that they lost me for a couple of seconds" (P7, L89)*, and *"am I going to get this? Am I going to get another shot? It does run through your mind" (P2, L201-202)*.

The typical youthful feeling of being invincible did not seem to exist within the cohort, *"I think to have that feeling [fear that anything could go wrong] is good because you can't feel like you are indestructible" (P8, L585-586)*.

Some participants seemed to have used this experience to make positive choices in their life, *"but you have to think about it this way this is a chance at a second life" (P9, L108-109)*, but at times this almost felt like a pressure.

However it is noted that this change in perspective, meant a loss of some of the exuberance of youth.

Before this I was carefree, I was living off adrenalin. I was a young fit 20 year old doing the stuff everyone else does. Now you have to think twice about what you do...you have to be careful. (P9, L441-442 & 445)

Some spoke about how difficult it was to know that somebody had died, so that they could live, *"I found it really, really traumatic to think that somebody had to die to give me my liver. I couldn't think about that at all"* (P4, L583-584). It also brought a sense of responsibility, *"so you are thinking what is so special about me? Why? Someone has to die for me to stay alive, so why am I so important?"* (P5, L331-332)

3.4 Unseen, Unspoken and Misunderstood Challenges

Participants spoke of a variety of challenges they faced in the course of transplantation. It seemed that those participants who had experienced more complex or serious difficulties, or who carried a greater sense of responsibility, had more trouble both finding identity and living life post-transplant.

3.4.1 Services as something else we have to deal with. Participants expressed a real frustration with the transition between paediatric and adult services.

Then just making the whole doctor-patient experience a little bit better and that kind of lags off when you are an adult, for no reason that I don't get, it is an intimidating thing. Hospital is a shit place you don't want to be there. (P6, L155-158)

One participant felt quite strongly about how they were spoken to, and outlined how this can impact on adherence to medical advice.

They get so stern all of a sudden. It is cool to tell someone their consequences but to a certain point I don't really think it's a child instinct we have it's just as human beings when someone gets told what to do or shouted at you instantly want to do the opposite. (P6, L170-172)

They had some practical ideas about how liver transplant recipients transitioning to adult services could be supported to maintain their medical regime as they become more independent, *"I would say there wasn't I'm not blaming anyone, but there wasn't enough training, that's how I would put it"* (P6, L217-218).

3.4.2 Collateral damage to many aspects of life. Participants spoke about some of the many additional physical and mental stressors they had to contend with, alongside their transplant, *"when I was in the hospital I lost my*

voice for three months" (P5, L549), and, "so I was really in pain and I couldn't take it anymore" (P7, L98).

Many acknowledged how difficult it had been for their families, *"it wasn't good for them, they weren't good at all" (Participant 7, L108), and associated feelings of guilt,*

You can't feel guilty because it's not my fault but at the same time I do feel guilty because the way that she [Mother] is and the way, she's had enough now, it's because of all of the things that have happened to me. So you can't not feel guilty but you do feel guilty at the same time. (P3, L351-354)

The impact of participants' experiences on their mental health was spoken about openly, *"you have to have experience of a lot of shitty life" (P5, L608), and, "also the effects of having what I've had done mentally as well, so that makes it difficult and then people don't understand that too. So yeah that's difficult" (P3, L80-82).*

Many spoke about how, *"recovery is the hardest part, it's not the operation itself. The operation you are fast asleep and don't have to worry about it. When you wake up it's the recovery that hits you more than most" (P2, L384-386).* With the general focus on physical health, it felt that participants' real struggle was being overlooked, *"physically I can go back to*

being 100% but mentally I am not OK, mentally I know it is not all me" (P9, L740-741).

3.4.3 Adherence to medication is complex. Whilst medication adherence is a top priority in research and clinical practice, it seems to be less of a priority for participants, *"well yeah just remembering it having to do it. I really don't like being told what to do or having to do something. It is something I really struggle with" (P6, L103-104),* and yet it feels like a real pressure, *"I had to because it was my responsibility, so it would be like shit I'm in trouble because I forgot it" (P6, L128-129).* When participants do not adhere to medical advice they, "do feel guilty for it and I do feel like I have let them [family] down" (P3, L314).

3.5 Adapting to Life After Transplant

Whilst all of the above themes seem to inter-relate, their outcome seems to be related to adjusting to life after transplant. This theme was about looking to the future, which encompassed both positive and more concerned perspectives. Many participants expressed a sentiment similar to leaving home, when talking about leaving hospital initially and also moving on to adult services. Those who viewed their transplant as a gift and an opportunity and took up a position of gratitude seemed to find it easier to adjust to life post-transplant.

3.5.1 Feeling like I'm on my own now. Leaving hospital after transplant seems to be a particularly vulnerable time for liver transplant recipients.

When you leave the hospital you sort of say you've had the transplant you'll be all right you're free to go. You don't get any aftercare, its pretty rubbish. (P2, L268-269)

One participant who had a form of childhood cancer for the first twelve years of their life, found it particularly difficult post-transplant. Although they were now essentially 'cured', the process of adjustment was very challenging, *"yeah I struggle with the fact I have to do it myself. I have always had doctors doing it for me"* (P10, L446-447).

3.5.2 Moving on with my life. Despite feeling on their own, participants expressed a new found appreciation for life, *"because you realise, it makes you think differently. Having a transplant makes you think differently and realise what actually is important"* (P3, L191-193), and, *"I just have to live life to the full because I'm alive for a reason"* (P4, L252-253). Participants' awareness of the fragility of life seemed to drive them on to live life to the full, *"I just think well I am blessed to be here"* (P8, L185).

3.5.3 Being grateful - given an opportunity. Moving on with their life seemed to be made easier by appreciating their experiences, *"it's probably older perspective I am experiencing and I am grateful for it, I wouldn't change who I am for anything"* (Participant 6, Lines 568 -589). There was a sense of participants having gained some additional inner strength through their experiences, *"I've learnt that if I can go through it I can go through anything"*

(P12, L642). Some also expressed a very positive philosophy of how they now live their life,

So for me it's even a blessing to be here in the first place because I've got that I should spread positivity out there, so people can understand what a blessing it is, and that what you give is what will return back to you. (P8, L221-223)

4. Discussion

The constructed theory, and associated model, presents the key aspects of young adult liver transplant recipients' experience, which impacts on their adjustment post-transplant. The model represents the complex interactions between each category, as well as the wide spectrum of experiences. Key findings will be presented in reference to the initial sensitizing concepts, linking to existing theory and research, and clinical and research implications discussed.

4.1. Sensitising Concepts

4.1.1 Concept 1. How do participants make sense of, or understand, the experience of having a new donated organ?

Adolescents generally do not like to be seen as different from their peers (Taylor, Gibson & Franck, 2008) and working out where one 'fits in',

seemed to be an important issue for participants. This seemed to link most strongly with issues relating to alcohol consumption. Links between belonging to a group and alcohol consumption have previously been made in the literature (Herring, Bayley, & Hurcombe, 2012).

The category relating to '*I still get to be me – a strong person*' seemed to link with the concept of Illness Centrality (Fredericks, Zelikovsky, Aujoulat, Hames & Wray, 2014), and also with the impact of time from transplant. Participants who had their transplant in infancy (4 months and 14 months) seemed to talk more about other aspects of their lives and interests. They did not seem to feel held back in the same way as those who had their transplants at later points in life, which often led to greater consequences such as missing school, thereby becoming a more central part of their identity and life and denying them experiences to help develop their sense of self. Illness Centrality is linked to impaired ability to self-care (Helgeson & Novak, 2007).

The concept of '*unseen, unspoken and misunderstood challenges*' incorporated a number of issues for participants that they seemed to feel were unheard, but which are frequently discussed in academic literature, including; impact on mental health, difficulties with medication, impact on family and struggles with medical services. Issues with medical services seem to link with the key aspects of SDT, and participants' need for autonomy, competence, and relatedness to be supported in the process of their health care experience in order to maximise their engagement and adherence.

'Life after transplant' highlighted issues relating to transition between services, but there was a noticeable positive narrative within the data, which seemed to relate to post-traumatic growth following transplant. A positive shift in perspective has also been reported in another study with young adults who had childhood illnesses (Devine, Reed-Knight, Loiselle, Fenton, & Blount, 2010).

4.1.2 Concept 2. Do participants feel that having a donated liver has impacted on their life and/or their identity? If so, how and why do participants feel it impacted on their life?

The category relating to *Finding Identity Post-Transplant* seemed to be a central part of participants' stories. There was a clear sense that some participants wished to know more about their donor, almost in order to know more about themselves. This seems to fit with Leventhal's SRT (Leventhal, 1970) whereby individuals' representations impact on their appraisal of an illness. Without knowing more detail of where their organ came from, perhaps participants cannot complete their appraisal. This may impact on their ability to integrate the donated organ into their own identity, as how can something be accepted as part of you if you do not know the details relating to it? Previous studies have found that identification, the practice in which an individual mentally assimilates aspects of another person into their own psyche (van der Velde, 1985), began when transplant recipients could think about their donor in a positive way (Sanner, 2003). In order for liver transplant

recipients to think about their donor in a positive way perhaps they need some, even minor, information regarding them.

Others did not wish to think or speak about their donor. It is discussed in the literature that transplant recipients may use a number of defence mechanisms to cope with the stress of transplant, and that denial may aid emotional adjustment in some recipients (Mai, 1986), particularly in the first 6 months post-transplant. This finding was upheld in this study as the participants with the shortest time since transplant (2 months and 4 months) denied having thought about their donor, suggesting that time from transplant can have an impact on how one may view their experience.

Many participants spoke positively about their scar and how it seems to be a badge of pride, which represents their experiences and story. To the author's knowledge this is a novel finding, not previously reported in literature relating to liver transplants.

4.1.3 Concept 3. How do participants think about adherence to medical care?

Participants raised that they often felt unheard by medical staff or lectured on the importance of adherence, which actually made them want to rebel and not adhere. This fits with SDT (Deci & Ryan, 2000; Ryan & Deci, 2000) which highlights patients' needs for autonomy and for this to be supported by medical staff.

Participants also raised the issue of feeling like they lack support post discharge from hospital and when transitioning to adult services. They also identified that they feel overwhelmed by all that is involved in taking medication. The theory of planned behaviour (TPB; Ajzen, 1988, 1991) and Perceived Behavioural Control (PBC, Ajzen, 1991), highlight self-efficacy (Bandura, 1977) as a fundamental part of behaviour change.

4.2 Limitations

This relatively small sample of 12 participants was all recruited from the same site and were all required to speak English. A large proportion of the participants in the sample (n=8) had previous contact with the Clinical Psychologist within the department. As such, the sample may not be representative of the general liver transplant population and diverse perspectives may not be represented within the data. Indeed, the researcher met a number of liver transplant recipients in clinic who did not wish to opt-in to the study, stating that they do not like to discuss their transplant. This self-selection bias may mean their experiences are not represented in these findings. Similarly, only one participant in this study received a liver from a living-related donor, meaning that this unique perspective may warrant further exploration.

There are limitations due to the cross-sectional design of one-off interviews. Adolescence/young adulthood is a unique developmental stage

where there are structural and functional changes in the brain up until the mid 20s (Blakemore, 2014), resulting in differences in the way young people think and see the world (i.e. struggling with more abstract thinking, different concepts of time, more transient feelings and opinions). The researcher only met with participants on one occasion, therefore capturing a mere snapshot of their experiences, as reported on that occasion.

Given the active role the researcher took in the co-construction of ideas, researcher's assumptions may have impacted on the data. However, some initial assumptions were challenged (i.e. participants would think negatively about their scar) suggesting that the measures taken to reduce researcher bias were successful.

4.3 Clinical and Research Implications

Knowing some of the story of their transplant was important for many participants. It seems that adopting an idiosyncratic approach would be best, whereby information is shared as it is asked for by liver transplant recipients. However, it is acknowledged that the wishes of the donor/donor family need to be respected. Photo albums of participants' time in hospital seemed valued, particularly by those who had their transplant at a young age. It may be advantageous to adopt this into common practice, especially as due to the rise in social media usage many aspects of life are being documented in a new way. Encouraging young people to use modern technology to record their

experiences will mean that they capture images, or thoughts, that are pertinent to them. Giving them something to look back on, to help thicken their narrative about the experience as, so often, when going through something traumatic people may disassociate and forget details. The development of a healthy identity was associated with adaptive, illness-specific coping strategies in diabetic adolescents (Luyckx et al., 2008). Research into whether this is helpful for young adults may identify implications for clinical practice in the acute care of this patient group.

Holding regular support groups for young adults is good practice, as they have highlighted that meeting with others who have had similar experiences help them to feel 'normal'. Participants spoke about their difficulties with life post discharge, and transition to adult services, and how they would like additional support with practical advice and mentoring. It seems that these two ideas could be linked to create a meaningful focus. Educating liver transplant recipients to raise their levels of self-efficacy, in line with the TPB (Ajzen, 1988, 1991), may have a positive impact on adherence. Research could be carried out to see if such a group has a positive impact on health-related behaviours. Furthermore, giving liver transplant recipients a sense of autonomy and control over their medical regime may result in better adherence, as per SDT (Deci & Ryan, 2000; Ryan & Deci, 2000). This may be achieved through Motivational Interviewing (MI; Rollnick & Miller, 1995), as SDT and MI have been found to be complementary in application to health behaviour change (Patrick & Williams, 2012).

5. Conclusions

The study presents a constructed ground theory of young adults' experiences of having a liver transplant. The complex interaction of processes, including; finding identity post-transplant, carrying responsibility and unspoken challenges were depicted in a model. These processes interact and have a bidirectional relationship with adaption to life post-transplant. The study highlights the importance of these processes in psychological adjustment post-transplant. Understanding this process is imperative, in order to improve health-related behaviours in a cohort with traditionally poor adherence. It also allows for the young transplant recipients' voice to be heard and practices to be developed; a process that will undoubtedly save lives.

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MAJOR RESEARCH PROJECT

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Section C

Appendices of Supporting Material

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2015

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix 1: Further Details of Literature Search

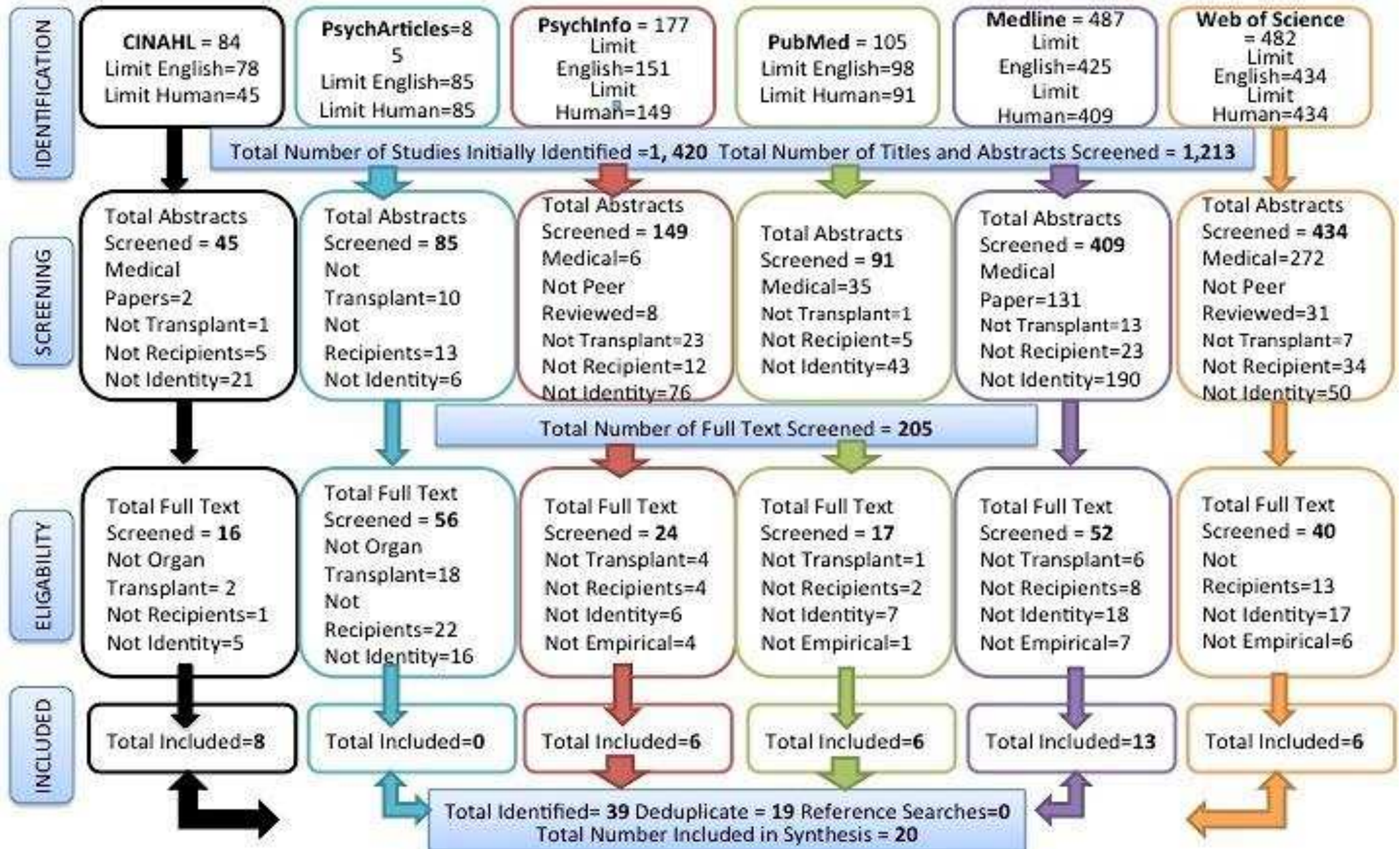
Preliminary electronic database searches were carried out to identify appropriate terminology for the systematic search. Pertinent search terms were obtained from relevant articles obtained through these initial searches. The terms used for the final search string were: Organ Transplant* or Heart Transplant* or Liver Transplant* or Lung Transplant* or Kidney Transplant* or Pancreas Transplant* and Identity or Self Concept or Self Perception or Identity Formation or Identity Crisis or Personality or Personality Development or Personality Formation and Recipient* or Organ Recipient or Patient*. Exploded Medical Subject Headings (MeSH) were included where possible to ensure that the broadest search strategy was employed. The following databases were searched: Ovid Platform: PsycINFO Medline, PsycARTICLES, EuropePMC Platform: PubMed Central, EBSCO Host Platform: CINAHL, Web of Knowledge: Web of Science.

The searches were all conducted using the appropriate search operators for each database, up to week 4, January 2014. The boolean operator 'OR' was used to ensure the results identified a Transplant Term (Organ Transplant* or Heart Transplant* or Liver Transplant* or Lung Transplant* or Kidney Transplant* or Pancreas Transplant*) an Identity Term (Identity OR Self Concept OR Self Perception OR Identity Formation OR Identity Crisis OR Personality OR Personality Development OR Personality Formation), and a Recipient Term (Recipient* or Organ Recipient or Patient*).

The boolean operator AND was used to combine the three separate search terms; the transplant term ("Organ Transplant*" or "Heart Transplant*" or "Liver Transplant*" or "Lung Transplant*" or "Kidney Transplant*" or "Pancreas Transplant*") AND the identity term ("Identity" or "Self Concept" or "Self Perception" or "Identity Formation" or "Identity Crisis" or "Personality" or "Personality Development" or "Personality Formation") AND the recipient term ("Recipient*" or "Organ Recipient" or "Patient*"). The truncation symbol (*) was used in the search terms, as detailed above, in order to expand the search and obtain a greater variety of terms.

Appropriate studies were identified through a four stage process; identification, screening, eligibility and inclusion. A flow chart, describing the process of this search and screening procedure, as per the PRISMA group guidelines (Moher, Liberati, Tetzlaff, Altman, The PRISMA Group, 2009), can be found in Appendix 2. At the identification stage a total of 1,420 citations were generated from the database searches, as described above. Following the preliminary identification stage whereby relevant papers were generated through the databases, the searches were then re-run with limits derived from the exclusion criteria resulting in 1,213 remaining citations. These limits included English language and human studies, however there were no time limits applied to the searches in order to ensure all the relevant literature was identified. The number of citations generated in each database following the addition of each limit can be found in the flow chart in Appendix 2.

Appendix 2 : PRISMA Flow Diagram of Database Searches and Paper Selection (Moher, Liberati, Tetzlaff, Altman, 2009)



Appendix 3: Summary Table of Papers Included in Systematic Review

	Author, Year of Publication and Country	Participants	Organ	Methodology	Measures	Key Findings related to identity
1.	Zhang, Huang, Wen, Hu, Jin, Shen & Cai. (2005) China	n=55 (4 female and 51 male) Mean age: 41.13 years. Mean time Post Tx: 11.8±12.39 months	Liver	Quantitative - Cross-Sectional design – Correlational Analysis	General Quality of Life Inventory (GQOLI-74), Medical coping Modes Questionnaire (MCMQ), Eysenck Personality Questionnaire (EPQ) General Condition Questionnaire	Psychological well-being is positively correlated with confrontation and negatively correlated with acceptance. Need to communicate frequently with the family, doctors and nurses about the details of their illness in order to obtain relevant information.
2.	Forsberg, Bäckman & Möller, (2000) Sweden	n= 12 (9 female, 3 male) Mean age: 51 years (range 24-63 years) Mean time Post Tx: 12 months	Liver	Qualitative-Modified version of a Phenomenological method (Karlsson, 1993)	–	7 categories emerged, which included different perspectives from different recipients. One category, Emotional chaos, included the code 'Becoming a new person'. (p.330)
3.	Durst, Horn, MacLaughlin, Bowman, Starnes, & Woo, (2001) USA	n= 19 (11 females, 8 males) Mean age: 15.7±2.7 yr Mean time Post Tx: 25.4 months (Range 1-58 months) Reason for tx: Cystic fibrosis (n=19)	Lung	Qualitative – Ethnographic study design	–	Successful psychological integration of organ. Few considered they had received donors traits All believed they had a stronger sense of self, post-transplant, emphasising a new, inner strength.
4.	Schmid-	n= 12 (5 female, 7male)	Kidney	Mixed methods-	Structured questionnaire	Qualitative: Theme: 'Managing changes

	<p>Mohler, Schäfer-Keller, Frei, Fehr & Spirig, (2014)</p> <p>Switzerland</p>	<p>Mean age: 52 years (Inter quartile range 42.25-65.25 years)</p> <p>Mean time Post Tx: 6.5 months (Inter quartile range 2.25-15.75 months)</p>		<p>Semi-structured interviews and a structured questionnaire.</p> <p>Interviews analysed by Content Analysis.</p> <p>Quantative data reported as frequencies</p>	<p>was developed to identify the presence of 44 self-management tasks</p>	<p>in self-perception'. Dealing with changes in appearance, managing reduced energy, bonding with the transplanted kidney. Feeling like the graft is not ones' own, difficulties defining if the kidney was his, or alien.</p> <p>'Is it alien, is it not alien? Is it mine? Is it not mine?' (P.12)</p> <p>Quantitative: Seven of eight self management tasks perceived as a challenge by at least half of participants, fell under the title of 'Emotions and self-perception', including balance between normality/feeling healthy and abnormality/feeling ill, changes in appearance and fears of harming the kidney.</p>
5.	<p>Inspector, Kutz, David, (2004)</p> <p>Israel</p>	<p>n = 35 (0 female, 35 male)</p> <p>Mean age: 50 years (range 22 to 68 years)</p> <p>Mean time Post Tx: 2 years (range 7 months to 6 years)</p>	Heart	<p>Mixed methods retrospective design – questionnaires and semi-structured interview</p> <p>Interviews analysed using content analysis.</p> <p>Quantative data reported as frequencies.</p>	<p>Depression Adjective Checklist (DACL)</p> <p>Post-Traumatic Stress Disorder Questionnaire (PTSD-Q)</p> <p>Symptom Distress Checklist –Revised (SCL-90-R)</p> <p>Heart Image Questionnaire (HIQ)</p> <p>Semi-Structured Interview (SSI)</p>	<p>SCL-90-R: 85% reported they were easily angered, and 76% reported increased inter-personal sensitivity</p> <p>SSI: 40% stated they had been 'reborn'</p> <p>8. 5% of those who had fantasies either before or after (n=8), considered transference of traits with the donated donor, compared to 20% (n=4) of those with no fantasies about the donor.</p> <p>Incorporating another's heart Is a complex and long process.</p>
6.	Adebäck,	n = 21 (9 female, 12	Liver	Quantitative Cross-	Weschler preschool and	Piers Harris Self Concept Scale: Mean

	Nemeth & Fischler, (2003) Sweden	male) Mean age: 9.6 years (range 4-16.9 years) Mean time Post Tx: 4.2 years (Range 1-9 years)		sectional study – Questionnaires and Interviews Fisher's exact Test, vhi-square test, Wilcoxon rank sum test, Spearman's test Interviews reported as frequencies.	primary scale of intelligence (WPPSI-R) Weschler Intelligence Scale for Children (WISC-III) Piers-Harris Self Concept Scale Koppitz Evaluation of Human Figure Drawings	score was 55, slightly above expected mean of 50. However wide distribution of scores. The Piers-Harris scale correlated positively to the IQ score (r=0.6, p=0.02) Interviews: They found that low self-concept coincided with cognitive and emotional problems in some children.
7.	Bunzel, Schmmidl-Mohl, Grundböck, & Wollenek, (1992) Austria	n = 47 (2 female, 45 male) Mean age: 47 years (range 17-66 years) Mean time Post Tx: 'about 3 months'	Heart	Qualitative – Semi-structured interview. No method of analysis described.	Semi-Structured interview	79% (n=37) stated that their personality had not changed at all postoperatively. 15% said their personality had changed, but not because of the donor organ, due to the life-threatening event. 6% reported a distinct change of personality due to their new hearts. Severe difficulties observed regarding graft incorporation, based on age-old ideas about the heart housing ones feelings and personality.
8.	Neukom, Corti, Boothe, Boehler, & Goetzman, (2011) Switzerland	n = 6 (3 female, 3 male), gave 8 narratives Mean age: Not stated Time Post Tx: 'at least 12 months'	Lung	Qualitative – Semi-structured interviews. JAKOB Narrative analysis.	-	In 5 narratives, they concern themselves with the person of the donor in terms of gender, age or specific personality traits. 3 Stage model theory of organ integration is evident in their sample, and is discussed in more detail in the paper.

9.	<p>Goetzmann, Moser, Vetsch, Klaghofer, Naef, Russi & Boehler, (2007)</p> <p>Switzerland</p>	<p>n = 14 (6 female, 8 male)</p> <p>Mean age: High compliance group 41 years (range 18-55 years) Low compliance group 37 (range 28-44 years)</p> <p>Mean time Post Tx: High compliance group 51 months (range 22-109 months) Low compliance group 46 months (Range 30-70 months)</p>	Lung	Qualitative – Content Analysis	Semi-standardised interviews. Nine questions referring to patient's perceptions of self, body, transplanted lung and their social network.	<p>Psychological processing of the transplanted lung itself related to compliance behaviour.</p> <p>Low-compliant patients expressed a loss of self-competence in the post transplant period.</p> <p>Psychological processing of the transplanted organ may be successful, if firstly the new organ is integrated into the self and secondly the donor perceived as a separate person. Low compliant patients seem to experience their organ as a foreign object, but the donor as close at the same time.</p>
10.	<p>Ordin, Karayurt, Wellard, (2013)</p> <p>Turkey</p>	<p>n = 21 (5 female, 16 male)</p> <p>Mean age: 48.67 years (range 19-64 years)</p> <p>Mean time Post Tx: 16 months (Range 1-52 months)</p> <p>Primary reasons for tx: Viral (n=11), HCC (n=6), Cryptogenic (n=2), PBS</p>	Liver	Qualitative Design – Individual or group interviews – Deductive Content Analysis	Interview form developed by investigators based on the literature, used to determine the LTR adaptation responses to LT	<p>Four themes identified, one of which was 'self-concept mode'. As there was a dramatic and fast change in patients' lives, the self-concept mode was greatly affected.</p> <p>Highlighted the importance of nursing staff to have an awareness of a TR's self-concept as they can play an important role in developing the recipients' self-concept and therefore their identity (Roy, 2009)</p>

)n=1), Autoimmune (n=1)				
11.	Jones, (2005) USA	n = 20 (5 female, 15 male) Mean age: Women, 46 years (range 26-59 years) Men, 43 years (range 18-59 years) Mean time Post Tx: All participants interviewed at 6 weeks, 6 months and 12 months post operatively.	Liver	Longitudinal qualitative study – Semi structured interviews at 6 weeks, 6 months and 1 year post transplant. Analysed using content analysis.	Semi structured interview questions relating to the pre and post transplant experience.	Identity issues emerged in the six month interviews. Many reported an unsettled sense of self. Participants described a major personality change and a diminished sense of self. Most reported identity changes achieved psychological integration by the 1-year interview.
12.	Ullrich, Schmidt, Scharf, Penkert, Niedermeyer & Schulz, (2010) Germany	n = 45 CF=27 (8 female, 19 male) Non-CF=18 (13 female, 5 male) Mean age: CF= 31.7 years (± 5.6 years) Non-CF= 32.7 years (± 5.4 years) Mean time Post Tx: CF= 5.3 years (± 3.0 years) Non-CF= 5.8 years (± 2.9 years)	Lung	Qualitative- Semi-structured interviews. Analyses using content analysis and frequency distributions	-	Time since tx was important. Recipients with a post-transplant interval below 3 years answered more 'neutrally' or 'positively', recipients with longer interval answered with 'exclusion' ($p=0.07$; thoughts of the donor are denied or declared futile or the alien character of the organ is denied or sharply downgraded). 7 years after collection of interview or 12 years post tx, on average, eight ppl had died. Remarkably 7/8 of these ppl answered with 'exclusion'. If patients who had undergone a redo tx are included this brings the number to 16.

						12/16 patients answered with exclusion.
13.	Nilsson, Persson, Forsberg, (2008) Sweden	n = 16 (10 female, 6 male) Four from each group of received organ. Mean age: 47.43 years (Range 21-63 years) Mean time Post Tx: 3.64 years (Range 3months to 10 years)	Kidney, Liver, Heart or Lung	Qualitative-Phenomenography	Little detail of the questions used. Followed a phenomenographic method.	One of the five domains of variations in perceptions of graft rejection was one's identity. Identity involved the perception of Graft rejection as a useful experience leading to trust in one's own strategies for mastering the health situation. 'Identity adjustment' meant adjusting one's self-perception in accordance with the results of tests. You are what the tests show.
14.	Collier, Nathanson, Anderson, (1999) USA	n = 15 (5 female, 10 male) Mean age: 16 years, (Range 13-18 years) Mean time Post Tx: 3.1 years	Heart	Cross-sectional, Quantitative Study. Results reported as descriptives.	Used the Million Adolescent Personality Inventory (MAPI)	Scores of 75 or above, were considered to be in a clinical range for that particular trait or characteristic. In the 'Expressed Concerns' section 40% of participants expressed significant degrees of concern, scoring 75 or above, for personal esteem, which relates to self-esteem and self-worth. 33% of participants scored 75 or above for Self-concept, which relates to clarity of role and self-concept.

15.	<p>Kaba, Thompspn, Burnard, Edwards, Theodosopoulou, (2005)</p> <p>UK</p>	<p>n = 42 (7 female, 35 male)</p> <p>Age Range: 32-61 years</p> <p>Range time Post Tx: 2-24 months</p>	Heart	<p>Qualitative - Grounded theory analysis using techniques described by Corbin and Strauss (1990) and Glaser and Strauss (1967)</p>	-	<p>Four categories emerged from the data including; 'traumatic experiences', 'that's a small price to pay for being alive', 'somebody else's heart inside me' and 'coping'. However the present paper just focused on presenting the 'somebody else's heart inside me' category.</p> <p>The category related to concerns' about the donor's heart and how getting someone else's heart might affect their own personality. Denial seemed to help participants cope with their concerns about the likeliness of their personality having changed. Denial was often expressed by patients saying that they did not wish to talk about the graft and/or the donor.</p>
16.	<p>Tong, Morton, Howard, Mc, Taggart, Craig, (2011)</p> <p>Australia</p>	<p>n = 22 (10 female, 12 male)</p> <p>Mean age: 15.6 years (range 12 -19 years)</p> <p>Mean time Post Tx: Not reported</p>	Kidney	<p>Qualitative - Grounded Theory and Thematic Analysis</p>	-	<p>Overarching theme identified was achieving a sense of normality. Five facilitators and five barriers to achieving a sense of normality were identified. Developing their own identity was one of the facilitators, whilst one barrier was identity crisis.</p>

17.	Sanner (2003) Sweden	n = 38 (15 female, 23 male) 35 were studied over the 2 year period. Mean age: Heart = Male 51.92y, female 51.8y Necro-kidney = Male 48.83y, Female 52.4y Living Kidney = Male 50.43y Female 36 y Mean time Post Tx: Not reported	Heart and Kidney	Qualitative – Not explicated stated, but seemed to use thematic analysis	-	<p>Few differences between heart and necro-kidney recipients. More prominent between living and necro recipients.</p> <p>Discussion of the idea of ‘suppression, avoidance and denial’ used by all transplant participants in the two-year follow up. Felt that these defensive strategies were used most in the 6 months immediately post transplant</p> <p>Overall one third of the recipients expressed fleeting thought about the influence of donor’s identity. No recipient who received a donation from a living relative spoke about the possibility of being influenced by the transplant, but the fact that they were related seemed to be favourable.</p>
18.	Biörck & Magnusson, (1968). Sweden	n = 15 (1 female, 14 male) Mean age: 36 years Mean time Post Tx: ‘short’ – 2 years	Kidney	Qualitative Interviews – No method of analysis described.		<p>The majority of recipients accepted the donated kidney as “their own” (p.183). In one case however, where the organ could not be accepted, the kidney had to be removed after three years.</p> <p>The author questioned whether anonymous donation made it easier for these recipients to incorporate the donated organ into their sense of self. He questioned whether reaction to donations from near relatives may be affected of feelings of affection or hostility towards the donor.</p> <p>Author highlighted that the recipients</p>

						remarkable acceptance of the donated organ may be achieved through denial or suppression of feelings, which may be dangerous if they came to the surface.
19.	Tisza, Dorsett & Morse, (1974) USA	n = 4 Mean age: 17 years Mean time Post Tx: Not stated	Kidney	Case Studies	-	Even the sickest adolescent, resisted regression, to hold onto their adolescent identity.
20.	Ådahl, (2013) Finland	n = 18 Mean age: Not reported Mean time Post Tx: Not reported	Kidney	Qualitative Interviews – Ethnographic research approach	-	<p>Recipients may anthropomorphise their transplanted organ, believing that personal features are carried over into their life, i.e. certain likes/dislikes they believe the donor to have had.</p> <p>Recipients may personify the donated organ in order to ascribe selfhood to the transplant organ as way of trying to mix the self of the kidney, with ones' own self.. 'It's my pet...I have the kidney's name day today..to my mond most [recipients] surely give it a name' (p.142)</p> <p>Some recipients spoke of a re-birth into a new kind of person, not just do to physical changes, but due to the creation of a new identity.</p>

Appendix 4: Guidelines for Qualitative Research

Elliott, Fischer and Rennie (1999)

A. Publishability Guidelines Shared by Both Qualitative and Quantitative Approaches

1. Explicit scientific context and purpose
2. Appropriate methods
3. Respect for participants
4. Specification of methods
5. Appropriate discussion
6. Clarity of presentation
7. Contribution to knowledge

B. Publishability Guidelines Especially Pertinent to Qualitative Research

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs. specific research tasks
7. Resonating with readers

Appendix 5: Quality Assessment for Qualitative Paper
 Adapted from Effective Public Health Practice Project (EPHPP, 2009)

COMPONENT RATINGS
A. SELECTION BIAS
Are the individuals selected to participate in the study likely to be representative of the target population?
Very likely
Somewhat likely
Not likely
Can't tell
What percentage of selected individuals agreed to participate?
80 - 100% agreement
60 – 79% agreement
less than 60% agreement
Not applicable
Can't tell
RATE THIS SECTION
B. STUDY DESIGN
Indicate the study design
Randomized controlled trial
Controlled clinical trial
Cohort analytic (two group pre + post)
Case-control
Cohort (one group pre + post (before and after))
Interrupted time series
Other specify _____
Can't tell
Was the study described as randomized? If NO, go to Component C.
No
If Yes, was the method of randomization described? (See dictionary)
If Yes, was the method appropriate? (See dictionary)
RATE THIS SECTION
C. DATA COLLECTION METHODS
Were data collection tools shown to be valid?
Yes
No
Can't tell
Were data collection tools shown to be reliable?
Yes
No

Can't tell
RATE THIS SECTION
D. WITHDRAWALS AND DROP-OUTS
Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
Yes
No
Can't tell
Not Applicable (i.e. one time surveys or interviews)
Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
80 - 100%
60 - 79%
less than 60%
Can't tell
Not Applicable (i.e. Retrospective case-control)
RATE THIS SECTION
F. ANALYSIS
Are the statistical/qualitative methods appropriate for the study design?
Yes
No
Can't tell
RATE THIS SECTION
GLOBAL RATING
COMPONENT RATINGS
A
B
C
E
F
GLOBAL RATING FOR THIS PAPER:

Appendix 6: Characteristics of good quality case study evidence

Adapted from Yin (2003)

1. The case study must be significant.
2. The case study must be 'complete' – collecting all the evidence possible, within set clear boundaries by having a clear guiding question.
3. Must consider alternative perspectives.
4. Must present supporting and sufficient evidence to support study claims.
5. Should be presented in a clear and engaging manner.

Appendix 7: Permission to Reprint Material from Wiley Publications

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Appendix 8: Example of Full Transcript with Initial Coding

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Appendix 9: Interview Guide

Given the grounded theory approach, I do not want to be too directive in my interviewing; therefore this is more of a guide than a schedule. I may not get through every question in this guide in every interview, however I hope to cover each of the main themes. The questions are also likely to evolve as interviews progress according to grounded theory protocol.

1. Could you please draw a representation/picture of your donated organ?
This may include, your liver; you and your liver; you, your liver and your donor; or any combination of the above. This is not about drawing a beautiful, perfect, aesthetically pleasing picture but is supposed to help with talking about your experience.
2. Could you please tell me about your picture?
3. There may be follow up questions following on from the participant's description.
4. Theme: Understanding and making sense of having a donated organ
 - a. Tell me about how you came to know that you needed to have a liver transplant (this may have been before or after the event).
 - b. Do you remember your experience of having the transplant?

- c. [If so,] What was it like? What did you think then? How did you cope with it? Who, if anyone, influenced your actions? Tell me about how he/she or they influenced you.
- d. Could you describe the events that led up to your transplant?
- e. Do you know who donated your new organ? If so, what do you know? If not, have you ever wondered about this person? Do you have an idea about who it might/might not be?
- f. What contributed to your understanding of what was going on for you then?
- g. What was going on in your life then? How would you describe how you viewed yourself/your family/the world before this happened? How, if at all, has your view of yourself/your family/the world changed?
- h. How would you describe the person you were then? Is this different to the person you are now?

5. Theme: Pertinent factors which contribute to this understanding or sense making

- a. What, if anything, did you know about liver transplants before your operation/ before you found out?
- b. Tell me about your thoughts and feelings when you learned about your transplant?
- c. What happened next?
- d. Who was involved in telling you? How were they involved? Do you remember how they told you? What words they used? What was that like?
- e. Do you tell others about your transplant in the same way? Do you use the same words/the same story? Does your 'story' differ to the one other members of your family tell?
- f. Tell me about how you learned to handle the experience of having a donated organ?

- g.** How, if at all, have your thoughts and feelings about your donated liver/ transplant changed since you first heard about it/ before it happened? Has your story changed?
- h.** What positive changes have occurred in your life since the transplant or because of the transplant? Has this become part of your 'story'?
- i.** What negative changes, if any, have occurred in your life since the transplant or because of the transplant? Has this become part of your 'story'?
- j.** What has been the most helpful thing for you when trying to make sense of having a transplanted liver?

6. Theme: Impact on self psychologically and physically

- a.** Tell me how you go about how you have to care for yourself because of your donated liver. What do you do?
- b.** Could you describe a typical day for you? Do you imagine this to be different from your peers who do not have a transplant? How?
- c.** What helps you manage your condition/your transplant? What problems might you encounter? Tell me the sources of these problems.
- d.** Do you ever talk about your experiences with friends/family? Do you have an opportunity to share your 'story'?
- e.** Tell me how you would describe the person you are now. What has contributed most to the person you are today?
- f.** As you look back on your experience of having a transplant/hearing about your transplant, are there any other events that stand out in your mind? Could you describe it/them? Why do you think this event stands out to you?
- g.** Could you describe the most important lessons you learned about yourself through the experience of having a donated liver?
- h.** Tell me about how your views and/or actions may have changed since you had your transplant/found out about your transplant?

- i.** How have you grown as a person since your transplant/hearing about your transplant? Tell me about your strengths that you discovered or developed through your experiences.
- j.** Where do you see yourself in two years [five years, ten years, as appropriate]? Describe the person you hope to be then. How would you compare the person you hope to be and the person you see yourself as now?
- k.** After having these experiences, what advice would you give to someone who has just discovered that he or she has to have a transplant?

7. Theme: Experiences of the interview

- a.** Is there anything that you might not have thought about before that occurred to you during this interview?
- b.** Is there anything you would like to ask me?

Thank you for taking part in this research

Appendix 10: Participant Invitation Letter

Dear Sir/Madam,

As a service providing care for young people with liver condition we are keen to find out more about your experiences of living with a liver condition. In order to do so, we are wondering if you would be interested in participating in one of the research studies we are currently running? Enclosed you will find a sheet with some more detailed information.

Please note that participation in the study is entirely voluntary. If you do not want to participate, you do not have to, and you are free to withdraw at any time without giving a reason. Choosing not to take part will not disadvantage you, or affect the treatment that you receive, in any way. If you decide to participate, none of the information you provide will be shared with your doctors or the other members of the clinical team.

The researcher, Rachel Falk, is carrying out this study as part of a qualification in clinical psychology (DClinpsy). The researcher may approach you at the hospital when you come in for your next clinic appointment, to discuss the study with you.

Please take a moment to read the research information sheet enclosed. If you think you would like to participate please contact Rachel by telephone on 01892 515152, or by email r.e.falk115@canterbury.ac.uk. Please also feel free to contact Rachel if you have any questions as you are making up your mind. Alternatively, you may speak with Dr. [REDACTED], if you have study-related questions or problems.

Thank you for your consideration.

Yours sincerely,



Dr [REDACTED]

Appendix 11: NRES Amendment Approval Letter

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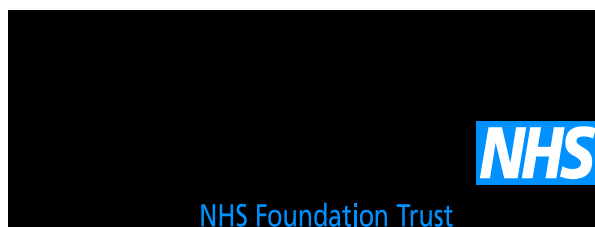
Appendix 12: R&D Amendment Letter

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Appendix 13: Research Flyer

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Appendix 14: Participant Information Sheet



Study Title: Young Adults' Experiences of Having a Liver Transplant

REC Reference Number: [REDACTED]

We would like to invite you to take part in a research study. This information sheet provides some details about the research, why it is being carried out and how you can participate. Before you decide we would like you to understand why the research is being done and what it would involve for you. **Rachel Falk, who is carrying out the research, will go through this information sheet and answer any questions you might have.** Talk to others about the study if you wish.

What is the research study about?

We would like to understand the issues faced by young people who have had a liver transplant. We would like to know more about what it is like to have a donated liver and how this has impacted on your life. We are also interested in how you have come to think about and understand having a donated organ, how it has become part of your identity and if you ever think about where your new liver came from.

We are also interested in using drawing, as a way of opening up the conversation about your experiences. We would like to hear your ideas about whether this is helpful or not.

Why have I been invited?

Young people (aged 16-24 years) who attend Young Adult Liver clinics at King's College Hospital, and who have had a liver transplant, are invited to take part in this study. If you do not want to participate, you do not

have to, and you are free to withdraw at any time without giving a reason.

Do I have to take part?

It is up to you to decide to participate in this study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Choosing not to take part will not disadvantage you or affect the treatment that you receive in any way.

What is the purpose of the study?

We are interested in how young people experience having a liver transplant. So far there is not much information available on this subject, and we would like to know more about the wellbeing of young people with a liver transplant.

What will happen if I take part?

If you agree to take part, the researcher will arrange a mutually convenient time to interview you. This might be at [REDACTED] or we can come and visit you at home. The interview will take up to one and a half hours. You will be asked to sign a consent form indicating that you have read and understood this information sheet and that you are willing to participate. The interview may perhaps be on the same day you attend a routine clinic appointment, if you wish. You will be asked to draw a picture relating to your experiences. You will then be asked questions about your picture and experiences and the interview will be recorded. You do not have to answer any questions you are not comfortable with. There is also a possibility that you may be invited back to do a follow-up interview. However, if this happens, you are not under any obligation to agree.

Do I have to be good at drawing?

Not at all! You may not like the idea of drawing a picture, however please don't let this put you off!

The task is not about drawing a beautiful, perfect or aesthetically pleasing picture. The purpose of using the drawing is to find out what the experience is like for you, positive or negative, helpful or unhelpful.

Who is carrying out the study?

The study is being carried out by Rachel Falk, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology undertaken at Canterbury Christ Church University. The study is supervised by Dr. [REDACTED] and Dr. Helen Caird, Clinical Psychologist at Canterbury Christ Church University. Dr. Marianne Samyn, Paediatric Hepatology Consultant is also involved in the project. Neither participation nor withdrawal from the study will affect your routine clinical care.

Will my taking part in the study and my responses be kept confidential?

The information collected in this study will be kept securely in compliance with the Data Protection Act (1998). The data will only be accessible to

the researcher and not shared with anyone outside of the research team. However, there are limitations to confidentiality. If the researcher feels that you, or another person, may be at risk of harm confidentiality may have to be broken. If this happens others may need to be informed, however this would be discussed with you beforehand, if at all possible.

What is the benefit to you of taking part?

Participation in the study is entirely voluntary and whether or not you take part will not affect your treatment in any way. Participation in the study may help us understand more about how to help young people with liver conditions in the future, but is unlikely to have any direct benefits for you. There is a possibility that you may find it upsetting to talking to the researcher about your illness. If this happens, and you wanted, you could be offered support by a clinical psychologist in the KCH Liver Transition team.

What if I change my mind after I have agreed to take part?

You may withdraw from the study at any time before, during or after the interview without having to give any reason, just by letting us know you wish to do so. If you have already completed questionnaires or done an interview, your data will be removed from the results and securely destroyed.

What will happen with the results of the study when it is completed?

The results will be written up in a thesis and stored at the University. A version of the report may be published in a scientific journal. The written reports will contain anonymous quotes from the interviews or feedback given. It will not be possible for anyone to identify you or any other participant in the reports.

Expenses and payment

All participants who complete the study will receive £20 as a 'thank you' for taking part.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Lancaster Ethics Committee.

What if I do not wish to be approached about this at the clinic?

Please send an email to r.e.falk115@canterbury.ac.uk or telephone/text 07523 570 014 giving your name and we will not contact you about the study again.

Questions / concerns

If you have any further questions about the research, please feel free to contact the researcher via email, details of which are below, or in person. In the unlikely event that participating in this research has caused you distress in some way, please contact your clinician.

Contact details of the researcher

Please contact Rachel Falk if you are interested in taking part in the study.
Email: r.e.falk115@canterbury.ac.uk or Telephone/Text: 07523 570 014.

Thank you for taking time to read this information sheet.

Appendix 15: Demographic Information Sheet



Basic Demographic Information

1. Name:
2. Age?
3. Ethnicity?
4. Are you in education or employment?
5. How many transplants have you had?
6. How old were you?
7. What liver condition do you have/did you have?

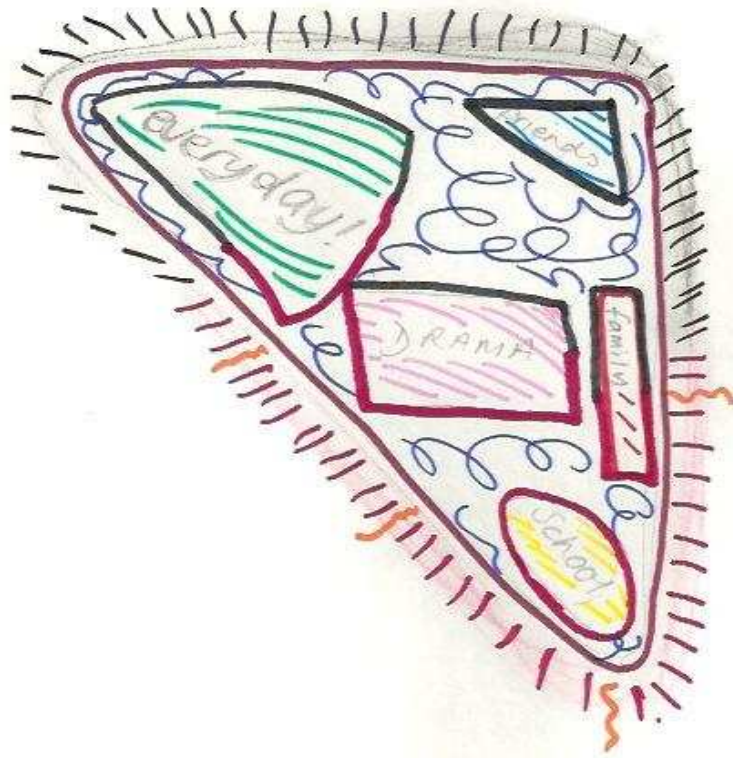
8. Do you/Did you have any other physical or mental health conditions?

9. Do you have to take medication regularly? How often?

10. Do you have regular medical appointments? How often?

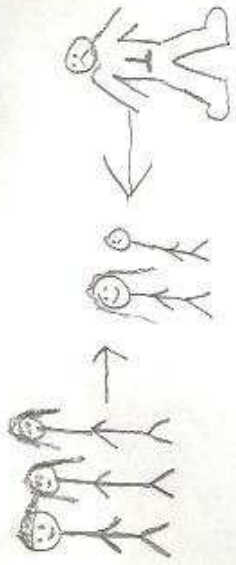
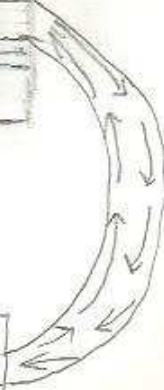
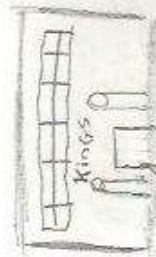
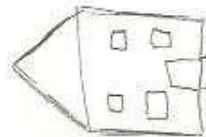
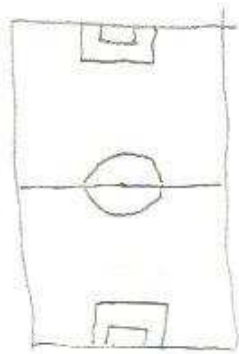
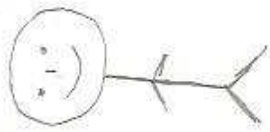
11. Anything else I should know about your condition?

Appendix 16: Examples of Drawings Completed in Interviews



LTFE

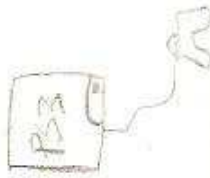
MUFC

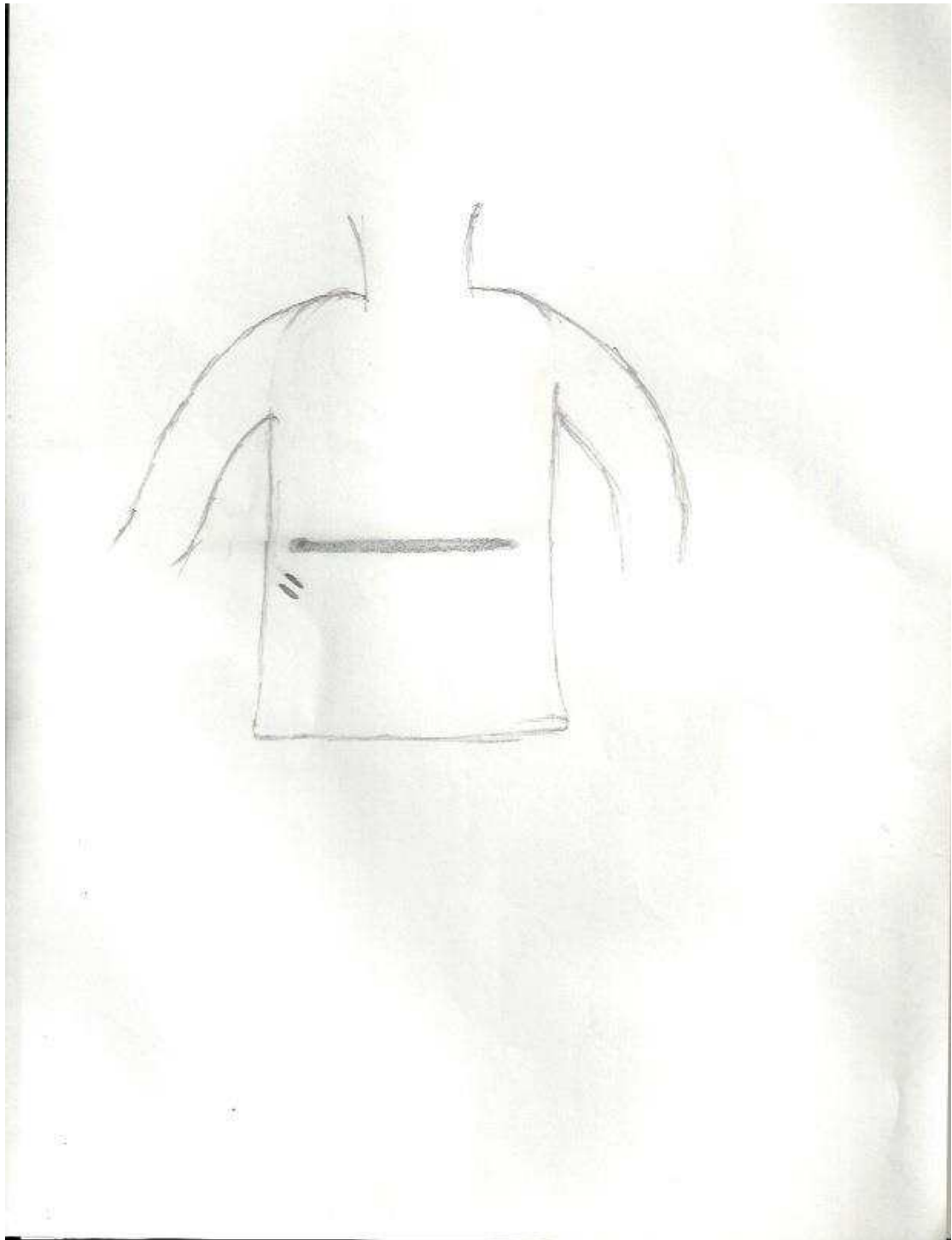


Eastenders



MRW







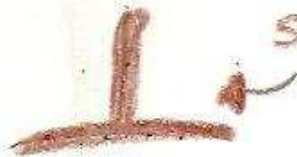
NOT ALLOWED TO EAT ORANGE X



GOOD DAYS



BAD DAYS



SCAR ON BELLY



Bloods. Injection.

Appendix 17: Assumptions Identified through Bracketing Interview

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Appendix 18: Abridged Research diary

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Appendix 19: NRES Original Approval Letter

Removed

Appendix 20: Participant Consent Form



Centre Number: **Study Number:** **Patient Identification**
Number:

CONSENT FORM

Project Title: An investigation of young adults' experiences of having a liver transplant.

Researcher: Rachel Falk

Please initial all boxes

I confirm that I have read and understand the Participant Information Sheet (dated 01.03.2014, Version No. 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that participation is voluntary and I can withdraw from the study at any time, without giving any reason. If I withdraw, all of my data will be permanently destroyed and will not be included in the results. I understand that if I do not wish to take any part in the study, my medical treatment or legal rights will not be affected.

I agree to be interviewed for up to two hours about my experience of having a donated liver and to complete a drawing about my experiences, which I will also be asked questions about.

I understand that after completing the interview I will be asked to fill in a brief questionnaire.

I agree to use of audio taping of my interview and that verbatim quotations from my interview may be used in publications relating to this study.

I agree to the use of photographs of drawings being used in publications related to this study.

I understand that data from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this study. I give permission for these individuals to have access to this information.

I agree to take part in the above study.

Name of Participant Date Signature

Researcher Date Signature

Tick this box to receive a results information sheet when this study is completed.

Copy:

1. For participant
2. For researcher

Appendix 21: Table of Codes and Categories

Themes	Categories	Sub- Categories	Focused Codes
<i>Finding Identity Post Transplant</i>	<u>Knowing whose story I'm carrying</u>	Gathering Information	Living donor
			Finding out who it was
			Wanting to know more – Is knowing more is better?
			Making a connection
	<u>Developing a sense of where I 'fit'</u>	Feeling like I belong	Growing to feel proud of scars - the mark of my tribe
			Family within transplant community
			Having friends in the same situation
			Cultural Issues
		Changing, growing and/or developing from experiences	Transplant Experiences
			Shaping Personality and/or Life Views
	<u>Getting my head around my own story</u>	Learning about my own 'history'	Adopting Donors Traits
			Coming to know about transplant
			Understanding what has happened
			Gradually finding out
			Strong family narrative of transplant story
			Becoming comfortable with my own transplant story
		Making sense of having a transplant	
		Is it mine?	
Happy to tell story			
You have to be worthy to hear my story			
No pressure to drink alcohol/go clubbing			
<u>I just want to feel, and be, a 'normal' young person</u>		Feeling very different	Feeling different to peers
	Adolescence is hard enough, without all this - Dealing with transplant in adolescence is hard		
	Wanting to feel 'normal'		
	Troubled by scars - I don't want to stand out		
	Will anyone ever love me for who I am?		
	Under pressure to drink alcohol/go clubbing		
	Doing everyday ,		
	I want to work/go to school		

		'normal' things that young people do, is really difficult	Can't pursue Interests Pressure to not drink Feeling like there are big consequences to drinking Feeling torn regarding drinking, wishing I could/should be able to drink. Feeling curious.
	<u>I still get to be me (a strong person)</u>	Living for self	Still parties! The other me – I'm more than just a transplant recipient Maturing/taking charge/asserting own needs Finding Balance (you only live once?!) Living for self/nothing holding me back
		Coping with the extraordinary	Detaching Self Support of Family Staying positive Importance of friends who understand
		Resilience	Acceptance of the unacceptable Fighting to be well Coming to terms with it
Carrying Responsibility	<u>I'm alive for a reason</u>	Feeling like I was chosen for something special	Best gift ever/A big big gift I am so lucky God picked me I'm Special
	<u>Having to grow up before my time</u>	Facing own mortality	Escaping death Aware of the fragility of life Fighting to live Writing my 'bucket list' Can't trust own body/I might die Feeling more mature than peers (Maturity as a burden?-Inflicted maturity?)
		Realising and living with the knowledge that someone had to die so that I could live	Someone died, so I could live
Unseen, Unspoken or misunderstood challenges	<u>Services as something else we have to deal with</u>	Struggling to deal with services – perhaps made more difficult because I'm a young person?	Transitioning to Adult services - Leaving 'home'
			Frustrations with medical staff
			Poor medical care

	<u>Collateral damage to many aspects of life</u>	The transplant is the tip of the iceberg	Even more medical problems
			Toll of multiple transplants
			Worried about things changing
		Implicit and explicit familial pressures	Expectation from family to 'deal with it'
			Guilt about what family has been though
			Seen as sick
			Special Treatment
			Penalised for being unwell
	People seem to think you use your illness as an excuse – you need to explain yourself		
	<u>Impact on mental health</u>	The extra hidden scars	People don't understand there are some really hard days
			Traumatic memories
			Secondary traumatisation
			Impact of finding out about impending transplant
			Post transplant recovery
Waiting for Transplant			
Haven't I dealt with enough?			
<u>Adherence to medication is complex</u>	The double-double bind of taking, or not taking, medication	Forgetting to take medication	
		Choosing not to take medication has consequences	
		Struggling with having to take medication	

			Guilt about not fulfilling responsibility to follow medical regime
<i>Adjusting to life after transplant</i>	<u>Moving on with my life</u>	Framing experiences in a positive way	Enjoying and appreciating life as still alive
			Being Grateful –given an opportunity
		Taking it all in my stride	It's not that big a deal!
	<u>Feeling like I'm on my own now</u>	Dealing with the reduction in support post transplant	I'm on my own now

Appendix 22: Progression of Theme Development Table

Themes	Categories	Sub- Categories	Focused Codes	Quotes
<i>Finding Identity Post Transplant</i>	<u>Knowing whose story I'm carrying</u>	Gathering Information	Living donor	<i>"they got that for me to send to mum, because she gave her left lobe to me" (Participant 2, Lines 129-130)</i>
			Finding out who it was	<p><i>"They get to know who's got it.... It was a big ask, they knew exactly who it was" (Participant 2, Lines 142-143)</i></p> <p><i>"I have thought about it but because the doctors won't ever tell you anyway so there is no point running away from it, it's a constant it's inside you. I have thought about it, whether they are old young but it is just wild guesses I guess. I might get it right but you never know." (Participant 9, Lines 730-733)</i></p> <p><i>With my transplant I still don't know who it came from all I know is it was from a young donor and they died in the same hospital and the same ward... They were probably from the same area and I probably used to get on the bus with their parents and friends. (Participant 10, Lines 166-167 & 168-169)</i></p>
			Wanting to know more – Is knowing more is better?	<p><i>"I think on the whole knowing more is better. Because although it gets difficult it means that I'm not wondering. I'd rather know and just be able to address that information when I want to address it than not know enough and be constantly having to ask questions." (Participant 4, Lines 405-408) (details of transplant)</i></p> <p><i>"Just as a kid you go through phases of wanting to know lots of stuff about everything and then wanting to know nothing about anything. That's completely normal." (Participant 4, Lines 710-712)</i></p> <p><i>"I think kids will ask when they want to know.... You just need to go at the speed of the kid because they will know when they want to know things or when they won't want to know things." (Participant 4, Lines 733 & 737-739)</i></p>

				<p><i>"I don't think I want to because it would probably feel like you were robbing someone. I don't think I want to know." (Participant 9, Lines 737-738)</i></p> <p><i>"I think it's just one of those that maybe I am not ready to think about it yet." (Participant 9, Lines 776-777)</i></p> <p><i>"It did trouble me that, because I know nothing about them." (Participant 10, Lines 183-184)</i></p> <p><i>"No I don't really know what happened to my donor I don't know if he is dead or alive to be honest?...No nothing about them. All I know is that I have a split liver so it's like me and this toddler that I was sharing the liver with. That is all I know. I don't know anything about my donor." (Participant 12, Lines 230 & 234-236)</i></p>
			Making a connection	<p><i>"You get to send a letter saying thank you and they get to send a letter back" (Participant 2, Lines 141-142)</i></p> <p><i>P5: "The mother of my donor gave me a photo of her". Researcher: "this is the donor?"... P5: yeah. I forget the meaning of hate when I look at her photo.(Participant 5, Lines 494-495 & 499)</i></p> <p><i>"I believe that souls never die. We just reconnect. So there is obviously that connection with that person in me." (Participant 6, Lines 530-531)</i></p> <p><i>"It was hard after the transplant, everything went so well and I wanted them to accept the better and they wouldn't. It was like well you have given me something so why are you not accepting what I have given you?" (Participant 10, Lines 179-181)</i></p>
	<u>Developing a sense of where I 'fit'</u>	Feeling like I belong	Growing to feel proud of scars - the mark of my tribe	<p><i>P6:"... I know exactly what you mean from the scar and people's perceptions of it. Yeah it's huge. I'm not going to lie its massive." Researcher:"Is it something that you worry about?" P6: "No." (Participant 6, Lines 430-434)</i></p>

				<p><i>"...But it is definitely a big factor 100 percent. It can make you think what's wrong with me? I have had thoughts where I have gone to my mum and granddad and been like is there going to be some kind of laser shit that is going to be able to remove this? Something like that. I don't even want to remove it now; it's a part of me I couldn't give a shit what people think. But I can see how it would affect people." (Participant 6, Lines 452-457)</i></p> <p><i>"having a scar to show for that is equally as weird, because you don't really feel different. The scar is the only thing that makes that visual in your head." (Participant 6, Lines 543-545)</i></p> <p><i>"The next one is the scar on my belly. It's like a T. I don't really mind it. It's OK" (Participant 7, Lines 42)</i></p> <p><i>"It doesn't get me down or anything so that is the good thing about it." (Participant 7, Line 53-54)</i></p> <p><i>"The reason why I have drawn that is because a lot of the time when people ask me especially my friends that know about my liver transplant the only real evidence I have to show them is my scar. So that kind of means a lot to me" (Participant 8, Lines 71-74)</i></p> <p><i>"Even at times when I go swimming and I take off my top and everybody sees my scar I still feel normal so I think that shows me that I have nothing to worry about." (Participant 8, Lines 274-276)</i></p> <p><i>"The scar thing was funny because one of my, when I woke up in ICU I was asking what was going on, because I was covered up so I couldn't see, so I was talking to myself, do you know what if you look at it from this way it looks like a T for the start of my name, I am fine with that." (Participant 9, Lines 799-803)</i></p> <p><i>"I love my scar, I am proud of it. I love showing my scar off." (Participant 10, Line 671-672)</i></p>
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				<p><i>"I don't like it but at the moment it's tossing and turning between its part of me, it shows that I did actually have a transplant and didn't make it up." (Participant 11, Lines 289-290)</i></p> <p><i>"It's annoying. It's just like a big line across the abdomen so yeah." (Participant 12, Line 303)</i></p>
			Family within transplant community	<p><i>"I shared my first liver with a little girl and I am still in contact with her now." (Participant 3, Lines 61-62)</i></p> <p><i>"He died on my sister's birthday so it's not a day that I can forget. I always think about it, I mean it was twelve years ago and I still think about it quite a lot actually. A few years later we got a phone call from Kings and they had said that his mum and dad had asked about me and asked for my telephone number and I thought they were just going to ring and ask how I was. So they called and they were having another baby and they named it after me. That is something that has always stuck with me." (Participant 3, Lines 554-559)</i></p> <p><i>P3: Before when I had my transplant there was nothing. There were no support groups or anything like that.</i> <i>Researcher: Really.</i> <i>P3: I went to Switzerland the hospital have a thing over there where one of their transplant patients has opened up a ski camp and I've been twice and they pay for it all. It's all just transplant patients, and that was just amazing. I still talk to people now who I met then. I've joined Facebook groups and things like that so over the last two or three years (Participant 3, Lines 586-591)</i></p> <p><i>"I know one girl who was on the ward at the same time as me and she's a year younger than me and we have stayed in touch and my parents are really good friends with her parents and we meet up." (Participant 4, Lines 443-445)</i></p> <p><i>"I like this fact a lot, that the liver has two parts and I only got one part and another girl on the ward got the other half of it, she was a teenager and she got the bigger half</i></p>

				<p><i>and I got the smaller."(Participant 4, Lines 593-595)</i></p> <p><i>"There was a guy I met there who was on the list and they didn't find him a suitable liver for over a month. So I didn't want to tell him I came here two days ago and got mine. I saw him last time, last month and he seemed to be doing all right." (Participant 9, Lines 241-244)</i></p> <p><i>"I told him just to have faith I guess." (Participant 9, Line 264)</i></p> <p><i>"their mum's had kept in contact with other mum's who's children had, had transplant whereas my mum had no one, to ring up and go my daughter is being sick is that right? Two weeks after a transplant is that right? Or she can't keep the tablets down, is that right? What should I do? She had nothing." (Participant 10, Lines 530-533)</i></p>
			<p>Having friends in the same situation</p>	<p><i>"I had a friend who was there and sometimes he would come in and give me a bit of psychiatric advice when I was feeling down." (Participant 2, Lines 226-228)</i></p> <p><i>"My friend who I met skiing lives in South Africa and I talk to him on a weekly basis and we basically are the same person like the way we feel about things, like everything even to the point where he said he has depression about what he has had done and stuff. We talk about how the tablets make you feel and how scared you can be in hospital, just little things really. It is really nice to have that there because there are people who know exactly how you feel when you have got people at home who see you every day, talk to you every day but have no idea how it really feels. He's nine thousand miles away and he knows exactly how I feel, and I have got my mum and dad who live two miles away and have no idea." (Participant 3, Lines 591-604)</i></p> <p><i>"You have got to talk to people who are going through the same thing as you. That's the best thing" (Participant 5, Lines 645-646)</i></p>

				<p><i>"But the funny thing that happened, was two days after when they were still trying to find him a liver, one of the nurses must have come up to him she said can you talk to him about what is going on. I was like I will then I was like what the hell do you know about this kind of stuff to talk to him about it." (Participant 9, Lines 253-257)</i></p>
			Cultural Issues	<p><i>"Where I come from for political reasons we don't like British people so having a donor, a British donor...It changes things. So it's with you all of the time that mentality." (Participant 5, Lines 136-137 & 139)</i></p> <p><i>"I think that is more of a cultural thing because in Nigerian society, no, but it is the sort of thing if you are male you have to be more stronger" (Participant 9, Lines 699-700)</i></p>
		Changing, growing and/or developing from experiences	Transplant Experiences Shaping Personality and/or Life Views	<p><i>"I think a lot of how I think and my personality comes from what I have seen ahead." (Participant 8, Line 424)</i></p> <p><i>P5: Transplant changes you emotionally and also growing up as well so that's another thing, I was young. I'm still only young but yeah. I was younger. I'm shaping my personality.</i></p> <p><i>Researcher: Do you think that having the liver transplant is helping to shape your views, personality and thoughts?</i></p> <p><i>P5: yes certainly it does yeah. (Participant 5, Lines 114-119)</i></p> <p><i>P6: Yeah. Definitely. I mean when I was born I think this was a story my mum told me my mum could hold my sister but because I was ill they had to take me off and put me in that intensive thing.. It was kind of like that when I was in hospital as well because my mum would have to be at home at some stage. Bless her she was there for three weeks but then she would have to go for a weekend and stuff. So obviously that has to do with the illness and I definitely think that would be probably 60 percent of what me as an individual today is, I am quite a strong person and I can get through a lot of things just with myself will power. (Participant 6, Lines 386-388 & 390-395)</i></p> <p><i>"Yeah I am very, very independent. But yeah definitely it</i></p>

				<p>would have a massive effect especially if you there was later or earlier in your life. I'm quite grateful it was earlier, definitely. I would have hated to have gone through that now or later." (Participant 6, Lines 402-404)</p> <p>Researcher: "If you could change things and not have had your liver transplant would you choose that path?" P8: "No. I think the reason I am saying no, I don't think I would be as strong minded as I am today." (Participant 8, Lines 734-736)</p> <p>"I think if I was to not have a liver transplant I wouldn't be so self-believing, so I wouldn't believe in myself so much. I think I would depend on other things." (Participant 8, Lines 741-743)</p> <p>"I feel wealthy in other ways already. One of the reasons for that is being here. I don't think, I think if I didn't have a liver transplant I wouldn't appreciate life as much." (Participant 8, Lines 750-751)</p> <p>It is annoying knowing that you can do something, like if you are an artist and you can draw and after something happens to you can barely draw, so it affects your confidence and if your life is based around drawing or football it's just something you love doing and then that happens it changes your perspective on life I guess. (Participant 9, Lines 465-471)</p> <p>"Yeah it's sort of like when this happened maybe it's time to let everyone know how you feel. Just explain yourself a bit more and be more open to people." (Participant 9, Lines 593-594)</p> <p>"I have a foreign object in my body that I am worried is going to reject, I am used to being around medical people and now you are sending me to school with everybody that has done their schooling and knows what to do. It still gets me now, with work, I have got no punctuality." (Participant 10, Lines 112-115)</p>
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				<p><i>"Now it is like you have got options and you can do this and this. If you end up working in a bar it's fine. Have some money but try and make sure you do stuff that is fun as well. Don't spend all your life worrying about money and school and stuff like that. It is kind of freeing I suppose." (Participant 11, Lines 570-573)</i></p> <p><i>"I still view the world the same but I can sympathise with people who have transplants not just liver transplants but transplants in general because I know what they have been through. I know the majority of people might have a tiny bit of fear, not a lot but there must be a tiny bit bothering them." (Participant 12, Lines 368-371)</i></p>
			<p>Adopting Donors Traits</p>	<p><i>" Sometimes I think, this is strange but it's not scientifically proven but my personality is affected because of my donor." (Participant 5, Lines 159-160)</i></p> <p><i>Researcher: "Will you talk to me about that in what way are you more British?"</i></p> <p><i>P5: " I just feel closer to the culture in general. I use to think they are them, they are happy and I am myself, I am different, I am not like them but now I do things that I like in the British culture whereas before I was like none of that." (Participant 5, Lines 244-247)</i></p> <p><i>"So that's why they say I am not me, like when I act weird they say I am someone else." (Participant 7, Lines 152-153)</i></p> <p><i>"yeah. That I have got a different personality" (Participant 7, Lines 163)</i></p> <p><i>P10: "I think they were Chinese."</i></p> <p><i>Researcher: "You think they were Chinese? Why do you think that?"</i></p> <p><i>P10: "Because I used to eat Chinese straight after my transplant."</i></p> <p><i>Researcher:"really?"</i></p> <p><i>P10: "I just ate Chinese every day. Every day was</i></p>

				<p><i>Chinese and Harribows. It was the only thing I would eat."</i> <i>Researcher: "So you think your donor was Chinese?"</i> <i>P10:" probably." (Participant 10, Lines 188-195)</i></p> <p><i>Researcher: "Going back to your donor is there anything else you think you might have got from them?"</i> <i>P10: "My mental health. I was never scared of anything... After my transplant it was like shit what's happened."</i> <i>(Participant 10, Lines 215-217 & 219-220)</i></p> <p><i>P12:"This may sound funny, but my taste buds. Because stuff that I am eating now I never really liked in the past... I never liked chicken and stuff like that in the past. I never really liked vegetables but I am starting to like them now."</i> <i>Researcher: "So do you think that is something to do with your donor's liver or not?"</i> <i>P12: "I think yeah because I had a bad liver I had a bad appetite and now I have a better liver I have a better appetite." (Participant 12, Lines 268-275)</i></p>
	<p><u>Getting my head around my own story</u></p>	<p>Learning about my own 'history'</p>	<p>Coming to know about transplant</p>	<p><i>"My mum said I could stay at my nan's, she never let me go anywhere in case they rang and the one night she let me go to my nan's they rung the next morning. My dad came to get me the next morning and I could see that he had been crying. I don't know why that stuck with me but it always has. He has never been one to show emotion."</i> <i>(Participant 3, Lines 368-371)</i></p> <p><i>"I think it had always been so present when I was younger I don't think I ever properly got told...It had always been part of my life. So I never essentially got told but when I started to understand, I went in to hospital and had my biopsy." (Participant 4, Lines 206-207 & 211-212)</i></p>
			<p>Understanding what has happened</p>	<p><i>"No. They still don't know, last time I spoke to the doctors they still don't know what caused it. My mum thought it was drinking, but I don't drink that much. Until now they don't know what caused it, whether it's hereditary."</i> <i>(Participant 9, Lines 40-42)</i></p> <p><i>"I had Wilson's disease. But that was only confirmed on</i></p>

				<p><i>the Explant so they didn't know going in whether it was Wilsons or not. But they confirmed it afterwards."</i> (Participant 11, Lines 64-65)</p> <p><i>"It's weird; it was like how can I have the same organ as you."</i> (Participant 12, Lines 230-236)</p>
			Gradually finding out	<p><i>"When I got chicken pox when I was little that sparked a lot of stuff off as well about like, because I didn't understand why that was such a big deal and why I needed up in hospital. Then they started to explain stuff to me a bit more."</i>(Participant 4, Lines 289-292)</p> <p><i>"I think being given more information I've definitely felt that in the last three years I have been given so much more information".</i> (Participant 4, 308-309)</p> <p><i>"So I started to know a lot more as I grew up. I was asking questions at a young age, like I said at about six or seven I think that is when my eyes started to open a bit more."</i> (Participant 8, Line 481-483)</p> <p><i>"Yeah, I'm sure I definitely heard because my mum and dad would not have kept the transplant from me, it was impossible because I had a massive scar. But I think that's when I started to realise the realness of it. I'm sure they told me at a very young age, maybe even before I could talk. Bu as I started to grow up I realised the importance of it."</i> (Participant 8, Lines 486-489)</p>
			Strong family narrative of transplant story	<p><i>"This is a photo album of all of the stuff in hospital and after I came out. My mum kept all of the pictures"</i> (Participant 2, Lines 123-124)</p> <p><i>"One thing I've really liked having is I have a picture album of photos of when I was actually in hospital and one photo which has always stayed with me and it's a bit weird but it's my dad holding my old liver after my transplant with me on his lap with my massive plaster and everything. Those sorts of photos because I was so young really matter to me, really matter to me, they especially mattered to me when I was younger because it</i></p>

				<p><i>helped me to understand that it was me and it started the emotional development. So I am really happy they did that. Although it must have felt a bit weird taking photos of your kid with a million tubes but actually when I am growing up I've really found that good to have."</i> (Participant 4, Lines 757-765)</p> <p><i>"She came up to my mum and said my son is dying I know your son needs a liver, you can have my son's liver, I think it was something along those lines. I know that there was a waiting list so I am grateful I got a liver when it was needed and before it was too late."</i> (Participant 8, Lines 441-443)</p>
		Becoming comfortable with my own transplant story	Remembering Transplants	<p><i>"I don't remember 17 or 18 months. So the third transplant for me was the first."</i> (Participant 2, Line 195)</p> <p><i>"I mean I never really like felt any of that when I was younger up until 13 it never really fazed me. But just recently I felt exceptionally down last year and a lot of it sprouted from this because I was just thinking about it more and realising more negative stuff about it rather than just being like I had a liver transplant" (Participant 4, Lines 108-101)</i></p> <p><i>"I think I have emotional memories which is weird."</i> (Participant 4, Line 196)</p> <p><i>Researcher: "So how many transplants have you had?"</i> <i>P6: "one. I think so it might be two, I am pretty sure it was two. Do you mean the operation or the in and out."</i> <i>Researcher: "The in and out of your liver."</i> <i>P6: "I think it might even be two because I think I had my first one when I was four and then something went wrong again I don't know two months after, maybe it just wasn't working or something. I don't know I was really young"</i> (Participant 6, Lines 51-57)</p> <p><i>"Yeah it's just little if you dig deep you just get little memories and stuff like that you know not flashbacks, just a feeling that's how you would describe it you don't really</i></p>

				<p><i>remember what people said it's just a feeling. It's the emotion you experienced at that present." (Participant 6, 327-330)</i></p>
			<p>Making sense of having a transplant</p>	<p><i>"I'm in transition clinic at the moment and my doctor was like do you know about your medications and stuff? To be honest no I don't know anything. So she had to explain that. It's like even at 16 I am still being told stuff to help me understand it, as in the technicalities. Because I don't know." (Participant 4, Lines 222-225)</i></p> <p><i>"But it's like I think it's about taking the stories and then I have to make the links to other things that I have heard and emotions that I get now and emotions that could link back to then. Sometimes it gets really messy because there are so many intertwined bits of information... sometimes, very rarely I get a ping moment of like I've got it makes sense now, this bit I understand." (Participant 4, Lines 254-257 & 259-260)</i></p> <p><i>"Then because there are photos I can ask my mum like why was I so yellow? Then that sort of starts off the questions." (Participant 4, Lines 771-772)</i></p> <p><i>"...when it came to feeding me through the tubes, my dad totally hated it and he felt like crying because I wouldn't sit still and he had to hold me down and force these tubes up my nose and I was trying to kick and punch and I was screaming. So putting it in and taking it out I was just screaming and fighting. I can imagine it's not nice to see. Things like that just make me think, even though things might have been a bit of a fight or a struggle for me at first because I live normal now when I hear about them stories I kind of laugh to myself. I think oh my days is that how I was?" (Participant 8, Lines 470-476)</i></p> <p><i>"I was laughing because I thought that would never happen because I played football and sports, and went to the gym, I didn't drink or smoke." (Participant 9, Lines 146-148)</i></p> <p><i>"I think what would have cleared my mind is if they could</i></p>

				<p><i>have found out what actually happened... I think because that would give me a bit of closure" (Participant 9, Lines 295-296&298)</i></p> <p><i>"Well that's the thing was I 17 or 18, it was on my birthday. We were trying to figure it out because what time the transplant was and when I was bon but we never got round it. I suppose 18." (Participant 11, Lines 53-54)</i></p>
			Is it mine?	<p><i>"No it's mine. It's definitely mine." (Participant 5, Line 509)</i></p> <p><i>"Recently I have been saying stuff like just subconsciously, my liver, wait not my liver. Little things like that which I have never done before and I don't know when that started." (Participant 4, Lines 572-574)</i></p> <p><i>"I find that really difficult to come to terms with whether it is mine because it's a part of me now or whether it's not because I wasn't born with it" (Participant 4, Lines 580-581)</i></p> <p><i>"It's obviously grown with me and I find that so cool, that's one thing where I'm like that is amazing every time...yeah that's the part that makes me feel it's more me." (Participant 4, Lines 595-596 & 598)</i></p> <p><i>"I just think that in the first place all of this liver isn't mine so I have to take care of it as much as possible, and because it isn't mine I just think that it could reject at any time." (Participant 8, Line 172-174)</i></p> <p><i>"it is weird to think oh my days this isn't totally mine, but it is nice to think that if I didn't have it I wouldn't be here so I am grateful for having it." (Participant 8, Lines 450-451)</i></p> <p><i>"Of course it's yours now for keeps so you have to look after it. " (Participant 9, Line 740)</i></p> <p><i>P10: "Once it is in your body and washed with your blood it is like anything really." Researcher: "It's yours then?"</i></p>

				<p><i>P10: "Yeah. It's like anything, you buy something from the charity shop once you put it in the washing machine and it smells of you, it's yours." (Participant 10, Lines 676-680)</i></p> <p><i>"It's weird that it's not mine, but it's in me and I don't feel any different. So it's not really affecting anything." (Participant 11, Lines 677-678)</i></p>
			Happy to tell story	<p><i>"I have nothing to hide anyway" (Participant 7, Lines 143)</i></p> <p><i>"Because it is part of me and I like people to know it. If people don't understand it, it frustrates me. " (Participant 10, Lines 487-488)</i></p> <p><i>"So I have no problem with people knowing I have had a transplant but it's when people don't know and they judge that it bothers me more." (Participant 11, Line 344-345)</i></p>
			You have to be worthy to hear my story	<p><i>"That's because, I only tell people who are worthy of knowing as well." (Participant 3, Line 666)</i></p> <p><i>"So I have a group of ten or so people who just know so I don't have to explain it anymore." (Participant 4, Line 167)</i></p> <p><i>"It isn't something that I would share with everyone you have got to earn their trust, why fuck knows but you do...Just if you are close enough with me. Just if you are connected on that level. Some people the connection isn't there." (Participant 6, Lines 585-586 & 588-589)</i></p> <p><i>"Some of them I haven't even told...I don't know it's just on a need to know basis. If you ask I might feel inclined to tell you if I don't then I won't I have told people I am on a project? The rest of them I don't know." (Participant 9, Lines 843 & 845-847)</i></p> <p><i>"If for me you have to be really close for me to tell you that...Because I feel like I'm letting you in to something pretty personal." (Participant 12, Lines 558 & 560)</i></p>
			No pressure to drink	<p><i>"All of my close mates know that I can only have a certain</i></p>

			alcohol/go clubbing	<p><i>amount and that I can't have anymore. So they know that if I did get to a time where I had had some already they would tell me. Even the barman at the local pub would say are you sure you want more."</i>(Participant 2, Lines 440-443)</p> <p><i>"alcohol is definitely something that I am not interested in." (Participant 8, Lines 597-598)</i></p> <p><i>"The doctor says to me don't get wasted and I am like good I don't want to get wasted anyway. Bad decisions happen when that happens. Now it is like I can't I'm not doing because I am being boring, I've got an excuse."</i> (Participant 11, Lines 722-724)</p>
	<u>I just want to feel, and be, a 'normal' young person</u>	Feeling very different	Feeling different to peers	<p><i>"When you are sick and you become sick on top of being sick, that always feels different"</i> (Participant 5, Lines 523-524)</p> <p><i>"Most 22-year-olds are out partying or drinking."</i> (Participant 7, Line 112)</p> <p><i>"...even though it is somebody else's organ make it feel like yours because you shouldn't have to feel like you have taken a step back from life because you have had an operation. You shouldn't feel any different to anybody else, and don't let anybody tell you can't do something."</i> (Participant 8, Lines 802-805)</p> <p><i>"It is annoying and because the rest of my mates are at uni doing working playing football doing the stuff I usually do"</i> (Participant 9, Lines 354-355)</p> <p><i>"I was getting bullied at school people didn't understand me,"</i> (Participant 10, Lines 155-156)</p> <p><i>"I can't deal with going to the shops and doing normal things like everyone else does. "</i>(Participant 10, Line 246)</p>
			Adolescence is hard enough, without all this -	<i>"Like I say I think I have always thought it's a really awkward age because you are just starting to be a young</i>

			<p>Dealing with transplant in adolescence is hard</p>	<p><i>adult, you are just starting to get your own ideas about things" (Participant 1, Line 409-410)</i></p> <p><i>"Sometimes when young adults have transplants you go through all of the stages of puberty, they have hormones raging and they are in hospital having a transplant" (Participant 2, Lines 47-49)</i></p> <p><i>"I remember being told that and never really processing it. But I think this year I have sort of been processing stuff and actually thinking about it and then asking more questions about also the emotional side of stuff. " (Participant 4, Line 230-233)</i></p> <p><i>" I mean like obviously just being a teenager is difficult and then with the added stress of thinking about my liver on top of that, I think that's why I just sort of exploded. I was like nope not anymore, I can't deal with all of this at once." (Participant 4, Lines 237-239)</i></p> <p><i>"I had a lot of problems caused by my liver. One of them was hormones." (Participant 5, Lines 580-581)</i></p> <p><i>"As a kid I don't think you should be conscious of that many things you shouldn't have that perspective yet, you should be living in the moment." (Participant 6, Lines 110-111)</i></p> <p><i>"For someone who is going in to their teenage years to have all of that put on top of you as well sometimes you feel like giving up." (Participant 10, Lines 153-154)</i></p> <p><i>P10: "Sometimes I wish I had the transplant when I was younger."</i> <i>Researcher: "How do you think you would be now if you had have done?"</i> <i>P10: "Normal." (Participant 10, Lines 329-331)</i></p> <p><i>"..yeah. No one tells you. That's another thing they should talk to you about. I didn't know anything about periods, or sex education because I missed out on it all, so they</i></p>
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				<p>should talk to teenagers about that." (Participant 10, Lines 709-711)</p>
			<p>Wanting to feel 'normal'</p>	<p>"I went to Malaga and I drank for a week day in day out and I regret that now because it was such a stupid thing to do. But at the time it was the first time I had ever felt normal, I actually felt that I could fit in with everybody and it was great. That still is the best week of my life by far because of what it actually meant." (Participant 3, Lines 248-251)</p> <p>P3: "I cancelled it again because I was well and I had arranged to go and see Robbie Williams with my sister, obviously I like his music." Interviewer: "sure that's important." P3: "And to actually start taking control of things and actually not letting the hospital control your life for a change was kind of nice and it didn't have a bad effect like before when I didn't take my tablets." (Participant 3, Lines 442-447)</p> <p>"Also me not wanting to stand out as much like I don't want to, like in primary school I got in the newspaper about it and everybody, I was a bit of a drama queen about it all. Now I'm like I just wish I was normal." (Participant 4, Lines 127-129)</p> <p>"if I go and meet lots of people and I find out that I'm just being really emotional about it or really different I would take that really personally and it would really affect me. But if I found I was just normal and everybody else kind of felt along that line as well I would be like oh OK phew. But I'd be too worried of the first one happening." (Participant 4, Lines 460-463)</p> <p>"So yeah everything that I get to do especially things that are quite dangerous it makes me feel like a normal person" (Participant 8, Lines 112-113)</p> <p>"Here it says after the transplant everyone says bye you are well now you are normal and there is me saying what is normal? I had no idea what was normal." (Participant</p>

				<p>10, Lines 96-97)</p> <p><i>"I wish I could be someone who had not had a transplant and hadn't been through the things that I have been through." (Participant 10, Lines 134-135)</i></p> <p><i>"I wish I was normal." (Participant 10, Line 139)</i></p> <p><i>"Probably feel like you are missing out on something that you could have had as well, like a normal life." (Participant 12, Lines 380-381)</i></p>
			Troubled by scars - I don't want to stand out	<p><i>"I had a very ugly scar because of the transplant and it does affect your life. Sometimes you don't want to take your clothes off even. I'm not sure if that is part of the reason why I am not keen to go to swimming. People look at you as an alien and it's annoying. You get all of these eyes on you they look at you and it doesn't feel good." (Participant 5, Lines 379-383)</i></p> <p><i>"I was thinking about it the other day and it's like if I want to do it professionally they might not cast me because of the scar" (Participant 4, Lines 86-87)</i></p> <p><i>"Obviously my scar I don't like it as much so actually I am thinking about having well possibly having an operation which can sort the scar out." (Participant 5, Lines 119-121)</i></p>
			Will anyone ever love me for who I am?	<p><i>"But it is difficult because you wonder, it kind of makes you doubt whether you have ever going to get anything right. I've had since I was sixteen I've had three girlfriends long term. None of them have worked and the talking point when we have broken up has been hospital and has been me being ill" (Participant 3, Line 676-679)</i></p> <p><i>"...Yeah because everyone just wants to be accepted and loved and shit." (Participant 6, Line 461)</i></p>
			Under pressure to drink alcohol/go clubbing	<p><i>"I have got a few friends and most of them are really understanding but I have got a couple who will be really, really annoyed like when I say I can't go out on Friday night because of how I'm feeling. That's difficult because I</i></p>

				<p>would love to go out and enjoy myself but I really can't so why are you getting annoyed with me?" (Participant 3, Lines 224-227)</p> <p>"It is difficult because I go out and have a coke and people are like oh you're boring". (Participant 3, Line 242)</p> <p>"Some of the friend stuff is really bad. Especially with parties and alcohol and not me and stuff, that's really difficult" (Participant 4, Lines 94-95)</p>
		Doing everyday , 'normal' things that young people do, is really difficult	I want to work/go to school	<p>"When I am not doing anything when I'm out of a job and I am doing physical stuff its OK and I think I am all right so I go and get a job then I get ill again. It's a catch 22. It's annoying. But I get so bored now as well" (Participant 3, Lines 44-46)</p> <p>"There are things that I couldn't do; I was not able to do even if I wanted to, no matter how hard I tried. For instance education." (Participant 5, Lines 261-263)</p> <p>"To be honest if I have work that day then I am not going to cancel because of a doctor's appointment I will always take work over it." (Participant 6, Lines 259-270)</p> <p>"Funnily enough I do miss uni I even miss the workload and the pressure from the workload I miss, which is weird. It's just one of those things, it was part of my life and now your life is changing but there are just some things that you want back." (Participant 9, Lines 356-359)</p> <p>"It was hard. Because I missed out on a lot of school so I found it hard in class. Especially with things like maths and science because that requires a lot of work. So I missed out on a lot of that so I found it hard. But I managed to pull my way through." (Participant 12, Lines 78-80)</p>
			Can't pursue Interests	<p>"I can't play football anymore or anything like that." (Participant 3, Line 33)</p> <p>"...playing rugby at school I'm not allowed to do that, my</p>

				<p><i>friend invited me to go to karate I was like yes, wait no I'm not allowed because of my scar because of my transplant." (Participant 4, Lines 558-560)</i></p> <p><i>"I could never go to sleep overs and stuff like that because if I didn't have my medicines on me, I couldn't just go from school to somewhere else" (Participant 6, Lines 107-109)</i></p> <p><i>"I like riding motocross bikes as well so that's quite dangerous. I'm not necessarily meant to do full on contact sports but that type of riding isn't classed as a full on contact sport so I am OK" (Participant 8, 110-112)</i></p> <p><i>"I told my teacher about my condition and he said well we are only working on the rugby pads, so in those training sessions I took part when it came to games I wasn't allowed to play. I didn't necessarily see that as a bad thing because I knew that rugby was quite a full on contact sport. So I didn't feel bad but at least I got to take part in the pads and actually feeling some of what rugby is about, so it shouldn't hold you back from everything." (Participant 8, Lines 233-237)</i></p> <p><i>"The first one is football pretty much. That is one of the things that I actually do miss the most about everything. Before this I was playing football for my Uni and I pretty much played sports all of the time." (Participant 9, Lines 84-86)</i></p> <p><i>"...Travelling was one of them until I learnt you can't travel." (Participant 9, Line 377)</i></p> <p><i>"...I might get hurt. So before you could get physical if I go back to football I will probably have to be a ref now I guess, just be on the side-lines." (Participant 9, Lines 469-471)</i></p> <p><i>"...I tried playing for a local team but the doctor said I could not play in competitive sport so my dreams were crushed. That's it." (Participant 12, Lines 62-63)</i></p>
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			<p>Pressure to not drink</p>	<p><i>"...not that I feel my family exert pressure on me, but I think if they knew all the times I'd gone out and got so drunk and smoked 20 cigarettes in a night they would be absolutely devastated. That is a pressure to me." (Participant 1, Lines 529-531)</i></p> <p><i>"... I really want to be able to have a drink, have a good time. But I know I can't do that because I'm not just letting myself down I'm letting this whole hospital down and my parents down and my sister down, but most of all I am letting [the surgeon] down because through [the surgeon's] trust he has given me the chance of life." (Participant 2, Lines 467-471)</i></p> <p><i>"yeah because everyone is expecting you to do the right thing all the time." (Participant 3, Line 284)</i></p> <p><i>"It actually makes me think that now that I know that I'm not allowed to do it [drink alcohol] if I didn't have a transplant would I push myself to do it, because it's not like I am missing out. It's never like I am missing out. So I think especially because I have grown up like this all my life I don't feel like I need to push myself to do other things that other people are doing." (Participant 8, 130-133)</i></p>
			<p>Feeling like there are big consequences to drinking</p>	<p><i>"That might lead to something going wrong and it would be my fault" (Participant 1, Lines 502-503)</i></p> <p><i>"So I drank and felt really bad like why did I do that?" (Participant 5, Lines 88-89)</i></p> <p><i>"To be perfectly honest with you the reason is I don't like the taste of alcohol and I don't like being drunk. If I liked the taste of alcohol and I liked being drunk I wouldn't give a fuck about the liver I would still drink. Obviously it's the main thing you should stay away from so subconsciously that is going to have some sort of effect. You know maybe that is why I don't like the taste." (Participant 6, Lines 285-289)</i></p>

				<p><i>"For instance the doctor said to me yesterday it's not that we can tell you there is a certain amount you can drink before your liver starts to not accept it, but I don't think to drink any of it so it is totally out of the equation."</i> (Participant 8, Lines 153-155)</p> <p><i>"I've never had a drink. I've never been drunk. I have probably had a sip of WKD. I have about a centimeter of Baileys at Christmas if I want to, but sometimes I get to panicky now to even have that."</i> (Participant 10, Lines 288-290)</p> <p><i>"It was funny because it was a week before my 18th when they said so you are going to have to have a transplant and that means you won't be able to drink anymore. I was like oh god the irony. I can't drink anymore and I have never even been technically legal. I was like oh my god. I did get really upset about that which seems so petty, because I suppose you can't help it it's such a big part of our culture. It seemed like a huge thing to me but such a weird thing to think about, like oh no I can't get drunk anymore."</i> (Participant 11, Lines 736-741)</p>
			<p>Feeling torn regarding drinking, wishing I could/should be able to drink. Feeling curious.</p>	<p><i>"That's what I struggle with when I do things like have a drink or put a cigarette in my mouth I don't feel like it's happening to me, I don't feel like that same person anymore I guess because I have not been ill for so long. I struggle with that."</i> (Participant 1, Lines 630-632)</p> <p><i>"That was brilliant and I drank far too much and I do regret that now because I shouldn't have but like I said that was still the best week of my life. So I don't regret it but I do regret it at the same time."</i> (Participant 3, Lines 256-258)</p> <p><i>"It hasn't ever got to the point where I've felt awkward about not drinking but it's got to the point where I wish I could if that makes sense"</i> (Participant 4, Lines 138-139)</p> <p><i>"When I am out with my friends and they are having a drink or whatever I don't regret it because I am blessed to be here in the first place but at the same time I think what</i></p>

				<p>would it be like for me to have a drink when I am out with my friends?" (Participant 8, Lines 112 -113)</p>
	<p><u>I still get to be me (a strong person)</u></p>	<p>Living for self</p>	<p>Still parties!</p>	<p>"Drugs wise every now and then, I never overdo it; I'll have an E or something like that. It probably does have some sort of effect." (Participant 6, Lines 291-293)</p> <p>"Oh, I still party" (Participant 7, Line 113)</p> <p>"Personally I think when a lot of people have a certain vibe around them let's just say that none of my friends, they don't really get drunk but if they have a little drink and a little party that bounces off on to me so a lot of people think that I am tipsy. So yeah I don't mind." (Participant 8, Lines 141-144)</p> <p>"When I go out to party's at houses I party like any other person. I don't take drugs. I just try to have fun like everybody else I don't think anything holds me back." (Participant 8, Lines 594-595)</p> <p>"Also the fact that I can still drink is like a big thing I suppose. At first they were like you can never drink and now they are like don't go crazy drinking. So I am like OK I can deal with that. I have done that already so I haven't lost out. But I can still go to a festival and have a few ciders with my friends." (Participant 11, Lines 627-630)</p>
			<p>The other me – I'm more than just a transplant recipient</p>	<p>"I am doing my nurse training, at the end of my second year with one year to go." (Participant 1, Line 16-17)</p> <p>"I mean I'm an actress, I want to act for a living" (Participant 4, Lines 535-536)</p> <p>"Well it would be any situation I think. But that is like any girl my age; you don't go outside of the house without makeup on. You always try and look your best as a teenager don't you. No reason that has to change just because you are in hospital." (Participant 11, Lines 268-270)</p> <p>"I enjoy playing football and I have always dreamt of</p>

				<p><i>playing football for Arsenal.” (Participant 12, Lines 61-62)</i></p>
			<p>Maturing/taking charge/asserting own needs</p>	<p><i>“But over the last four or five years I’ve actually put a stop to that and I have actually taken charge of what is going on. Because I started to realise that it is actually about you and not other people sometimes and how you feel and what you want to happen. I always used to sit and think about what my family want and making them happy but that kind of didn’t help me. So I had to stop and realise you have to make the decisions because you are the one it is happening to. That’s helped me a lot over the last few years.” (Participant 3, Lines 432-437)</i></p> <p><i>“I think it’s just because I’m obviously mature now I can obviously think about this stuff more.” (Participant 4, Line 252-253)</i></p> <p><i>“I’m quite proud of the way I have dealt with it because the doctors and nurses did say to me we’ve never had someone like you before you haven’t cried before” (Participant 11, Lines 428-429)</i></p>
			<p>Finding Balance (you only live once?!)</p>	<p><i>“It’s taken me 15 years nearly to get that balance. Like you said one way you have no life because you are doing everything everyone else tells you to do all the time and the other way you can have your life but you are not going to have your health. So it’s not something that comes quickly that’s something that a lot of people don’t understand in a way” (Participant 3, Lines 462-465)</i></p> <p><i>“...It probably does have some [negative] effect, but you know I could get hit by a bus tomorrow so I’m not going to not do it just because of that...That’s one thing I have never done I have never ...I have never gone oh just because, not necessarily bad, but like this could be detrimental blab la, and just fully stayed away completely from that, like stop eating salt or not put oil on that, so I have never gone like that. I try and balance it with what I want to do” (Participant 6, Line 296-297 & 299 & 303-305)</i></p> <p><i>“So things that are pushing the boundaries I don’t feel like if I push them there’s going to be consequences. So I just take my time and let time take its place.” (Participant 8,</i></p>

				<p><i>Lines 370-371)</i></p> <p>Living for self/nothing holding me back</p> <p><i>"As much as it has been donated the person didn't live, and I have never really felt that I had to live my life because of that. I have always put a huge amount of pressure on myself to achieve and live the way I want to live because for me because I'd say for a certain proportion of my childhood I was too ill to do much" (Participant 1, Lines 588-591)</i></p> <p><i>"I think overall nothing has stopped me from doing anything that I want to do. Out of all the things I think that is the main thing. Because after the liver transplant as you get older you want to live life, you want to explore, you want to be independent and so far there are no hurdles especially to do with my liver transplant, so I feel normal." (Participant 8, Lines 621-624)</i></p> <p><i>Researcher: "Do you think it has given you a different appreciation for things?"</i> <i>Participant 9:" Most definitely. I am trying to learn a new language now." (Participant 9, Lines 365-366)</i></p>
		Coping with the extraordinary	Detaching Self	<p><i>"I just detached myself from everything the same as I do now, it was like this isn't happening to me" (Participant 1, Lines 750-751)</i></p> <p><i>"I think I probably changed. I've always found it very difficult to talk about until I started having regular sessions for my PTSD and anxiety. That helped me to cope with things" (Participant 1, Lines 780-781)</i></p> <p><i>"Sometimes you do feel like you just want to sit on the sofa and watch TV for the day, curl up in a ball and feel sorry for yourself." (Participant 10, Line 657-658)</i></p> <p><i>"I think I used to. I think I have forgotten about that." (Participant 12, Line 248)</i></p>
			Support of Family	<p><i>"The most important thing for me is my family because they have always been here and I know that is what families are for but I've been here sometimes when there have been people who don't have anyone come in, but</i></p>

				<p><i>my family were there every day no matter what"</i> (Participapnt 3, Lines 92-94)</p> <p><i>"My mother and my dad they helped me a lot through this"</i> (Participant 5, Line 220)</p> <p><i>"My grandma was always there to overlook the scene as it was going on. When I was becoming ill, at the time when I was in the hospital getting my operation and the months that I spent in the hospital. I did spend a long, long time in there. I guess it was her words that actually made the whole family have so much strength to believe in me."</i> (Participant 8, Lines 90-93)</p> <p><i>"I remember my mum telling me that a lot of my family were there at the time, for instance my aunty and my grandma, my dad and some cousins as well. They were there at the time of the operation so there was a lot of backup behind me and a lot of strength."</i> (Participant 8, Lines 464-466)</p> <p><i>"...so lots fussing over me. I had two aunties ringing every single day. They knew what I ate, what time I went to bed and this was my mum telling them. Then there was my dad's side as well. I was like if this is what they have to do to reassure themselves that I am fine and I am going to get better let them do it."</i> (Participant 9, Lines 518-522)</p> <p><i>"He would come back from college and sleep on the floor in the hospital and then go back to college. He would help my mum out because my dad really wasn't there. My mum would look after me during the day while he was at college and then he would be there at night."</i> (Participant 10, Lines 386-387 & 388-389)</p> <p><i>"My mum's side of the family are very emotional and I had so many calls in tears from them."</i> (Participant 11, Line 386)</p>
			Staying positive	<i>"If you literally just put this to the test just think for a week that you are happy and making that effort of being</i>

				<p><i>grateful, just writing the things that you are grateful about. It puts you in that deserving perspective, you are more likely to have a good day than when you wake up and are like fuck I hate life." (Participant 6, Lines 366-369)</i></p> <p><i>"I don't know my mind revolves around positivity." (Participant 8, Line 199)</i></p> <p><i>"And I think I have had my own way of dealing with my liver transplant which is just thinking positive and feeling like I am no different from anyone else." (Participant 8, Lines 669-670)</i></p> <p><i>"So I think if you mix the science and the spiritual there are good books that explain that we are just vibrations and that human beings are antennas of information and we project and give information. So it is just about your thoughts and stuff you project your thoughts and create your own reality and stuff like that." (Participant 6, Lines 361-364)</i></p> <p><i>"Yeah as you know my dad is a Rasta and positivity revolves around that religion a lot. I was reading up on it the other day the guy said something about don't worry about man who is out there with a load of riches because the earth is your bed and that is your riches or something like that. So that is how I feel you shouldn't worry about what other people have." (Participant 8, Lines 398-401)</i></p> <p><i>"Of course I have days when I am not in the best of moods but the mood is never to do with my liver transplant. I think sometimes what makes me get over it is just thinking about how lucky I am. So I am never really, oh man my life is a bit different because I had a liver transplant and I can't do this and I can't do that, because I don't feel like I can't do nothing." (Transplant 8, Lines 364-367)</i></p> <p><i>"It doesn't affect me that much. I still prefer to smile so it's all good... I think be happy I guess I prefer being happy." (Participant 9, Lines 655-656 & 666)</i></p>
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				<p><i>"Think yourself in to repairing yourself mentally and physical, and that's what I did. It did help a bit, I can't complain." (Participant 9, Lines 675-677)</i></p>
			<p>Importance of friends who understand</p>	<p><i>"He understands exactly how I feel; he'll sit there and listen to me for hours talking about anything. He won't say a word, he'll just listen and that's what you need sometimes." (Participant 3, 630-632)</i></p> <p><i>"The friends that I have especially one's that know about the whole liver transplant procedure they treat me totally normal, yeah they do treat me totally normal. For instance some of them offered me drink and forgot that I even have a liver transplant. So yeah I do feel normal. Normal enough to do what I think anybody else could do." (Participant 8, Lines 280-283)</i></p> <p><i>"Yeah it was good to vent to your close peers because at times they know what to say." (Participant 12, Line 618)</i></p>
		Resilience	<p>Acceptance of the unacceptable</p>	<p><i>"I'm used to having tubes out of me or having something inside of me. So I am not particularly bothered. Other people find it scary. They said when they did the third transplant you might find it scary in the ICU unit. I walked in and didn't feel scared at all. Here we go again" (Participant 2, Lines 190-193)</i></p> <p><i>"I was like wait if that had succeeded that specific operation I wouldn't have needed a transplant, but because it failed I had to have a transplant. It's getting my head around that which is really difficult and the sort of thing of like it could have been different but it wasn't." (Participant 4, Lines 237-240)</i></p> <p><i>"it doesn't make me feel grossed out or anything but it definitely makes me feel a bit odd." (Participant 4, Lines 571-572)</i></p> <p><i>"I wasn't scared to have the transplant because I was in pain and I had to get it done." (Participant 7, Line 100-101)</i></p>

				<p><i>"Now it's still sad I try not to cry but you get used to it." (Participant 7, Lines 110)</i></p> <p><i>"But before it was twice a day and I was just thinking what do I have to do this every day for the rest of my life? I know you asked me before do I feel totally normal? Before I didn't in some ways, I felt like I am going to have to be taking these tablets twice a day for the rest of my life and I don't really want to do that. Now I am used to it." (Participant 8, Lines 509-513)</i></p> <p><i>"When I came out I could barely walk so it was sort of like, I wouldn't say degrading but it was annoying. It was just weird but it was all right I guess" (Participant 9, Lines 287-289)</i></p> <p><i>"So it was the package that comes with being a uni student, just being independent I guess. Now I am back home. But it's all good." (Participant 9, Lines 363-364)</i></p> <p><i>"People think that must be terrible how do they get through it it's like well you just do." (Participant 11, Line 594)</i></p>
			Fighting to be well	<p><i>"I did have problems after the transplant. The thing that makes me proud is that I really fought it like I properly wanted to get on." (Participant 3, Lines 59-61)</i></p> <p><i>"But I am going to give myself a few months I can give myself a year. After a year then I think most of that will be sorted." (Participant 9, 345-347)</i></p>
			Coming to terms with it	<p><i>"I always remember them saying the first year is the year when things can go wrong. So for that year I lived in fear of it really because it had been drilled in to me and as the years went on I just feel slowly and slowly I have become less attached to that." (Participant 1, Lines 695-698)</i></p> <p><i>"I just have to wait for them to tell me something and I just carry on living my life. Since then I have been trying to put it to the back of my mind but it keeps coming up. Its just</i></p>

				<p>life I guess." (Participant 9, Lines 328-330)</p> <p>"Like I said I think it made me quite a strong person. So I got through it." (Participant 11, Lines 622-623)</p>
<p>Carrying Responsibility</p>	<p><u>I'm alive for a reason</u></p>	<p>Feeling like I was chosen for something special</p>	<p>Best gift ever/A big big gift</p>	<p>"For me it is one of the most beautiful gifts that any human being can give, and anyone who does get it should appreciate it from the bottom of their heart because it is another chance to live" (Participant 2, Lines 35-37)</p> <p>P2: "In some situations you get reminded of why you are here". Researcher: "So why are you here?" P2: "Through someone else's life. Through their gift. And it's a wonderful thing to give someone a chance, and they don't ask to." (Participant 2, Lines 437-440)</p> <p>P5: "So you have got to, sometimes you feel responsible and you take care of yourself. It's a big big gift." Researcher: "Does it feel like a gift?" P5: "It certainly does yeah." (Participant 5, Lines 89-92)</p> <p>Researcher: "Literally on your 18th birthday. That's incredible that's quite a unique story." P11: "It's quite a present." Researcher: "Absolutely yeah." P11: "I would have preferred a car but I think a liver was pretty good as well. I think I needed the liver a bit more. I'm not counting anything out." (Participant 11, Lines 56-60)</p> <p>P11: I think of it more as a present. Researcher: Particularly because it was on your 18th birthday. P11: Exactly. So whoever is up there thank you because it was a nice present. I think that is a good idea, you know if someone gives you a jumper it is yours because it is your possession but you didn't buy it. (Participant 11, Lines 683-689)</p>

			<p>I am so lucky</p>	<p><i>"So I got put on the list in December 2000 and had the transplant in January 2001, so it was around four weeks, I was really lucky...16 days the second time. So six weeks altogether for two transplants is really good I am very lucky".(Participant 3, Lines 5-7 & 13)</i></p> <p><i>"I am immensely lucky to be alive, immensely lucky and there is some reason that I survived this so I have to just go with it and be as positive as I can." (Participant 4, Lines 362-363)</i></p> <p><i>"I think I am quite lucky because I have had a lot of stuff happen that makes me strong and defines me as a person" (Participant 6, Lines 436-437)</i></p> <p><i>"You feel like I am lucky to be awake today." (Participant 10, Line 634-635)</i></p> <p><i>"I'm lucky that I am still alive I was unlucky because I had to go through certain things." (Participant 12, Line 436)</i></p>
			<p>God picked me</p>	<p><i>"she said that 15 year old has died and she's possibly a match. It is the only time we have all gone to church. We lit a candle and did all of that. By the time we walked in they were on the phone telling us to get back there the liver is a match.". (Participant 2, Line 146-149)</i></p> <p><i>"Why did I get picked? I mean like I'm quite spiritual and religious and stuff so it's like god why did you make me do this, why out of everybody you could have picked". (Participant 4, Lines 354-356)</i></p> <p><i>"The illness, the treatment, all of those problems that I went through to be here today it feels really special. That's why I say it comes from god. So it's a very big price." (Participant 5, Lines 308-310)</i></p> <p><i>"That's why god is here you know. That's why this whole god label exists so when you feel alone and you don't have anyone to talk to you have alone time and you say things to yourself but also to god. I denied it but then after</i></p>

				<p><i>all of this I have changed. There is definitely something because, it's not just the transplant you start realising how this world works. It's too systematic, too organised everything is there for a reason. So there must be something." (Participant 5, Lines 322-327)</i></p> <p><i>"My grandma being a Christian believer makes me think that god is the reason that I am here in the first place and he has given me a blessing to carry on especially as strong as I am today because I have no problems whatsoever especially how healthy I feel. My dad I think that's where the main positivity comes from like never thinking negative even when you are at your lowest of the lowest, so when you feel really poor wealth-wise or when you feel that your friends are not there for you, or whatever. You can't let that determine the way you are going to live." (Participant 8, Lines 411-416)</i></p> <p><i>"Well people were praying for me. So I have to like believe their prayers will work and will benefit me and I will stay healthy. Because of that I was in an out of hospital for my transplant within 10 days. So that was really great." (Participant 12, Lines 671-673)</i></p>
			I'm Special	<p><i>"I'm different from everybody, I can sort of brag about it. Which is what you kind of do when you are younger" (Participant 4, Lines 111-112)</i></p> <p><i>"I really liked knowing about it, I found it interesting and it made me feel special at that age, which I really, really, liked." (Participant 4, Lines 326-327)</i></p> <p><i>"I think sub-consciously it's affected me more in a way of making me feel abnormal but consciously I've kind of made it make me feel special if that makes sense. so it sort of sub-consciously divides me because I'm really self-conscious about it and I'm a bit like I'm a bit weird for these people so I can't really get too close. But on the surface I am like no it makes me really cool and really special and that's awesome." (Participant 4, Lines 523-527)</i></p>

				<p><i>"So I have all this, I have problems but then I always got more opportunities than everyone else. So I feel very special." (Participant 5, Lines 305-306)</i></p> <p><i>"I feel so special with myself. I'm not even sure if I am using the correct term but yeah I feel very expensive. So I live for the life of two people, myself and someone else. So that's not everyone else is it?" (Participant 5, 509-511)</i></p> <p><i>"Over the years the story about my liver transplant got explained to me a bit more and that's how I came to know that I was a special baby and lucky to be living today." (Participant 8, Lines 460-462)</i></p> <p><i>"So I got the dominant gene form both of them a 1 in 4 chance and 1 in 30 thousand people have Wilsons. So I am special." (Participant 11, Lines 157-158)</i></p> <p><i>"I am grateful for it, because you can get a quarter sometimes and they wait for it to grow back. You only need a quarter of a liver donated and I got a whole one. So it's like I'm special one. " (Participant 11, Lines 667-669).</i></p>
	<u>Having to grow up before my time</u>	Facing own mortality	Escaping death	<p><i>"When I was eleven I was told when I had my first transplant if I didn't have it I was going to die simple as that." (Participant 2, Lines 79-80)</i></p> <p><i>"They didn't think that I was going to make it at the time and my heart was quite weak at the time". (Participant 3, Line 22-23)</i></p> <p><i>"I'm really bad with death anyway it really gets to me, as it does most people but I really can't deal with that at all. Possibly because I have been so close to it, I don't know." (Participant 4, Lines 585-587)</i></p> <p><i>"They said that they lost me for a couple of seconds" (Participant 7, Line 89)</i></p>

				<p><i>"My mum said no that's not my son, and the doctor was like yeah that's your son and we nearly lost him a few times" (Participant 8, Lines 97-98)</i></p> <p><i>"But you have to think about it this way this is a chance at a second life." (Participant 9, Line 108-109)</i></p> <p><i>"Everything happens for a reason because when I was in ICU there was a woman opposite me she looked like she was on life support; I was like that could have been me, because I only had one machine. She had everything. It was hard to look at." (Participant 9, Lines 430-432)</i></p> <p><i>"there was in's and out's as to whether I was going to stay alive or not." (Participant 10, Lines 589-590)</i></p> <p><i>"I knew there was a chance that it would go wrong and I wouldn't make it. But she told me it was a 1 in 6 chance kind of thing. She said it could reject straight away which means we'll put you in to intensive care. I was all right with it, it was the 1 in 6 people, 1 in 6 die in the operation apparently, and I thought that's quite high." (Participant 11, Lines 511-515)</i></p> <p><i>"... my mum got to this point, she did it with my granddad when he was really ill, I just want to ask you, and just in case do you have any wishes for your funeral? Do you want to be buried or cremated? It makes people laugh because I got quite excited. She told me and I was shocked, I was like I don't know I suppose cremated. Then I was like it would be nice if you could scatter my ashes in the sea because then it would be like I was travelling all the time and I have always wanted to travel. Then she was like do you want anything at your funeral/ I was like yeah we should get this music and these flowers. I was like make sure the food is good afterward because there is nothing more depressing when there is only sandwiches afterwards, no one wants that. She was like OK stop." (Participant 11, Lines 963-971)</i></p>
			Aware of the fragility of	<i>"Am I going to get this? Am I going to get another shot? It</i>

			life	<p><i>does run through your mind." (Participant 2, Line 201-202)</i></p> <p><i>"I know you should not fear anyone really, you shouldn't fear anything. But I have slight fear, I don't know like I said I think anything can go wrong at any time that is the only fear that I have. I don't fear anything else." (Participant 8, Lines 578-580)</i></p> <p><i>"I think to have that feeling [fear that anything could go wrong] is good because you can't feel like you are indestructible." (Participant 8, Lines 585-586)</i></p> <p><i>"The future is unpredictable I guess. Things happen." (Participant 9, Line 618)</i></p> <p><i>"So I was walking in getting a life and they were walking out losing a life" (Participant 10, Line 167-168)</i></p> <p><i>"I sat in the bathroom and cried because I was like oh god I could die." (Participant 11, Line 547)</i></p>
			Fighting to live	<p><i>"It's like something in your head telling you to give up and go and don't bother anymore. It's only pure will that you are fighting it. Pure will just to say no I am going to stay alive. Just that little belief that you are going to get over this." (Participant 2, Lines 215-218)</i></p> <p><i>"Like, I went to the doctor didn't feel well and then they were like your dying. I was like OK, all right then; well I'll get on with that then." (Participant 11, Line 458-459)</i></p>
			Writing my 'bucket list'	<p><i>"so I was just thinking about things I needed to do, I had a list in my head of stuff to do." (Participant 9, Lines 373-374)</i></p> <p><i>"But it's just the list was quite long but I had to take stuff off because some of it was just stupid. Sky-diving was never going to happen because I am scared of heights. That was optimistic." (Participant 9, Lines 385-387)</i></p>
			Can't trust own body/I might die	<p><i>"Because I had felt the best that I had felt for a while, and to go from feeling that and that things were slowly getting better to them being the worst they had ever been in the</i></p>

				<p><i>space of 24 hours was a really scary feeling because you don't know what to trust now". (Participant 3, 140-143)</i></p> <p><i>Researcher: "It tells me a certain bit about where you were at in your head at that time, maybe you were thinking"</i></p> <p><i>Participant 9: "This is it." (Participant 9, Lines 396-398)</i></p> <p><i>"I wasn't really worried about dying." (Participant 9, Line 544)</i></p> <p><i>"...thinking I am going to bed and I am not going to wake up tomorrow morning" (Participant 10, Lines 325-326)</i></p>
			<p>Feeling more mature than peers (Maturity as a burden?-Inflicted maturity?)</p>	<p><i>"Yeah. I mean to a certain degree I had to grow up really quickly because from the age of 10 I was around adults all of the time. I didn't really spend a lot of time with kids because I was always ill" (Participant 3, Lines 419-420)</i></p> <p><i>"I think I went through a phase at about 13 of thinking, of finding it really difficult, the amount that I knew because I found it difficult thinking that I had to be that much more mature than everybody else because I had to know about a really, really in-depth medical side of things." (Participant 4, Lines 683-686)</i></p> <p><i>"I was a bit like actually I feel like I am to mature for my age because I have to know this other stuff, because I have to be aware that I am going to miss X Y and Z, stay off school because I'm away at hospital or whatever. That was hard." (Participant 4, Lines 691-693)</i></p> <p><i>"Yeah. That is probably why I am more mature than most 19 year olds; I have always had to be conscious of it because it is such an important thing." (Participant 6, Lines 113-114)</i></p> <p><i>"I feel like I think older than I am and I try to especially in school I try to help people especially young people with bad behaviour to stay on track. I think the reason why I may think a tiny bit older is actually to do with my liver transplant because it just makes me feel grateful to be</i></p>

				<p><i>here in the first place." (Participant 8, Lines 192-195)</i></p> <p><i>"No. Before this I was carefree, I was living off adrenalin. I was a young fit 20 year old doing the stuff everyone else does. Now you have to think twice about what you do because it doesn't just affect you anymore it affects everyone around you. But before then it was like I can do this and that and it doesn't matter. But now you have to be careful." (Participant 9, Lines 441-445)</i></p> <p><i>"[My friend] comes over and he is like if I don't get in [to univerisyt] I will die, it is the end of my life if I don't get in. I've tried to say to him it's not going to be a huge thing if you don't get in. But he is like no it will be the end of it; everything will be horrible if I don't get in to this one school. I'm like there are other options." (Participant 11, Lines 575-577)</i></p>
		Realising and living with the knowledge that someone had to die so that I could live	Someone died, so I could live	<p><i>"I found it really, really traumatic to think that somebody had to die to give me my liver. I couldn't think about that at all." (Participant 4, Lines 583-584)</i></p> <p><i>"So I feel very special. I'm still alive for the price of someone's life. What else can I say, I am very expensive. So someone has died so I can stay alive. So there is that as well" (Participant 5, Lines 306-308)</i></p> <p><i>"so you are thinking what is so special about me? Why? Someone has to die for me to stay alive, so why am I so important?" (Participant 5, Lines 331-332)</i></p> <p><i>"That makes me think wow I have taken someone's organ so even though he was dying anyway, he kind of died for me." (Participant 8, Lines 448-450)</i></p> <p><i>"I would go to bed and say thank you I'm sorry that you had to die for that. I think about the person's family and stuff like that." (Participant 11, Lines 695-696)</i></p>

<p><i>Unseen, Unspoken or misunderstood challenges</i></p>	<p><u>Services as something else we have to deal with</u></p>	<p>Struggling to deal with services – perhaps made more difficult because I'm a young person?</p>	<p>Transitioning to Adult services - Leaving 'home'</p>	<p><i>"I'm in transition clinic at the moment and my doctor was like do you know about your medications and stuff? To be honest no I don't know anything. So she had to explain that. It's like even at 16 I am still being told stuff to help me understand it, as in the technicalities. Because I don't know." (Participant 4, Lines 217-220)</i></p> <p><i>"Then just making the whole doctor patient experience a little bit better and that kind of lags off when you are an adult, for no reason that I don't get, it is an intimidating thing. Hospital is a shit place you don't want to be there." (Participant 6, Lines 155-158)</i></p> <p><i>"They get so stern all of a sudden. It is cool to tell someone their consequences but to a certain point I don't really think it's a child instinct we have it's just as human beings when someone gets told what to do or shouted at you instantly want to do the opposite. You think fuck you I'm not going to take my medicines instantly. Maybe it is just the rebel in me but I think that is just how most people think. I think it is just a bit unnecessary." (Participant 6, Lines 170-175)</i></p> <p><i>"So when a new person starts a bar job and six months later his progress will depend on the initial two week training he has had from that superior how well you train people affects development. It's the same thing when you set someone off for a big, you know when someone is hitting that age when they should be doing their medicines or picking up the prescriptions or going to the GP on their own, that sort of stuff on a regular basis. I would say there wasn't I'm not blaming anyone, but there wasn't enough training, that's how I would put it." (Participant 6, Lines 211-218)</i></p>
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			<p>Frustrations with medical staff</p>	<p><i>"I struggled at that point when I was unwell and rejecting because it was unexplainable having a few doctors who I'd known for a long time suggested that I wasn't taking my medication and I was quite upset about that, because in all of my eleven years since having the transplant I could never dream of not taking my medicine and actually if I don't I am quite mortified even still that I have forgotten" (Participant 1, Lines 605-609)</i></p> <p><i>"I'm still a human being I'm not a dummy on a table that they practice on, I am a human being, and should be given a little bit of respect" (Participant 2, Lines 64-66)</i></p> <p><i>"They said oh we won't put you on those again and they did six months later. That's when I got pneumonia. The doctor who put me on it, her boss said you are never allowed to put him on that again you shouldn't have the first time." (Participant 3, Lines 395-397)</i></p> <p><i>"I think one thing that annoys me about the comfort side of things is people saying I know, or I understand a lot of the time, and when I got to about twelve that really, really annoyed me because I was like you don't understand you don't know what its like, nobody does. It's like that thing of you can imagine but you don't know." (Participant 4, Lines 746-749)</i></p> <p><i>"I think it's just about thinking, I know it sounds so weird but sometimes it feels slightly rehearsed I felt that a lot and they don't think about what is going on." (Participant 4, Lines 790-792)</i></p> <p><i>P6: "Yeah, I just don't know, I think just when you are interacting with people on a human level, I always feel like I'm on trial in places like that."</i></p> <p><i>Researcher: "Being interrogated kind of thing?"</i></p> <p><i>P6: "Yeah it doesn't really make me want to open up; I just go yeah I'm fine do what you have got to do so I can get out of here". (Participant 6, Lines 190-194)</i></p>
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				<p>Researcher: "Who do you hear saying that it should hold you back?"</p> <p>P8: "Doctors for one".</p> <p>Researcher: "OK".</p> <p>P8: "Definitely doctors. It's not that I don't believe them or I don't listen to them it's just sometimes when you are out there and you feel that you are capable, you want to push yourself" (Participant 8, Lines 238-139 & 241-242)</p> <p>"I felt disappointed because I gained trust with someone and after transplant the trust wasn't there anymore, it was the same with all the hospitals, there was no trust." (Participant 10, Lines 542-543)</p> <p>"I had really nice doctors and was in a really lovely ward with all these nurses, and it put things in to perspective." (Participant 11, Lines 624-625)</p> <p>"All of them were really, really nice and I appreciated that they never tried to hide anything from me because I was 17, which is probably like a baby to them. They didn't patronise me and they told me how things were. They helped. They saved me so that's fine. You have got to be nice to them. And they were all really funny as well. So they were all of them really nice and they would talk about things that weren't hospital with me. I had an American surgeon who was doctor all righty. He would always come in and be like let's get those drains off, all righty then. I was watching Cool runnings on the TV and he was like my daughters love that film, we always have to sit and watch it. When you see them every day they kind of become like friends." (Participant 11, Lines 845-849 & 852)</p>
			Poor medical care	<p>"When you leave the hospital you sort of say you've had the transplant you'll be all right your free to go. You don't get any aftercare, its pretty rubbish. You don't even know about aftercare unless you are chasing it up all of the time. You have to chase it up time after time after time"</p>

				<p><i>(Participant 2, Lines 268-271)</i></p> <p><i>"Because when I was in [university], funnily enough I went to see a GP... and she gave me Gaviscon. So it was funny then that she didn't do anything, because before then I actually knew what was happening, but I didn't know what stage, because I think there are three stages before your liver actually fails. But I thought I was in the first stage, but I realised it was quite serious. I walked up to her and she gave me Gaviscon. I knew it was the wrong thing, but I thought she had the knowledge so I took it. After a day I stopped, the day afterwards it got worse so I went to another GP and that's when she sent me for a blood test." (Participant 9, Lines 109-107)</i></p> <p><i>After that nothing improved. Because they had told me to come back in six weeks I was like OK I will just sit it out for six weeks.. The next day my dad came and we went to the GP and the GP wrote an emergency letter to the A&E at [nearby hospital]. We got there and they kept me in from then till December. (Participant 9, Lines 117-119 & 201-203)</i></p> <p><i>Researcher: "there are two big times there where you've kind of put your trust in the medical system."</i> <i>Participant 9: "Yeah and they have completely done me over" (Participant 9, Lines 208-210)</i></p>
	<p><u>Collateral damage to many aspects of life</u></p>	<p>The transplant is the tip of the iceberg</p>	<p>Even more medical problems</p>	<p><i>"So they cleared all of that out, and then they found that the collateral stuff had affected the right kidney. So they had to make a decision keep hold of it and make it become more workable or take it out. They took it out." (Participant 2, Lines 160-163).</i></p> <p><i>"Until they do my heart then I won't be able to do it, because it's that that stops me now not my liver. Before it was my liver and that got better, now it's my heart." (Participant 3, Lines 48-49)</i></p> <p><i>"When I got pneumonia that was worse than my</i></p>

				<p><i>transplant because it was so unexpected and I didn't know what was going on. When it happens basically what happened was I got really bad pains in my side because the septic shock was in my lungs and stuff because of the pneumonia and a liver infection as well so I got bad pains in the side of my liver and stuff, to the point when the paramedics got there they gave me morphine because of how much pain I was in. That's the last thing I can remember and I was in a coma for a week." (Participant 3, Lines 147-153)</i></p> <p><i>"I have a stoma, so that is like a tank." (Participant 5, Line 415)</i></p> <p><i>"when I was in the hospital I lost my voice for three months" (Participant 5, Line 549)</i></p> <p><i>"So I was really in pain and I couldn't take it anymore" (Participant 7, Line 98)</i></p> <p><i>"But straight after the liver transplant I wouldn't eat...that's when I was getting fed through the tubes." (Participant 8, Lines 85& 87)</i></p> <p><i>"It's just not being able to do the easy stuff; even now my coordination isn't working at all." (Participant 9, Lines 344-345)</i></p> <p><i>"It's still there but I have the chemo to kill my cancer." (Participant 10, Line 257)</i></p>
			Toll of multiple transplants	<p><i>"I think particularly before the fourth transplant in hospital. I was in no mood for any sort of attitude" (Participant 2, Line 55-56)</i></p>
			Worried about things changing	<p><i>"Honestly I don't think it will be the same. People change I think what really worries me, is people's opinions and perceptions of you" (Participant 9, Lines 480-481).</i></p>

				<p><i>"But from what I am thinking it might change you never know. But yeah I am worried about it I can't change that"</i> (Participant 9, Lines 487-488)</p>
		Implicit and explicit familial pressures	Expectation from family to 'deal with it'	<p><i>"It does vary it depends what mood my family are in to be honest whether they are just like we'll come with you or we won't.... So yeah their expectation is in a way, sometimes I think they expect me to keep it simple for them, even if I want to it's not that simple not all of the time. They do find coming here difficult because of the things that I have had done here and even more so over the last two years since I was in with pneumonia they have found it really difficult to be here. It's annoying but I can understand why."</i> (Participant 3, Lines 318-319 & 322-326)</p> <p><i>"It's not like they were trying to start something new it was reassuring. Like OK we know what you are capable you are going to get better so this is your time to, yeah, just be you I guess."</i> (Participant 9, Lines 717-720)</p> <p><i>"She would come to the hospital after my transplant. But since I have been back she thinks everything is normal, and that everything should go back to normal."</i> (Participant 10, Lines 457-459)</p>
			Guilt about what family has been though	<p><i>"It wasn't good for them, they weren't good at all"</i> (Participant 7, Line)</p> <p><i>"I've got loads of uncles anyway and they are all kind of big hard people who don't show any emotion and a couple of years ago when I was here my uncles came to see me because they found out how ill I was and my dad said that they were crying. For me to see grown men this tough person who doesn't let anything get to them no matter what it is to then know that they have shown emotion to their own family as well as other people kind of really got me because it was a bit like well, I don't know it was a weird feeling I kind of felt guilty in a way."</i> (Participant 3, 126-132)</p> <p><i>"You can't feel guilty because it's not my fault but at the</i></p>

				<p><i>same time I do feel guilty because the way that she is and the way, she's had enough now, it's because of all of the things that have happened to me. So you can't not feel guilty but you do feel guilty at the same time." (Participant 3, Lines 351-354)</i></p> <p><i>"But also the way that it has affected her to the point of she is really, really scared about being ill she always thinks about am I going to be like [my sister]? Will I end up in hospital like [my sister]? So it's the subtleties of things that she says where I am like hold on that line to my liver that makes sense now. which is really weird and it makes me feel responsible for that like I've got to a point before where I felt really, really bad about the fact that she feels that specific way because of my transplant. I feel really guilty about that sort of thing and that sort of added to some of the pressures of it all. (Participant 4, Lines 830-837)</i></p> <p><i>"When I was at [the hospital] it was hard seeing my brother cry... I don't like seeing people cry." (Participant 9, Lines 500 & 502)</i></p> <p><i>"It was hard to see because the only time I have seen them fuss over me that much when me and my cousins were younger, the family was close and at Christmas everyone was fussing collectively. So I have never really seen any of them sad." (Participant 9, Lines 530-534)</i></p>
			Seen as sick	<p><i>"So they always have this image in their head of me as sick ill person." (Participant 5, Lines 178-179)</i></p> <p><i>"I don't like being centre of attention and I don't like being treated differently. For example when you are ill I don't like all of these people fussing about. So I am just like get me better and I will be on my way. But with this people will fuss because it is not just something that goes away after a month I have it for the rest of my life. I'm going to have to live with it and so do they." (Participant 9, Lines 490-494)</i></p>

				<p><i>"When they brought a wheelchair to take me to the ultrasound I was like I can walk even though I got tired really quickly. I only started sitting in the wheelchair when I really had to. I wanted to keep my dignity and not be pushed around in a wheelchair." (Participant 11, Lines 223-225)</i></p>
			Special Treatment	<p><i>"I think that sprouted from being put on the special needs register in school which my family found hilarious because obviously it's never really been classed as that. But obviously at school it has to be" (Participant 3, Lines 688-691)</i></p> <p><i>"You see I have always been treated differently and a lot of people feel jealous sometimes." (Participant 5, Lines 520-521)</i></p> <p><i>"...and the fact that it was I had a lot of extra attention from my family over that if you know what I mean, and I hated that as well. That was one thing I really didn't like... Yeah you know everyone is always checking if I am eating and if I am all right." (Participant 6, Lines 135-238 & 239)</i></p> <p><i>"The primary school molly coddled me I used to go in when I was ill because I just used to love the attention. I used to get a lot of help from primary school. Nurses used to come in and teachers used to take me to hospital if anything happened." (Participant 10, Lines 31-33)</i></p> <p><i>"I don't want to be pitied and stuff like that, if it makes you feel some type of way I understand but I don't need pity and I don't need, for example once I was doing my GCSE's and one of my teachers was like do you need extra time? I was like no I am all right. Those type of things I don't like it because it makes me feel a bit restricted to doing certain things and stuff like that." 9Participant 12, Lines 573-577)</i></p>

			<p>Penalised for being unwell</p>	<p><i>"If I was healthy enough I wouldn't have had to pay a penny...But because I am 19 even though I have had all of these problems they can't give an exception. Which I feel is stupid. I feel it is unfair to all the kids that are in that bracket of no fault of their own and it is like they are paying for their illness" (Participant 2, Lines 503-505)</i></p> <p><i>"I think a lot of people think because I talk about it a lot I use it as an excuse. I used to get that at school quite a lot, that I was using it as an excuse to get out of everything; I was like no it's just the truth." (Participant 3, Lines 210-212)</i></p> <p><i>"In secondary school people who had 100% attendance would go to a place at Thorpe Park but because of what I went through I couldn't go. I had to go to hospital appointments at kings." (Participant 12, Lines 460-461)</i></p>
			<p>People seem to think you use your illness as an excuse – you need to explain yourself</p>	<p><i>"But people's understanding how it affects you is, they don't have a clue. That's difficult. You do feel like you need to justify the reasons why you feel the way you feel when you really shouldn't. In one of my previous jobs my supervisor was the same as my dad really, kind of get on with it no matter what. When I used to phone in sick because I literally couldn't get out of bed, the next day I would go in and he would be really off with me. It's like I'm not, I want to be here." (Participant 3, 617-622)</i></p> <p><i>"yeah, you are not dumb you feel it that behaviour. You do sense it. They respond in a way that you are using your illness as an excuse." (Participant 5, Lines 282-283)</i></p> <p><i>"If I can give an excuse as such or a reason they are a bit more like OK cool whatever" (Participant 4, Lines 174-175)</i></p> <p><i>"his thing is you don't need to see all of these people you make out you are a sick child and you are not." Participant 10, Lines 573-574)</i></p>

	<p><u>Impact on mental health</u></p>	<p>The extra hidden scars</p>	<p>People don't understand there are some really hard days</p>	<p><i>"Also the effects of having what I've had done mentally as well, so that makes it difficult and then people don't understand that too. So yeah that's difficult." (Participant 3, Lines 80-82)</i></p> <p><i>"I think it comes and goes. I think like I can have really fine days about it all where it doesn't really phase me and I am like cool whatever but I can also have really, really bad days where I am like I don't understand anything, I don't know why it has to happen to me." (Participant 4, Lines 347-349)</i></p> <p><i>"I was an angry person because of my illness." (Participant 5, Line 222)</i></p> <p><i>"You have to have experience of a lot of shitty life" (Participant 5, Line 608)</i></p> <p><i>"The bad days is when I might feel tired, bitterness. The jaundice might come back. Just no energy really" (Participant 7, Lines 36-37)</i></p> <p><i>"I am vulnerable but that is more a mental vulnerability rather than physical. Physically I will be fine mentally I might not be but then again it will come in a sense that I have a second chance so it wouldn't play a fact." (Participant 9, Lines 768-770)</i></p> <p><i>"Yeah and it just completely ruined it. It's still like it to this day. I have days where I can't even get out of bed because I am just so confused about everything and wishing that I was someone else." (Participant 10, Lines 129-131)</i></p> <p><i>"...And now I am just mentally sick." (Participant 10, Line 433)</i></p>
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			<p>Traumatic memories</p>	<p><i>"It was more that they labeled it PTSD around the flashbacks I was having" (Participant 1, Line 472-473)</i></p> <p><i>"obviously I suffer with depression and anxiety as well quite a lot and that has all come from the way people see me and things that have been said to me before about my liver and stuff. It's difficult because it sticks with you" (Participant 3, Lines 205-207)</i></p> <p><i>"...I am more aware of the impact, also the way you die too I guess. It's not good to think about it. If it's not horrible then it's all good." (Participant 9, Lines 562-564)</i></p> <p><i>"When I was getting all the tubes taken out it left a whole but it has cleared up now. It was sort of like weird there was something sticking in the side of you; it's the sort of thing you see on 24 hours in A&E." (Participant 9, Lines 788-790)</i></p>
			<p>Secondary traumatisation</p>	<p><i>"The week I was going home this little boy had come in for a transplant and he was really ill. His parents were lovely. They came and spoke to me because I was the eldest in there, everyone else was babies. Basically they came and sat and spoke to me and said how do you feel because they couldn't grasp how he was feeling because he couldn't tell them. He had his transplant the day I went home. Then I got ill with septicaemia a couple of weeks later and came back to Kings and asked how he was, and he had died. That was really really hard at the time because I had got so close to his mum and dad and him as well". (Participant 3, Lines 546-552)</i></p> <p><i>"The stage where you don't know where you are and who you are, because I suppose it's a bit unusual when I was in the room it was the day they told me about it, so you will get to a stage where you might not recognise your parents and you won't know where you are. I was like OK, right, but that night I couldn't sleep but this man came screaming out of the high dependency unit running down the corridor with something in his hand, it turned out to be</i></p>

				<p><i>a bed pan, because he had gone in to the confused stage. He had just gone mental, security had to be called and he was attacking staff. I slid down under my bed in my room and hid because I was like what if he tries to kill me. Because he had just completely lost it.” (Participant 11, Lines 950-957)</i></p>
			<p>Impact of finding out about impending transplant</p>	<p><i>“I remember I was called at 4AM or something like that, I have still got that phone call on my call log, and I never delete it.” (Participant 4, Lines 27-28)</i></p> <p><i>“They just said look this is what needs to happen, you need to have a transplant, and this involves spending six weeks in hospital. At that time you think at the age of 10 six weeks you can’t grasp how long that is really. Then telling me about how it was done was, that was the bit that made me scared.” (Participant 3, Lines 509-512)</i></p> <p><i>“So she went and my parents were like are you OK? How do you feel? And I was like I am fine. I am just going to go and get some water. I left my room and had this panic attack kind of thing. I think one of my nurses Alex came along and was like just calm down. I went back in to see my parents and was like yeah I’m fine because I didn’t want them to see me freak out because if I freak out they are going to freak out.” (Participant 11, Lines 521-525)</i></p> <p><i>“This is the point where I don’t like admitting that it scared me. Because I was so stoic for the whole thing. I wanted to be like it didn’t scare me at all. But I have to admit that it did. “ (Participant 11, Lines 903-905)</i></p> <p><i>Researcher: “But were you always ready to if they called to say is there a liver here?”</i> <i>P12: “Was I ready?”</i> <i>Researcher: “Yeah.”</i> <i>P12: “I don’t think anybody is ready to be honest.”</i> <i>Researcher: “Say a bit more.”</i> <i>P12; “It is more like you are happy for yourself but at the same time it is scary because you don’t know if it will go well or go bad. You are more worried than happy.”</i></p>

				<p><i>(Participant 12, Lines 130-136)</i></p> <p><i>“Yeah. It was a Sunday night I was ironing my school clothes for the next day. My dad got the phone call to say the liver is ready, then you have to pack everything and then I started crying because I wasn’t ready...I was just scared so fear.” (Participant 12, Lines 138-140 &142)</i></p> <p><i>“It was just very shocking because I thought it wasn’t going to come any time soon but it came. Then that bombshell lead to me being scared. Then I was thinking about the whole process what’s going to happen after I have the new liver? Will I be fine? Or will I be worse?” (Participant 12, Lines 146-148)</i></p> <p><i>“The ambulance came as soon as they called. So when they called the ambulance was already on its way.” (Participant 12, Lines 168-169)</i></p>
			Post transplant recovery	<p><i>“Recovery is the hardest part; it’s not the operation itself. The operation you are fast asleep and don’t have to worry about it. When you wake up it’s the recovery that hits you more than most.” (Participant 2, Lines 384-386)</i></p> <p><i>“Physically I can go back to being 100percent but mentally I am not OK, mentally I know it is not all me.” (Participant 9, Lines 740-741)</i></p> <p><i>“P10: Before my transplant the only condition I had was the cancer but no I had nothing, I was a happy girl. Researcher: And after? P10: Panic attacks, depression anxiety, phobias and a little bit of an eating disorder.” (Participant 10, Lines 50-53)</i></p> <p><i>“I think the hardest thing is after, it is harder than before.” (Participant 10, Lines 637-638)</i></p>

			<p>Waiting for Transplant</p>	<p><i>P5: I was so stressed you know. I worked so hard during those two years, so it was like don't go crazy.</i> <i>Researcher:: You were waiting two years then for your liver?</i> <i>P5: yeah. That was OK, it was exactly what they told me, they said for your blood group this is the estimate.</i> <i>(Participant 5, Linse 50-54)</i></p> <p><i>. It was the process, I wasn't really put on the waiting list but they were talking about putting me on the waiting list. So when I got in to year 8 I was put on the waiting list, and when I was in year nine I got called up for it.</i> <i>A: So do you know how long you were waiting on the waiting list.</i> <i>P12: It must be about two years." (Participant 12, Lines 120-124)</i></p> <p><i>P12: "Yeah I was too scared.</i> <i>Researcher: "What were you scared about?"</i> <i>P12: "I was just scared that everything would be more worse than good." (Participant 12, Lines 201-203)</i></p>
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			Haven't I dealt with enough?	<p><i>"Then going back to my spirituality I was like why god? You've already made me have a liver transplant why couldn't secondary school be easy?" (Participant 4, Lines 376-378)</i></p> <p><i>"But the scar you can do something about that, you can get rid of it. But the stoma is a big big change in your body image. I still won't say that I don't like the way I look because I don't care basically but I would prefer to take the scar away it would make the problem a little bit lighter." (Participant 5, Lines 419-422)</i></p> <p><i>"Doubting panicky, depressed, and a bit in a bubble. It does feel like you are in a bubble and you can't get out of it. " (Participant 10, Lines 413-414)</i></p> <p><i>"So I know that the stretch marks won't fade entirely and it is embarrassing, and it is one of those things that is either associated with fat people or pregnancy." (Participant 11, Lines 313-315)</i></p>
	<u>Adherence to medication is complex</u>	The double-double bind of taking, or not taking, medication	Forgetting to take medication	<p><i>"Just me being stupid. I just fell off it for a little bit. Got in to one of those depressive states and stuff. I just forgot everything to take my medicines and stuff." (Participant 6, Lines 81-82)</i></p> <p><i>"...there would be times when I would get like just really depressed and not be yourself. I would have my meds in my hand and be like nah fuck that. Now the only time I miss it is if I forgot." (Participant 6, Lines 257-259)</i></p> <p><i>"Sometimes I might forget to take it" (Participant 7, Lines)</i></p>
			Choosing not to take medication has consequences	<p><i>"I've had rejection and stuff, that's been the main problem. I went through a stage of not taking my tablets so I was mostly to blame for that. But it has been a bit all over the place really since; I've spent most of my time here to be honest" (Participant 3, Lines 14-16)</i></p> <p><i>"Yeah I just mess up my medicines every now and then and then they have to do biopsies and stuff." (Participant</i></p>

				<p>6, Lines 181-182)</p> <p><i>"..without it my other organs will reject my liver. That seems deadly to me so I have to take it." (Participant 12, Lines 514-515)</i></p>
			<p>Struggling with having to take medication</p>	<p><i>P3: "They don't realise how they make you feel as well, like the side effects of them"..</i> <i>Researcher: "Do they make you feel rotten?"</i> <i>P3: "Yeah all the time. That was some of the reason why I stopped taking them because they did have side effects" (Participant 3, Lines 291-294)</i></p> <p><i>"Well yeah just remembering it having to do it. I really don't like being told what to do or having to do something. It is something I really struggle with." (Participant 6, Lines 103-104)</i></p> <p><i>"It's weird. I notice I don't like taking my medicines a lot more than I thought I didn't. The remembering it, do you know what I mean? I remember waking up feeling grumpy but I never remembered waking up feeling grumpy because I had to take my medicines." (Participant 6, Lines 318-321)</i></p> <p><i>For example my medication I'm going to have to use that for the rest of my life and that could limit what I could do. (Participant 9, Lines 482-483)</i></p>
			<p>Guilt about not fulfilling responsibility to follow medical regime</p>	<p><i>"So their expectations are not just of me doing the right things but to stop all of that from happening, and then when it does happen, I don't think they blame me but I do feel guilty for it and I do feel like I have let them down." (Participant 3, Line 312-314)</i></p> <p><i>"I had to because it was my responsibility, so it would be like shit I'm in trouble because I forgot it." (Participant 6, Lines 128-129)</i></p>

<p>Adjusting to life after transplant</p>	<p><u>Moving on with my life</u></p>	<p>Framing experiences in a positive way</p>	<p>Enjoying and appreciating life as still alive</p>	<p><i>"I'm still here so I might as well enjoy it" (Participant 7, Line 115-116)</i></p> <p><i>"As I said I booked a holiday before I was ill and I was out of hospital in nine days and I went and my family weren't happy with me for that because they were like you nearly died what are you doing? I was like well I'm not wasting £600, and I didn't it was great."(Participant 3, Lines 163-165)</i></p> <p><i>"because you realise, it makes you think differently. Having a transplant makes you think differently and realise what actually is important". (Participant 3, Lines 191-193)</i></p> <p><i>"I just have to live life to the full because I'm alive for a reason" (Participant 4, Lines 252-253)</i></p> <p><i>"Having that version of life and wanting to do so many things, like they say life is short. This just makes me think I know it's not, but I interpret it as my life is shorter so I want to do as much as possible and show people that especially operations if it allows you to do as much as you could without the operation it shouldn't stop you from doing anything. So it definitely doesn't put boundaries against me." (Participant 8, Lines 152-166)</i></p> <p><i>"I just think well I am blessed to be here in the first place and because it's such a vital organ as well, it makes me think that anything could go wrong at any time. So I just try to live life to the fullest." (Participant 8, Line 185-187)</i></p> <p><i>"..yeah definitely and show people that you don't have to, an operation, especially something that was quite deadly at the time it could have gone wrong, shouldn't hold you back from being a different person so a lot of people think that oh that person had this operation so they are not able to do this, it's not like that at all." (Participant 8, Lines 225-228)</i></p> <p><i>"So enjoy life and don't take it to seriously, I say don't</i></p>
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				<p>worry all the time because I did that before. Now you have been given a second chance and it is freeing." (Participant 11, Lines 707-709)</p>
			<p>Being Grateful –given an opportunity</p>	<p>"I think because I know that somebody has died, I have been given their organ and been given another opportunity really". (Participant 1, Lines 519-520)</p> <p>"But you know that it's someone else's that they have given to you and if you drink and stuff you have wasted it and you won't get another chance" (Participant 2, Lines 425-427)</p> <p>"there are points where I am like well I have been given this opportunity" (Participant 4, Lines 361-362)</p> <p>"It's probably older perspective I am experiencing and I am grateful for it, I wouldn't change who I am for anything" (Participant 6, Lines 568 -589)</p> <p>"So for me it's even a blessing to be here in the first place because I've got that I should spread positivity out there, so people can understand what a blessing it is, and that what you give is what will return back to you." (Participant 8, Lines 221-223)</p> <p>"So I am grateful to be here, very grateful." (Participant 8, Line 98)</p> <p>"It definitely makes me appreciate every step that I take. Especially, I don't regret, that's one thing I don't regret it...So it makes me feel that I am blessed to be here. It actually makes me feel like I am not meant to but because I am it is a blessing so I should take everything as an appreciation." (Participant 8, Line 100-101 & 102-104)</p> <p>"I don't know if it is a lesson or a gift I just think everything happens for a reason. If this thing happened now then, I don't know. The reason for this one even if I don't know it</p>

				<p><i>now but maybe in the future I might see why it happened but I still don't know. It's an unfinished story I guess.</i> (Participant 9, Lines 432-436)</p> <p><i>"It's a good opportunity and someone is willing to do this for someone they are never going to meet. It's good."</i> (Participant 9, Lines 748-750)</p> <p><i>"Be a bit more grateful you had a transplant that did save your life. Try and think about that."</i> (Participant 11, Line 371-372)</p> <p><i>"So it's like be grateful for your liver because it is a present. So I do think about the person. I think I said to myself say thank you every night when you go to bed and I know that's not necessary now. That got me through the times after transplant as well if I was feeling sorry for myself and fed up of the hospital I would be like think of that person and their family they are going through a worse thing than you at the moment. You have been given this gift, appreciate it and don't complain or screw up your life."</i> (Participant 11, Lines 687-702)</p> <p><i>P12: I was just thinking about saying thank you.</i> <i>Researcher: And why would you want to say thank you to them?</i> <i>P12: So I don't have to deal with what I have dealt with in the past.</i> (Participant 12, Lines 250-252)</p>
		Taking it all in my stride	It's not that big a deal!	<p><i>"Because I guess I treat it in a flippant way, like Oh yeah I had a liver transplant, that's cool and don't really, because I was so young, think about what it actually meant."</i> (Transplant 4, Lines 96-98)</p> <p><i>"Yeah it's just like I don't obsess about it. I don't think about it that much. I have had other things on my mind that depress me more than this. It's never been something as big to be on my top agenda sort of thing."</i> (Participant 6, Line 373-375)</p> <p><i>"Because I was so healthy everybody now just literally, no one treats me differently. So it's just like I am just another</i></p>

				<p><i>child in the family. Especially these days it never really gets mentioned, Oh be careful, because you had a liver transplant. It's like everybody expects me to know, and because I have grown up with it for so long I do know. I'm not really worried and I don't think they are worried either." (Participant 8, Line 540-544)</i></p> <p><i>"...but then I still don't see it as a big thing which sounds, I keep trying to explain to people that I know I have had a transplant, I know it is a huge thing and I know it is going to impact on me for the rest of my life but I don't I am quite casual about it." (Participant 11, Lines 376-378)</i></p> <p><i>"I have always wanted a tattoo but I am afraid of needles I thought it would really hurt but I know I can get through it now, I have been through worse. So I will book that as soon as I can much to my parent's disgust." (Participant 11, Lines 647-649)</i></p> <p><i>"I've learnt that if I can go through it I can go through anything." (Participant 12, Line 642)</i></p>
	<p><u>Feeling like I'm on my own now</u></p>	<p>Dealing with the reduction in support post transplant</p>	<p>I'm on my own now</p>	<p><i>"When you leave the hospital you sort of say you've had the transplant you'll be all right your free to go. You don't get any aftercare, its pretty rubbish. You don't even know about aftercare unless you are chasing it up all of the time. You have to chase it up time after time after time" (Participant 2, Lines 268-271)</i></p> <p><i>"yeah I struggle with the fact I have to do it myself. I have always had doctors doing it for me." (Participant 10, Lines 446-447)</i></p>

**Appendix 23: Letter to National Research Ethics Service (NRES)
Committee North West- Lancaster**

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Appendix 24: Letter to Research and Development Department

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Appendix 25: Letter to Participants

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Appendix 26: Summary for Ethics Committee

1. Background:

Positive health-related behaviours are beneficial and important in transplant recovery. However, evidence indicates that adolescents in particular are less likely to engage in these behaviours, putting their post-transplant health at risk. Furthermore, evidence suggests that young adult transplant recipients that struggle to integrate their transplant experience into identity are poor adherers to medication and appointments, and engage in more high-risk behaviours. Overall, limited research has elucidated adolescents' experiences, particularly those of liver transplant recipients', where positive health-related behaviour is particularly important. It would be useful to develop understanding about such experiences and the process of adjustment post-transplant, to inform practice and increase adherence to beneficial behaviours.

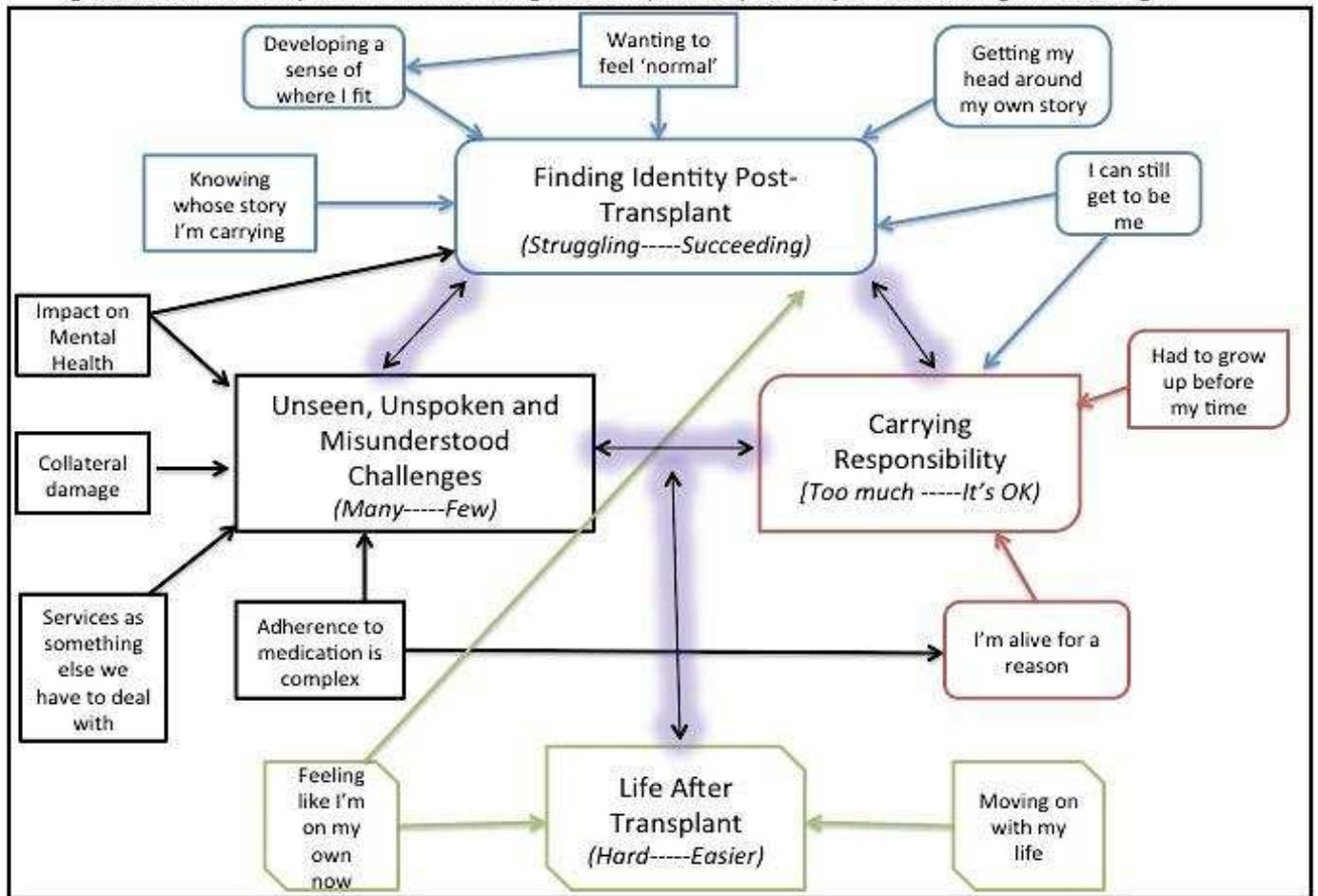
2. Methods:

A qualitative study was carried out to investigate adolescent liver transplant recipients' experiences and adjustment. Specifically, the study aimed to construct a grounded theory of young adults' experiences of having a liver transplant. Twelve liver transplant recipients, aged 16-24, were recruited through a hospital-based clinic and participated in semi-structured interviews. Five of the participants were female and seven were male. Interviewees had received transplants at various ages, with a range of 4 months old to 20 years old. Interviews were transcribed verbatim and the grounded theory method involved constant comparative analysis, as the researcher moved between data collection, analysis and theory development. This meant that emergent categories and concepts were compared both within and between interviews, to ensure that data fit with the developing theory. Also, themes were grounded in participant quotes to ensure validity.

3. Results:

The analysis resulted in four overall themes: *Finding identity post-transplant*, *Carrying responsibility*, *Unseen, unspoken and misunderstood challenges*, and *Life after transplant*. These themes were developed through codes and subcategories and a model of their interaction was proposed, to raise the analysis to a theoretical level. A 'bottom-up model' was devised to represent the dynamic relationships between these main constructs. Please see the grounded theory model below:

Figure 1: Grounded Theory Method Model of Young Liver Transplant Recipients' Adjustment to having a Donated Organ



The model can be understood as representing the processes young adults go through as they adapt to their lives post-transplant.

3.1 Finding identity post-transplant: Interviewees spoke about the various ways they experienced identity following their transplant. This included coming to terms with their experiences and accepting their donated organ as a new part of themselves. This included the following categories:

Knowing whose story I'm carrying – Involving concerns around knowing whose organ they had received and its history.

Developing a sense of where I fit – This related to positive experiences of integrating their transplant into identity, such as pride around operation scars and the sense of family in the liver transplant community. This indicates the importance of offering spaces and routes for connection amongst transplant recipients.

Getting my head around my own story – This related to a process of understanding and coming to terms with the events surrounding their own transplant. This seemed to be important in acceptance of the donated organ.

I just want to feel like, and be, a 'normal' young person – This captures the challenge to integrate the 'difference' of being a recipient into identity in a positive way. For example, interviewees spoke of internal struggles around drinking alcohol and how they experienced additional health responsibility compared with peers.

I still get to be me – a strong person – It seemed important for interviewees to hold onto aspects of identity that were separate to being a transplant recipient. Through developing other parts of their identity, such as studies or hobbies, interviewees seemed more accepting of their transplant.

3.2 Carrying responsibility: Having a donated organ appeared to shape how interviewees saw themselves. This involved a sense of responsibility and pressure as they lived not only for themselves, but for medical staff and their donor and donors' families. It encapsulated the following categories:

I'm alive for a reason – This related to a sense of participants feeling their lives had extra meaning and extra worth, due to a 'second chance' at life.

Having to grow up before my time – Once given this 'gift', many interviewees experienced a change in perspective and loss of the invincibility of youth.

3.3 Unseen, unspoken and misunderstood challenges: A variety of challenges were experienced over the course of transplantation. It appeared that those who experienced more complex difficulties had a greater struggle to adjust post-transplant.

Services as something else we have to deal with – This incorporated challenges related to accessing services, such as tensions between paediatric and adult services, and unhelpful ways they were spoken to by professionals.

Collateral damage to many aspects of life – There was a sense interviewees experienced additional physical and mental stresses, including the difficulties experienced by their families.

Adherence to medication is complex – This related to dilemmas between adhering to medication or not, including feelings of guilt if they did not follow medical advice.

3.4 Adapting to life after transplant: This theme was about looking to the future, which encompassed both positive and concerned perspectives:

Feeling like I'm on my own now - This related to post-transplant experiences and how no longer being in constant contact with medical professionals could leave interviewees feeling vulnerable.

Moving on with my life – This connected to a new found appreciation for life, which appeared to make them live their lives to the full.

Being grateful – given an opportunity - The process of moving on was assisted by an appreciation of their experiences and the inner strength they had developed.

Overall, the model focuses on *how* these young adults have experienced life, *why* they have experienced it in that way and the *how* and *why* of the impact on them. Respondent validation was obtained by contacting two participants who feedback that the results seemed to fit with their experiences

5. 1 Research limitations: Limitations include the small sample size and self-selection bias. Also, most participants had previous contact with a clinical psychologist, meaning that the sample may not be representative of the general liver transplant population. Future research with more diverse populations appears to be warranted, including with those who received a liver from a living-related donor and studies adopting longitudinal designs.

5.2 Clinical implications: Regular support groups would appear to be helpful with this population, as they would normalise experiences and help

mitigate challenges. Memories of transplant can be traumatic; documenting experiences, such as photographs of time spent in hospital, seemed valued and could be useful in reconstructing these narratives. Additionally, educating young people to raise their self-efficacy may help with adherence.

6. Conclusions: The study presents a constructed grounded theory of young adults' experiences of liver transplant. A number of processes seemed to make up psychological adjustment post-transplant and these were depicted in a model. A deepened understanding of these processes may help improve health-related behaviours in a population that struggle with adherence.

Appendix 27: Author Guidelines for Chosen Journal

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