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### Kidney Transplantation: Investigating Sexual Functioning in Female Recipients and Exploring the Lived Experience of Donors

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**Kidney Transplantation: Investigating Sexual Functioning in Female Recipients and  
Exploring the Lived Experience of Donors**

**Bangor University**

**2016**

**Lucie Elisabeth Rutter**

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## **Thesis Summary**

This thesis explores aspects of kidney transplantation across three papers.

A systematic literature review focuses on the sexual functioning of women following kidney transplant (KTx). A review of quantitative studies found that having a KTx improved sexual functioning when compared to other renal replacement therapies. However, as the studies were methodologically flawed it was difficult to conclude how much improvement in sexual functioning is gained. Some studies found sexual functioning was restored and is comparable to general population whereas others found problems continued following KTx.

An empirical study explores the lived experience of living non-couple donors. Using interpretative phenomenological analysis, six living donors agreed to share their stories. Three themes evolved from the data which revealed complexities in the decision making process, difficulties regarding loss and adjustment during and following the donation and donors' minimisation of their difficulties. This appeared to contribute to the donors' perception of a lack of care and support during their donation. Clinical recommendations include enhancing information and further preparation during the assessment process, access to psychological support and independent advocates and increasing clinician awareness of the barriers that prevent donors sharing any difficulties.

A final paper considers the impact of the findings in both research and clinical fields. This paper highlights the lack of good quality research investigating psychological aspects of donating and receiving a kidney. The implications and recommendations for renal services are discussed, focusing on the increased utility of advocacy, psychology involvement and increasing clinicians' awareness of the emotional impact of donating. In addition, this paper contains personal reflections regarding the research process and findings.

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## **Acknowledgements**

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Lastly, special thanks to my family and friends, for all of your patience, encouragement and support during this time.

I would like to dedicate this thesis to the memory of my mother, Catherine Rutter (1964-2000), who is a constant source of inspiration.



## **Paper 1: Literature Review**

**Female Sexual Functioning Following Kidney Transplantation: A Systematic Review of the Research (1995-2015).**

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## **Abstract**

**Background:** There is a high prevalence of sexual problems in individuals with chronic kidney disease (CKD). Research has been undertaken to determine whether sexual function improves following a kidney transplant (KTx). Studies in this area tend to focus on physical problems and therefore have tended to explore male sexual problems such as erectile dysfunction with less interest in female sexual functioning.

**Aims:** The aim of this paper was to carry out a systematic review of the literature examining the sexual functioning of women following a KTx.

**Methods:** A systematic search of three databases, Psycinfo, Medline and CINHALL and an additional hand search identified 10 studies that met inclusion criteria.

**Results:** It appears that having a KTx does improve sexual functioning when compared with other renal replacement therapies and pre-dialysis. However as the evidence lacks consistency in regards to methodologies and measures it is difficult to conclude how much improvement in sexual function is gained. Some studies suggest sexual functioning following a KTx is restored and is comparable to the general population whereas other studies suggest problems persist. Sociodemographic, mental health and clinical factors which may help to understand sexual problems in female renal populations were explored.

**Conclusions:** Receiving a KTx can improve sexual function in females with CKD, however the prevalence and nature of sexual problems that persist following a KTx is unclear.

Clinical implications and recommendations for further research are suggested.

**Keywords:** kidney, renal, transplant, sexual functioning, female.

## 1.0 Introduction

Sexual functioning is an essential aspect of an individual's physical, social and psychological life (Yilmaz & Ozaltin, 2011). Sex is included in Maslow's (1943) hierarchy of needs as a basic survival need in relation to belongingness and love. Sexual functioning is a complex human behaviour which can be affected by illness, psychological distress and interpersonal difficulties. The World Health Organisation's quality of life measure (WHOQOL, 1997) includes sexual activity as a factor contributing to overall quality of life.

Sexual dysfunction is described by Diemont et al. (2000) as "*a disturbance in the sexual response cycle.*" According to the human sexual response cycle theory (Masters & Masters, 1986) this may include difficulties with physical pleasure, desire, preference, arousal or orgasm. Sexual dysfunction has been found to have a negative impact on an individual's quality of life (Robinson & Molzahn, 2007; Lew-Starowicz, & Gellert, 2009).

Estimated prevalence rates of sexual dysfunction in the general population are varied. A 2001 review found prevalence rates to be between 0-5% for males and 3-10% for females (Simons and Carey, 2001). A review in 2008 found a higher prevalence rate of 10-20% of males and 20-25% of females (DeRogatis & Burnett, 2008). The later review found that sexual dysfunctions increased directly with age for both men and women. Chronic illness and poor general health were associated with higher occurrence of sexual dysfunction. Steinke (2013) also found an increase in the prevalence of sexual dysfunction in those living with chronic illnesses and/or multiple comorbidities. Fatigue, malaise and changes in body image have been suggested as factors which may contribute to reduced sexual activity in those with chronic health conditions (Filocamo, 2009).

Sexual dysfunction is common in patients with Chronic Kidney Disease (CKD; Navaneethan et al., 2010; Stewart 2006; Palmer, 2003). CKD is a condition defined as an

irreversible loss of renal function (National Kidney Foundation, 2016). In order to survive, individuals with end-stage CKD require renal replacement therapy such as haemodialysis, peritoneal dialysis or kidney transplantation. Kidney transplantation is regarded as the gold standard in regards to renal replacement therapy (Lee & Tang, 2007). Having a KTx is associated with lower mortality and improved quality of life (QOL) compared with dialysis treatment (Port, Wolfe, Mauger, Berling & Jiang, 1993; Schnuelle, Lorenz, Trede & Van Der Woude, 1998). Tonelli et al. (2011) found QOL to be significantly and substantially better among transplant recipients compared with dialysis treatment.

The Transplant Learning Centre (TLC) was a programme established in 1997 in America designed to improve QOL in solid organ transplant recipients. A TLC study investigating QOL found that decreased sexual interest or ability was extremely important to the respondents (Hricik et al., 2001). They found a 60% prevalence of sexual problems and these problems had a large impact on QOL. A later study focused on life satisfaction and adverse effects in KTx recipients using a longitudinal analysis (Matas et al., 2002). It found decreased sexual interest or ability was the strongest correlate of decreased QOL in recipients who were on average 5 years post-transplant. Muehrer & Becker's (2005) review of health-related QOL highlighted that sex is an important aspect of QOL, often ignored. Hricik et al. (2001) noted that previous work addressing sexual functioning has often focused on sexual problems in males with an emphasis on specific problems such as erectile dysfunction and intercourse frequency. This is often the case in sexual dysfunction research due to the complexity of female sexual functioning (Wincze & Weisberg, 2015).

A review by Pertuz Castaneda, Rincon & Lozano (2014) exploring sexual functioning following a KTx transplant examined 13 studies that have been carried out over the last 15 years. They concluded that kidney transplantation improves sexual functioning by improving sexual desire and overall sexual satisfaction. The review reported a difference between males

and females in terms of sexual functioning. In CKD populations sexual dysfunction affects 87% of males and 60-80% of females. Following a KTx sexual functioning was found to improve to 40-78% of males and 25-30% of females. A higher number of studies focused on males ( $n=9$ ) compared to females ( $n=3$ ), with one study including both genders. This review was not systematic and therefore may not be comprehensive, particularly regarding sexual functioning following a KTx in the female population.

The rationale for the present review is threefold: i) to focus on sexual function following a kidney transplant to highlight an often neglected aspect of QOL; ii) to focus solely on female sexual functioning as previous research has tended to focus on males; iii) to conduct a systematic review of evidence from all relevant studies over the last 20 years.

## **1.1 Aims**

The present systematic review aimed to answer the following questions:

- What is the prevalence of sexual dysfunction following a KTx?
- Is a KTx more effective in resolving sexual problems associated with end-stage CKD compared to other renal replacement therapies (RRT)?
- What other variables contribute to sexual function/ dysfunction in females following a KTx?

## **2.0 Methods**

### **2.1 Definition: Female sexual dysfunction**

The most widely used diagnostic approach of sexual dysfunction is *The Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.; DSM-5; American Psychiatric Association, 2013). The DSM provides diagnostic categories and criteria for the most commonly seen sexual problems. The categories for female dysfunction are: female sexual interest/arousal

disorder; female orgasmic disorder; genito-pelvic pain/penetration disorder and substance/medication induced sexual dysfunction. A criterion of marked distress or interpersonal difficulty is required to meet a diagnosis of sexual dysfunction. The classification system has been criticised for not including sexual satisfaction which is considered to be an important factor in sexual functioning (Rosen et al., 2000). Sexual functioning appears to be more complex than the function/dysfunctional classification system. However, despite its complexity, the majority of measures of sexual functioning currently classify individuals as sexually 'functional' or 'dysfunctional'.

## **2.2 Measuring sexual functioning**

Several tools have been developed in an attempt to measure sexual dysfunction in females. Laboratory-based examinations which seek to measure sexual response (e.g. vaginal blood flow) have been used to objectively measure arousal (Toorians et al., 1997). However, these have been criticised as they remove the naturalistic setting and therefore responses may lack validity (Rosen et al., 2000). The preferred measuring tool has been self-report. A number of measures have been developed specifically focusing on female arousal, satisfaction, pain/discomfort and inhibited orgasm, reflecting the DSM-5 diagnostic categories. The measuring tools adopted in the studies in this review are detailed in section 3.1.3.

## **2.3 Search strategy**

A systematic search was conducted between October 2015 and February 2016 using a four stage process. Stage one involved searching for potential abstracts and references using three electronic databases: CINAHL, Medline and Psychinfo. The following search terms were inputted in various combinations: '*transplant*', '*kidney*', '*renal*', '*female*', '*sex*', '*dysfunction*' '*function*' and associated derivations (e.g. *sex\**). Date parameters were restricted to include

studies since 1995 in order to reflect medical advances in kidney transplantation in recent years (Terasaki, Cecka, Gjertson, & Takemoto, 1995).

Stage two entailed reviewing the abstracts and references according to the following inclusion criteria:

- Adult participants who had undergone KTx.
- Reported measures of sexual functioning
- Female participants included in the study
- English language papers
- Must be published in peer reviewed journal

Stage three involved examining the remaining studies to ascertain which studies investigated sexual function in female participants who had undergone kidney transplantation. Studies were excluded if they did not provide information on the female population in their findings, or if research methods or findings were insufficient to enable comparison with other studies.

Stage four involved hand-searches of the reference sections and citations of the papers that had met the inclusion criteria. Two additional papers were identified. Figure 1 is based on the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines (PRISMA Moher, Liberati, Tetzlaff, & Altman, 2009) which displays the study selection process detailing the number of papers retrieved and included/ excluded at each stage. A total of ten studies which addressed sexual functioning in females following KTx were included in the review.

[INSERT FIGURE 1]

## **2.4 Quality assessment**

Sanderson, Tatt and Higgins (2007) conducted a systematic review and found there was a lack of adequate tools to measure study quality in observational epidemiological studies.

Therefore the studies included have been reported as per author's descriptions and issues of quality will be raised when identified throughout the review.

## **2.5 Data synthesis**

The studies included in this review had a variety of methods, measuring tools and outcome data and therefore it was thought appropriate to present the results as a narrative analysis. The results are presented in three sections: the first providing an overview of the study design and participant information; the second presents the various outcome data on female sexual function following KTx; and the final section reports on the sociodemographic, mental health and clinical factors which may impact female sexual function following a KTx.

## **3.0 Results**

### **3.1 Description of studies**

#### **3.1.1 Design and methods.**

[INSERT TABLE 1]

Table 1 provides a summary of the designs, methods, measures and key outcomes extracted from each paper in chronological order. All of the studies employed primarily quantitative methods. One study (Muehrer, Keller, Powwattana & Pornchaikate, 2006) included additional qualitative information gathered through an open-ended questionnaire. Eight of the studies adopted a cross-sectional design. Four out of these eight compared sexual function in female transplant recipients to females who were on other renal replacement therapies (Peritoneal Dialysis (PD), Haemodialysis (HD)), control groups (Diemont et al., 2000, Basok

et al., 2009; Koca, Koca & Ersoy, 2012) or another chronic condition (Toorians et al., 1997). One of the eight compared the sexual function of female KTx recipients to that of female Haemodialysis patients with no control (Noohi et al., 2010). Of the three remaining cross sectional studies, one asked participants to recall their sexual functioning prior to and following a KTx (Kucuk, Turkman & Kucuk 2013), one measured sexual functioning in females following KTx (Özdemir, Eryilmaz, Yurtman & Karaman, 2007) and one looked at the sexual functioning of females who had received a simultaneous kidney and pancreas Tx (Muehrer et al., 2006). A simultaneous kidney and pancreas Tx provides treatment for individuals with end-stage CKD and type one diabetes. There were two prospective designs in which sexual functioning in female KTx recipients was measured prior to and following a KTx (Filocamo et al., 2009; Kettas, Cayan, Efesoy, Akbay & Cayan, 2010).

### **3.1.2 Sample characteristics.**

Table 2 provides a more detailed description of the participants included in the studies. The studies used convenience samples of female KTx outpatients recruited from hospital units. Eight out the ten studies included female participants only.

[INSERT TABLE 2]

Six out of the ten studies were carried out in predominantly Muslim countries. Five out of the ten studies took place in Turkey and two of these studies provided information on religious practice stating participants were of Islamic religion (Kucuk et al., 2013 and Kettas et al., 2010). Although Koca et al. (2012) did not state information regarding cultural characteristics, they did provide information on the percentage of participants in arranged marriages. One study was conducted in Iran and there was no information regarding cultural/religious preferences of the participants, however they did report that some individuals had refused to take part due to cultural and religious issues (Noohi et al., 2010). The remaining



four studies were carried out in Western, mixed-cultural, predominantly Christian countries. Two took place in the Netherlands, one in America and one in Italy.

The number of female KTx recipients included in the sample ranged from 20 - 100. All participants were aged 18 + with the mean ages ranging from 35.04 to 49.5 years. Most of the studies provided information on relationship status, with the majority of participants being married or in a relationship. Four studies provided specific information on the transplant, for example if the transplant was from a living donor or cadaveric and whether it was the first transplant that participants had received. Seven of the studies reported information on the type and length of dialysis prior to transplantation.

### **3.1.3 Outcome measures.**

The tools used to measure sexual function are detailed in Table 1. The most common measures used in the studies were self-report measures such as the Arizona Sexual Experiences Scale (ASEX;  $n=4$ ) and the Female Sexual Functioning Inventory (FSFI;  $n=3$ ). Both have been found to have good internal consistency, reliability and validity for measuring sexual dysfunction (McGahuey et al., 2000; Rosen et al., 2000). Four of the seven studies that used the ASEX and FSFI used validated translated versions of the measures. Of the remaining studies, one used a Persian translated version of the Relationship and Sexuality Scale (RSS). Although the RSS had previously been used in Iranian populations (Kazemi-saleh, Pishgou, Assari & Tavallaii, 2007), it was not possible to obtain information regarding the measure's validity and reliability. One study generated their own questionnaire followed by an interview. Lastly, one study objectively measured sexual function by using a psychophysiological test to measure arousal with an additional interview to determine diagnosis of sexual dysfunction (Toorains et al., 1997).

### **3.1.4 Clinical cut-off scores.**

The ASEX was used in four studies, however the clinical cut-off score adopted differed between the studies. Both Muehrer et al. (2006) and Koca et al. (2012) refer to the ASEX original paper outlining the reliability and validity of the ASEX, where it suggests that if an individual's total score was  $\geq 19$ , or any one item had a score of  $\geq 5$ , or any three items had a score of  $\geq 4$ , they would be classified as sexually dysfunctional (McGahuey et al., 2000). In the studies conducted by Özdemir et al. (2007) and Kucuk et al. (2013) they refer to a paper by Soykan (2005) which looked at the reliability and validity of the ASEX in Turkish End Stage Renal Disease (ESRD) patients undergoing dialysis. This paper proposes using a cut-off score of  $\geq 11$  as an initial screening tool. They note that this cut-off point establishes a higher sensitivity however it reduces specificity and suggest that any positive cases from screening need to be followed up with a more specific diagnostic method. As the paper recommends the use of this cut-off score specifically with patients with ESRD it is not appropriate to be used with transplant recipients.

Three studies examined sexual function using the FSFI. Filocamo et al. (2009) and Kettas et al. (2010) refer to Wiegel, Meston and Rosen (2005) who developed clinical cut-off scores for the FSFI, proposing a total score of  $\leq 26.55$  was the optimum score for differentiating women who have sexual dysfunction. Basok et al. (2009) used a Turkish validated version of the FSFI (Oksuz, 2006), which has been proved reliable and valid in the Turkish population with a cut-off score of  $\leq 25$ .

### **3.1.5 Additional outcome measures**

In addition to sexual functioning, the studies examined whether other variables have an impact on sexual functioning in female KTx recipients. These include: socio-demographic variables ( $n=6$ ), depression ( $n=4$ ), anxiety ( $n=1$ ), and self-esteem ( $n= 1$ ). Studies have also

looked at other clinical variables to examine their relationship with female sexual function, including hormone profile ( $n=2$ ), chronic co-morbid illnesses ( $n=4$ ), and kidney function ( $n=3$ ).

The studies measuring depression used the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961; Beck & Steer, 1988) and the Hospital Anxiety and Depression Scale (HADS; Snaith, 2003). Anxiety was also measured using the HADS. Both measures are used extensively in research and have been found to have good reliability and validity in the renal population. (Martin, Tweed & Metcalfe, 2004; Craven, Rodin & Littlefield, 1989).

One study (Muehrer et al., 2006) used a measure of sexual self-esteem to identify any relationship between sexual functioning and sexual self-esteem. The Sexual Self-Esteem Scale (Buzwel & Rosenthal, 1996) measures to what extent an individual's sexual self-esteem is low. The reliability and validity of the measure was not reported and it was not possible to obtain this information for this review.

## **3.2 Outcome data on female sexual functioning**

### **3.2.1 Prevalence of sexual dysfunction.**

As previously discussed, Özdemir et al. (2007) and Kucuk et al. (2013) relied on a clinical cut-off score for the ASEX which is not appropriate for the transplant recipient population. The outcomes from these studies were particularly high with a reported 79% (Kucuk et al., 2013) and 93.8% (Özdemir et al., 2007) of females found to have sexual dysfunction following a transplant. As the cut-off score was lower and therefore more sensitive, it is likely this may have produced higher percentages of females with sexual dysfunction. In addition to the incorrect use of the measure, Kucuk et al. (2013) relied on participants' abilities to remember their sexual functioning prior to transplant. Participants who had

received a transplant were asked to complete a questionnaire based on their memory of sexual functioning prior to the transplant and then complete one for their current sexual functioning. The average time since receiving a KTx was 6.45 years. The authors reported that some individuals had difficulty remembering the previous period and therefore it is likely that the information recalled was not accurate. Due to the methodological issues raised, the prevalence results from these studies have been excluded from the conclusions.

The remaining studies reported prevalence rates of sexual dysfunction in female KTx recipients ranging from 18.2% to 57.1%. Three of the ten studies included control groups and found sexual dysfunction in these participants to range from 2.9% to 50%. Five studies included other RRT groups and they reported prevalence of female sexual dysfunction to be from 37.2% to 100%.

Muehrer et al. (2006) used the standard ASEX cut-off to measure sexual functioning in 65 females who had received a simultaneous pancreas and KTx and found 27% had sexual dysfunction. In addition, they sought to identify women who reported sexual problems but were not dysfunctional by examining how individuals' scored on individual items (e.g. normal sexual functioning was classified when an individual answered with a 3 or less on every item). This resulted in 39% of the female transplant recipients being classified as 'normal' functioning and 34% as having some sexual difficulties. Participants were recruited from a transplant centre with a reported 43% response rate, therefore the results may not be representative of the population. As the paper included women who had a simultaneous kidney and pancreas transplant caution must be taken when comparing to studies with KTx only participants.

Koca et al. (2012) also used the ASEX to explore the difference in sexual functioning between female participants on dialysis, those who had received a KTx ( $n = 33$ ) and a control

group. The rates of sexual dysfunction were; control group 2.9%; KTx group 18.2%; Peritoneal Dialysis (PD) 37.2%; and Haemodialysis (HD) 74.4%. The HD group was significantly higher than the other groups. Although the KTx group had a lower rate compared to the dialysis group, the prevalence of sexual dysfunction was higher than the control group which comprised of premenopausal healthy females. Diemont et al. (2000) found similar results using questionnaires gathered from patients on HD and PD, KTx recipients and a control group. However, this study used a simple three item questionnaire asking if people experienced sexual problems rather than using a measure of sexual functioning. The results found the prevalence of sexual problems was significantly higher in the KTx recipients (44.4%) compared to the control group (14.9%). KTx recipients had significantly lower sexual problems compared with female PD and HD patients (66.7% and 75% respectively). The questionnaire was validated by structured interview whereby 102 out of 104 were found to be correctly classified as having a sexual problem.

Basok et al. (2009) found contrasting results using the FSFI to ascertain prevalence rates of sexual dysfunction between females who had CKD and were pre-dialysis, females receiving HD or PD, KTx recipients and a control group (described as healthy female volunteers). There was no significant difference between the prevalence rate of sexual dysfunction in female KTx recipients and the control group (50%). The authors comment that this figure is in line with other studies using the FSFI with the Turkish female population. The pre-dialysis group had a significantly higher rate of sexual dysfunction (81%) compared to control and KTx groups. The rates for the PD and HD groups were 66.7% and 75% respectively. The study suggests that rates of sexual functioning following a KTx are comparable to that of the general population, however the number of participants in each group was low ( $\leq 24$ ).

The two prospective studies (Kettas et al., 2010; Filocamo et al., 2009) explored female sexual function via following women through the process of a KTx and measuring sexual functioning prior to and following the transplant. Filocamo et al. (2009) used the FSFI with 39 participants. The questionnaire was initially administered when individuals were on dialysis and put onto a transplant waiting list and re-administered 12 months following the KTx. Prior to the transplant 41% of the participants reported an active sex life. Following the transplant this rose to 88% of the participants (N.B all participants were in stable heterosexual relationships). In regards to sexual dysfunction, prior to the transplant 62.5% were found to have sexual dysfunction with that reducing to 32.35% following transplantation. Interestingly, when asked to report the reasons for the continued absence of sexual activity, 12.8% reported it was due to the presence of the transplant specifically. Kettas et al. (2010) also used the FSFI with 21 females. They found a significant improvement in their FSFI scores,  $17.57 \pm 7.07$  prior rising to  $25.3 \pm 3.28$  following the KTx. However mean score following the transplant remained in clinical range ( $\leq 26.55$ ). Interestingly, if the authors had used the same clinical cut-off as Basok et al. (2009;  $\leq 25$ ), the mean score following KTx would be just outside clinical range. This firstly indicates the importance of clinical cut-off scores as they can have a huge impact on the interpretation of results and secondly highlights the difficulty of using measures where they draw a line between 'normal' and 'dysfunctional'. These two prospective studies indicate that having a KTx improves sexual functioning in females, however they highlight that there may still be problems in sexual functioning following a KTx. A limitation of both studies was the small number of participants.

Noohi et al. (2010) included a larger number of participants ( $n=79$ ) in a study which compared the sexual function of KTx recipients and CKD patients receiving HD. The study used the RSS which is scored from 0-36 with a higher score indicating a poorer state. The

study found that KTx recipients had significantly better scores on each of the subscales compared with participants receiving HD. The total score for KTx recipients was 17.7. However as there was no information regarding clinical cut-off it is difficult to interpret the outcome. The study found that 29.2% of KTx recipients reported good sexual satisfaction and 37.5% reported not being satisfied sexually. These results suggest that in terms of renal replacement therapies, KTx provides better outcomes for sexual functioning compared to HD, however there may continue to be difficulties in relation to sexual functioning following a KTx.

Toorians et al. (1997) compared four groups: three renal replacement therapies (PD, HD and RTx) and a comparison group of patients with rheumatoid arthritis (RA). There were 27 female KTx recipients included. The comparison group was employed to investigate whether sexual dysfunction in CKD is due to the disease itself, the treatment modality or whether it was due to more generally having a chronic disabling condition such as RA. The study aimed to see whether treatment modality (HD, PD or RTx) influenced the incidence or severity of sexual dysfunction using an interview and DSM III-R to classify sexual dysfunction disorders. They found the prevalence of sexual dysfunction disorders was at least the same if not more in females compared to males. In regards to specific disorders the prevalence of hypoactive sexual desire disorder<sup>1</sup> was significantly lower in KTx recipients compared to the three other groups. The prevalence of other disorders did not differ between female groups.

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<sup>1</sup> Hypoactive sexual desire disorder - Lack of desire for sexual activity resulting in distress or interpersonal difficulties.

### **3.2.2 The nature of sexual dysfunction.**

The nature of sexual dysfunction in female KTx recipients was explored in several studies with the aim of facilitating understanding of the sexual problems. Diemont et al. (2000) analysed a questionnaire sent out to KTx recipients and found that the most frequently reported complaints of females was reduced libido (75%), reduced lubrication (38%), orgasm complaints (28%) and pain during intercourse (20%).

Toorians et al. (1997) was the only study to measure sexual function through a psycho-physiological test procedure: a laboratory method which measures subjective and physiological sexual arousal. The genital physiological responses did not differ between the four groups (PD, HD, RTx and RA), suggesting that sexual dysfunction may not be due to biological failure to perform sexually.

Filocamo et al. (2009) detailed the difference in the domains of the FSFI (desire, arousal, lubrication, orgasm, satisfaction and pain) prior to and following transplantation. There were significant improvements in all domains following KTx. There was no difference between any of the individual domains with the mean scores ranging from 4.48-5.02 across all six domains. Similarly Kettas et al. (2010) compared pre and post KTx domain scores and also found significant improvements across all domains following transplant. Basok et al. (2008) also found the mean scores on each of the domains were fairly similar, ranging from the lowest mean score for arousal ( $3.3 \pm 1.97$ ) to the highest mean score for pain ( $4.3 \pm 2.39$ ).

There are 5 domains in the ASEX measure which are similar to the FSFI. Unlike the FSFI, a higher score reflects an impaired sexual function. Koca et al. (2012) found the highest mean score ( $3.2 \pm 0.8$ ) for reaching orgasm and lowest mean score was for orgasm satisfaction ( $2.7 \pm 0.7$ ). It was thought to be appropriate to review the data collected for the individual domains from Özdemir et al. (2007) and Kucuk et al. (2013) as this was not



affected by clinical cut-off scores. Özdemir et al. (2007) provided a bar chart but not actual scores from the ASEX which displayed little variation between domains. Kucuk et al. (2013) found a similar pattern with minimal differences between mean scores. There do not appear to be significant differences between the domains measured by the FSFI or ASEX and therefore the nature of the problem remains unclear. As these measures only question particular areas of sexual function it is possible that other variables may be contributing to sexual function in individuals who have received a KTx.

### **3.3 Variables which may have an impact on sexual functioning**

Several of the studies collected and analysed other data to explore whether these have a relationship to sexual functioning. Table 3 provides details of the variables included in each paper.

[INSERT TABLE 3]

#### **3.3.1 Socio-demographic variables.**

Socio-demographic variables included participants' age, relationship status, working status, education and some collated information on spouses and children. Diemont et al. (2000) and Kettas et al. (2010) found there was no relationship between sexual functioning and age. Koca et al. (2012) analysed participant's demographics and found that age was not a significant risk factor for sexual dysfunction. However, Basok et al. (2009) investigated the relationship between females with sexual dysfunction and those without and found older age was the only demographic variable to be independently and significantly associated with female sexual dysfunction. Kucuk et al. (2013) found significant correlations between higher ASEX scores and older patient age and older spouse age.

Koca et al. (2012) calculated Socio-economic status (SES) for each participant using a 28-item questionnaire. SES was not found to be a risk factor for sexual dysfunction. Kucuk et

al. (2013) found significant correlations between higher ASEX scores and poorer financial status and lower levels of education. Similarly, Özdemir et al. (2007) found that females who were less educated produced higher ASEX scores.

Koca et al. (2012) found the only independent risk factor for the renal replacement therapy population (PD, HD and KTx) was marital duration: the longer an individual had been married the more likely they will have poor sexual function.

### **3.3.2 Mental health status.**

#### ***3.3.2.1 Depression.***

Four studies included a depression measure to examine whether mood had an impact on sexual functioning. Kettas et al. (2010) and Filocamo et al. (2009) found that mean BDI scores decreased following transplantation (i.e. participants' mood improved). Further analysis found that there was no relationship between depression score and sexual function. Therefore, improvement in mood was not related to better sexual function using the FSFI. Özdemir et al. (2007) investigated the ASEX scores between individuals who they defined as depressed (BDI score  $\geq 17$ ) and those who were not. ASEX scores were significantly higher in the depression group versus non-depressed group and further analysis found BDI was correlated with ASEX score. Using the HADS, Koca et al. (2012) found depression scores in the RRT groups to be higher than those in the control group, however logistic regression analysis found that depression was not an independent risk factor of sexual dysfunction in the RRT population.

#### ***3.3.2.2 Anxiety.***

One study explored the role of anxiety in female KTx recipients using the HADS (Koca et al., 2012). Mean anxiety scores were significantly higher in the PD (5.5) and KTx group (6.6) compared with the control (3.8) and HD groups (3.9), however these mean scores remain

under the clinical cut-off point ( $\leq 8$ ). Anxiety was not found to be a risk factor of sexual dysfunction in the KTx group.

### ***3.3.3 Self-esteem.***

Muehrer et al. (2006) examined sexual self-esteem to see whether this impacts upon sexual functioning in simultaneous pancreas and KTx recipients. The ASEX was found to be negatively correlated with the overall sexual self-esteem scale, meaning higher sexual self-esteem scores were associated with better sexual function. The study reported that although there was a difference between the groups, overall the sexual self-esteem scores across all participants were relatively high.

### **3.3.4 Clinical variables.**

#### ***3.3.4.1 Kidney function.***

Kidney function can be measured via testing the blood for levels of creatinine. The kidneys maintain the blood creatinine levels within normal range (0.6-1.3 mg/dL). Higher levels of creatinine in the blood indicates the kidneys are not working optimally and that kidney function is impaired. Following a KTx individuals have blood tests to ensure their kidneys are functioning well and remain in 'normal' range. It has been hypothesised that there may be a relationship between high levels of creatinine and sexual dysfunction. Koca et al. (2012) measured participants' creatinine levels and found, as expected, that creatinine levels were significantly lower (1.2mg/dL) in KTx recipients compared with PD (4.8mg/dL) and HD (6.1mg/dL). No further analysis was conducted to see whether there was a relationship between creatinine levels and sexual dysfunction.

Kettas et al. (2010) did carry out further analysis and found that higher levels of creatinine were not associated with sexual dysfunction. However Basok et al. (2009) found

that females with sexual dysfunction had a significantly higher mean amount of creatinine in the blood (5.47mg/dL) compared with individuals in the 'normal' sexual functioning group (2.87mg/dL). These contrasting results make it difficult to make a conclusion about the direct impact on kidney function on sexual function.

#### ***3.3.4.2 Chronic co-morbid conditions.***

Toorians et al. (1997) speculated that renal failure *per se* does not explain sexual dysfunction in renal patients. Their study included females with Rheumatoid Arthritis (RA) and found that patients with RA have similar prognosis in regards to sexual dysfunction as patients with CKD. The study suggests that the nature of what comes with having a chronic illness, for example, fatigue, may be the driving factors in sexual dysfunction in these individuals.

Muehrer et al. (2006) aimed to investigate whether co-morbid chronic illness had an impact on sexual functioning in transplant patients, however the whole sample was found to have at least one co-morbid condition and therefore further analysis was not undertaken.

Basok et al. (2009) investigated parameters such as blood pressure and cholesterol levels in females following KTx. These were not found to be a risk factor associated with sexual dysfunction. The authors had an additional interest in diabetic patients and reported that despite the number of diabetic patients in the study they did find a statistically significant difference in glucose levels between women with sexual dysfunction and those without.

Similarly Kettas et al. (2010) divided the female KTx recipients in to a group with and a group without diabetes. They also found that scores on the FSFI were significantly higher following KTx in women without diabetes compared to women with, suggesting that women without diabetes improved more on their sexual function score.

### ***3.3.4.3 Hormone profile.***

Two studies investigated whether there was a relationship between hormone levels and sexual dysfunction in female KTx recipients. The studies had contrasting results with Filocamo et al. (2009) finding that improvement in hormonal status and restoration of menses was positively associated with sexual function, whereas Basok et al. (2009) found no significant correlation between hormone levels and sexual function. Filocamo et al. (2009) compared females prior to and following a transplant. Whereas Basok et al. (2009) divided participants into two groups ('sexually dysfunctional' and 'normal sexual function') and looked for correlations in hormone levels across RRT groups (HD, PD and KTx). It is not clear how many KTx participants were included in 'sexual dysfunction' and 'normal sexual function' groups. Mean age was significantly higher in the 'sexual dysfunction group' compared with 'normal functioning' group and it is not stated that this was controlled for during the analysis, therefore this may have had an impact on the outcomes.

### **3.4 Qualitative information**

Muehrer et al. (2006) asked participants to provide written information on the consequences of having a transplant. Of the women, 32% listed only positive effects (e.g. more sex drive, better lubrication and arousal, enhanced self-image etc.), 28% reported only negative effects (e.g. decreased sexual functioning, body image – scarring, decreased energy etc.) and 29% reported no effect.

## **4.0 Discussion**

The first aim of this review was to investigate the prevalence of sexual dysfunction in females following a KTx. This review found a range from 18.2% to 57.1% of females continued to have sexual dysfunction following a KTx. Both prospective studies found an improvement on a measure of female sexual functioning following a KTx. The second aim

was to discover whether receiving a KTx was more effective in resolving sexual problems associated with end-stage CKD compared with other RRTs. The cross sectional studies that compared KTx recipients to other forms of RRT all found that KTx recipients scored more favourably on sexual functioning scales. The prevalence of disorders was found to be lower in the KTx recipients compared with other RRT groups. Sexual satisfaction was higher in the KTx participants compared with RRT groups. The third aim was to explore what other variables contributed to sexual dysfunction in female KTx recipients. The results from the studies reviewed were mixed across all variables and therefore are discussed individually later in the discussion.

It appears that having a KTx improves the sexual functioning of females who have end-stage CKD. However, what is unclear is how much improvement in sexual function is gained. This review found mixed results with some studies finding sexual functioning is comparable to control groups (i.e. sexual functioning restored) and other studies reporting that there continued to be problems with sexual functioning following a KTx. The outcomes of the studies in this review echo a TLC study's conclusion that *transplantation is not a definitive cure for sexual dysfunction associated with renal failure* (Matas et al., 2002 pp.119).

A recent review estimated the prevalence of sexual dysfunction to be 20-25% of females in the general population (DeRogatis & Burnett, 2008). This review found the prevalence of sexual dysfunction in the female KTx population to vary hugely across studies. Differences in the samples, the measures adopted, classification of sexual functioning and cultural context may account for this variation. The studies included had small sample sizes (<100 female KTx recipients per group). Estimates of prevalence based on small samples are likely to be inaccurate as they produce large confidence intervals (e.g. Roberts, Attkisson & Rosenblatt, 1998).

Understanding the nature of sexual dysfunction in females following KTx and assessing additional factors which may contribute towards sexual problems may help to explain sexual dysfunction in female KTx recipients. Several studies examined the domains within sexual functioning measures. Following a KTx, females were found to improve across all domains with no particular item found to improve significantly more than another. Toorians et al. (1997) was the only study to measure arousal levels objectively. They found the genital physiological responses between dialysis, KTx and RA patients did not differ, suggesting the mechanics of sex were intact within each of these groups. They concluded that they were not able to relate any biochemical or endocrine variables to sexual functioning, rather sexual dysfunction was found to be predominately related to lack of sexual desire / libido. This study has its limitations as the response rate to participate was low (27%) and this may have resulted in there being no effect of group.

Several studies investigated socio-demographic variables with mixed results. Three studies found older age not to be a risk factor for sexual functioning whereas two studies found that it was. It was not possible to conclude whether age is a risk factor in female KTx recipients. Studies of the general population found ageing is related to sexual dysfunction (DeRogatis & Burnett, 2008). A global study of sexual attitudes and behaviours in people over forty found the prevalence of sexual dysfunction tended to increase with age (Nicolosi et al., 2004). As there is a possibility that age has an impact on sexual functioning it is important for research to control for age as a confounding variable.

The impact of mental health problems on sexual functioning was explored. Of the four studies that included a depression measure, two found that mood improved following transplantation and two that mood was better in KTx recipients compared to dialysis groups. Özdemir et al. (2007) found that individuals who had reached the threshold for clinical depression ( $BDI \geq 17$ ) had higher scores of sexual dysfunction versus those who were not

classified as depressed. However, through further analysis in three studies depression was not correlated with sexual dysfunction or found to be an independent risk factor of sexual dysfunction. It appears that having a KTx improves mood on a depression psychometric measure and this may play a role in the improvement of sexual function, however the relationship between the two remains unclear. One study explored anxiety and found scores to be highest in the KTx group compared to dialysis and control groups, however anxiety was not found to be a risk factor for sexual dysfunction in KTx recipients. The nature of the anxiety was not explored or detailed and the mean anxiety scores were below the clinical cut-off.

Self-esteem was measured by one study which identified a relationship between sexual self-esteem and sexual function in the transplant recipient population, however the sample size was small (n= 65). The sample included simultaneous pancreas and KTx and therefore there may be other factors that explain this finding.

Clinical factors that may contribute to sexual problems were measured in a small number of the studies. The results regarding the impact of kidney function on sexual function in female KTx recipients were inconclusive. There is an increase in the prevalence of sexual dysfunction in those living with chronic illnesses and/or multiple comorbidities (Steinke, 2013), and therefore it is likely that additional co-morbidities such as diabetes may play a factor in sexual functioning following a KTx. The studies in this review found that female KTx recipients were more likely to have sexual dysfunction if they had co-morbid diabetes. This finding is consistent with literature suggesting that diabetic women have a higher risk of sexual dysfunction compared to women without (Doruk et al., 2005; Laumann, Paik and Rosen, 1999). There is a high comorbidity rate of diabetes and renal failure (Levey et al., 2003). None of the studies in this review controlled for diabetes as a confounding variable.



Most of the studies did not include any information regarding patients' co-morbidities and therefore the impact that additional health conditions may have on sexual function is unclear.

Previous studies have found that CKD and dialysis can have a negative impact on menstruation and fertility due to the alterations in hormones (Holley, Schmidt, Bender, Dumler & Schiff, 1997; Peng et al., 2005). The two studies that investigated this found contrasting results and therefore it remains unclear whether the restoration of hormones positively influences sexual functioning.

Additional variables that have not been explored in this review may account for continuing problems with sexual functioning in females following a KTx. The role of medication has had little attention. Medical drugs may play a role in sexual dysfunction as recipients are required to continue on immunosuppressant medication following the KTx. There is a high prevalence of sexual dysfunction in individuals with chronic pain (Ambler, Williams, Hill, Gunary & Cratchly, 2001). Studies have found the prevalence of pain in KTx recipients to be between 53%- 63% (Forsberg, Lorenzon, Nilsson & Backmana, 1999; Masajitis-Zagajewska et al., 2011). Pain may play a role in the prevalence of sexual dysfunction and this could explain the high rates of sexual dysfunction in the RA group in the Toorians et al. (1997) study.

#### **4.1 Limitations of the studies reviewed**

There are a number of methodological issues apparent in the reviewed studies including small sample sizes, inappropriate use of measures and a lack of control over potentially confounding variables such as age and co-morbidities.

There is bias in sex research due to volunteer participation (Strassberg & Lowe, 1995) and studies have found males to be significantly more likely to volunteer compared to women (e.g. Wochick, Braver & Jensen, 1985; Wiederman, 1999). Studies have also found differing

attitudes of volunteers, with those agreeing to participate having a more positive attitude towards sex (Strassberg & Lowe, 1995), less sexual inhibition (Morokoff, 1986) and less conservative sexual attitude (Dunne et al., 1997). Diemont et al. (2000) and Muehrer et al. (2006) reported a response rate of 12% and 43% respectively. It is speculated that some individuals may not have wanted to take part due to the nature of the studies, however this information was not collected so remains unknown.

The issue of measuring sexual functioning is complex. The majority of the studies included in the review used measures that are based on the DSM diagnostic criteria and categorise individuals into sexually functional or dysfunctional. There is ongoing debate in the field of human sexuality over the DSM classification system with a concern about the lack of specificity resulting in questions such as *when does a sexual problem becomes a sexual dysfunction?* (Sungur & Gunduz, 2014). The inconsistency in the outcomes of the reviewed studies may be a product of the lack of a robust classification system. Sexual functioning is an individual and subjective area and therefore measuring problems is extremely difficult. Reliance on self-report measures has its difficulties with regards to subjectivity, however, the use of laboratory measurements has been criticised for lacking validity (Rosen et al., 2000). The use of measuring tools is helpful in order to gain the data from large numbers and enables comparisons across different groups, however they are not able to capture the details and nature of the problems.

A difficulty in defining and measuring 'normal' and 'dysfunctional' sexual frequency is the impact of culture and ethnicity. The prevalence rates of sexual dysfunction following a KTx in the predominantly Muslim countries was higher ranging from 18.2% to 57% (mean = 39.4) compared to studies in non-Muslim which ranged from 27% to 44.1% (mean = 33.61). There is a variety of sexual practices and traditions in different countries and cultures and this may be the reason for the disparity in outcomes in the reviewed studies. The studies in

predominantly Muslim countries reported data on percentage of arranged marriages. Kucuk et al. (2013) reported that females included in the study were highly likely to be virgins at the time of marriage. One study was conducted in Iran (Noohi et al., 2010) and the authors note that talking about sex, especially for women, was particularly difficult due to cultural and religious issues. It is likely that these cultural differences will have had an impact on the female participants and their sexual functioning and therefore findings cannot be generalised.

#### **4.2 Clinical Implications**

Treatment of sexual problems requires a multidisciplinary approach with input from both medicine and psychology (Wincze & Weisberg, 2015). Key to a good clinical assessment is a comprehensive medical, sexual and psychological history (Goldstein, 2007). Assessment of sexual functioning should be routine practice in clinical care following a KTx, however clinicians are often found to overlook issues related to sex (Phillips, 2000; Diemont et al., 2000). Siegal (1999) recommended that *renal professionals are most helpful when they can openly discuss the effects of renal disease on a patient's sexual patterns, including ability and desire* (p.34).

#### **4.3 Future Research**

Research investigating female sexual functioning with any medical illness is scarce. Specifically there have been a limited number of studies investigating female functioning following KTx. There is a dearth of research in Western countries and therefore further studies in countries where there are more liberal views regarding sex is essential. Future research must address the quality issues raised in this review regarding small sample sizes and lack of control over confounding variables.

Future research is required to explore the relationship between mental health status and sexual dysfunction in female KTx recipients. Furthermore, research into body image and

sexual self-esteem in the female KTx population may assist in further understanding female sexual dysfunction. Regarding clinical variables, additional research investigating creatinine levels in KTx recipients is required to address whether poorer kidney function is related to sexual dysfunction. It remains unclear whether the restoration of hormones positively influences sexual functioning and therefore more research is required. Attention towards the impact of medication on sexual functioning is required particularly as transplant recipients remain on medication for life. It may also be useful to investigate factors that were not explored such as levels of pain in KTx recipients.

Future research may consider the use of technology and computer assisted techniques that increase anonymity and improve validity. Using qualitative methods may be useful to gain insight from female KTx recipients regarding their sexual difficulties as opposed to analysing outcomes from measuring tools that researchers believe to be relevant.

With regards to interventions for female sexual functioning, there are some recent best practice guidelines (British Medical Journal, 2016) which suggest that clinicians should conduct a detailed assessment in order to provide treatment for specific problematic areas. Treatment approaches may address mood, self-image, interpersonal issues or physiological problems such as reduced lubrication. Suggested treatment modalities with a small evidence base include psychoeducation, cognitive behavioural therapy, sex therapy and mindfulness. Evidence for these treatments with female KTx recipients with sexual dysfunction is lacking and therefore further research with this population is recommended.

## **5.0 Conclusions**

The limited number of studies, small sample sizes, and methodological issues in this review make it difficult to draw reliable and valid conclusions. The geographical and cultural nature of the studies, in addition to the low response rates, presents an issue of representativeness to

Western cultures. Despite these limitations there is evidence to suggest that receiving a KTx may contribute to improvements in sexual function in females, however problems with sexual functioning persist in some individuals. Healthcare professionals must address sexual functioning as part of routine assessment following KTx in order to identify any problems and intervene early. Higher quality research with larger samples will help to understand this neglected subject further.

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**Table 1.** Description of the study designs, country of origin, sample size, measure of sexual functioning used and a summary of the findings.

No.	Study	Country	N (total sample)	N (female KTx)	Sample	Design	Sexual function measure	Findings
1	<b>Toorians, Janssen, Laan, Gooren, Giltay, Oe, Donker &amp; Everard (1997)</b>	Netherlands	281	27	Male and female PD, HD + KTx recipients and RA patients	CS	Interview + classification according to DSM V  Laboratory psychophysiological test procedure to measure arousal	Prevalence of SD at least the same if not more in females compared to males. The female KTx recipients had significantly lower prevalence of hypoactive sexual desire disorder compared with PD, HD and RA groups (31% vs. 67-100% respectively). The prevalence of other SDs (which were lower across all groups) did not differ between the female groups. Genital physiological responses did not differ between the groups.
2	<b>Diemont, Vrugink, Meuleman, Doesberg, Lemmens &amp; Berden (2000)</b>	Netherlands	1291	99	Female PD, HD + KTx recipients + control	CS	Author's questionnaire+ interview	There were significantly higher reports of sexual problems in female KTx group (44.4%) vs control (14.9%), however the KTx group had significantly less sexual problems compared to dialysis groups (PD = 66.7%; HD = 75%).
3	<b>Muehrer, Keller, Powwattana &amp; Pornchaikate (2006)</b>	USA	65	65	Female simultaneous kidney and pancreas Tx recipients	CS	ASEX + Qualitative questionnaire	39% reported 'normal' SF; 34% reported problems with SF; 27% reported SD. 28% reported negative effects of transplant on sexuality 33.3% reported positive effects 29% no effect.
4	<b>Ozdemir, Eryilmaz, Yurtman &amp; Karaman (2007)</b>	Turkey	98	33	Female and Male RTx recipients	CS	ASEX – Turkish Translation	SD in females was higher (93.8%) compared to males (56.9%).

No.	Study	Country	N (total sample)	N (female KTx)	Sample	Design	Sexuality measure	Findings
5	<b>Basok, Atsu, Rifaioğlu, Kantarci, Yildirim &amp; Tokue (2009)</b>	Turkey	106	20	Female pre-dialysis, HP, PD + KTx recipients + control	CS	FSFI	There was no statistically significant difference between the control group and KTx group on SD (50%). Participants on dialysis had higher rates of PD (HD = 75%; PD = 66.7%). Pre-dialysis had the highest rate (81%) and this was significantly higher than the KTx group.
6	<b>Filocamo, Zanazzi, Marzi, Lombardi, Del Popolo, Mancini, Salvadori &amp; Nicita (2009)</b>	Italy	39	39	Female KTx recipients	P	FSFI + Questionnaire	Prior to KTx 41% reported active sex life, this rose to 88% following KTx. Prior to KTx 62.5% had SD reducing to 32.35% post KTx. Post KTx 12.8% reported absence of sexual activity due to presence of transplant
7	<b>Noohi, Azar, Behzadi, Barbati, Haghshenas, Amoozgar &amp; Karami (2010)</b>	Iran	119	79	Female HD + KTx recipients	CS	RSS	Score on the RSS = RTx – 17.7; HD - 23.2 37.5% of KTx recipients reported being not satisfied sexually (47.5% HD group) 29.2% of KTx recipients reported good sexual satisfaction (15% in HD group).
8	<b>Kettas, Cayan, Efesoy, Akbay &amp; Cayan (2010)</b>	Turkey	21	21	Female KTx recipients	P	FSFI – Turkish translation	There was a significant improvement on FSFI scores following KTx (17.57 to 25.3) however the mean score remained in SD clinical range (cut off <26.55). 95.2% had SD before KTx. 57.1% had SD after KTx.

No.	Study	Country	N (total sample)	N (female KTx)	Sample	Design	Sexuality measure	Findings
9	<b>Koca, Koca &amp; Ersoy (2012)</b>	Turkey	115	33	Female PD, HD + KTx recipients + control	CS	ASEX – Turkish translation	SD in: RTx = 18.2% Control = 2.9% HD = 74.4% (sig) PD = 37.2%
10	<b>Kucuk, Turkmen &amp; Kucuk (2013)</b>	Turkey	100	100	Female KTx recipients	CS	ASEX – Turkish translation	Sexual functioning was reported to be better in period following KTx, however 79% of recipients continued to have SD.

Note. KTx= Kidney Transplant; PD = Peritoneal Dialysis; HD= Haemodialysis; RA = Rheumatoid Arthritis; CS = cross-sectional; P= prospective/longitudinal ASEX= Arizona Sexual Experiences Scale; FSFI = Female Sexual Functioning Inventory; RSS = Relationship and Sexuality Scale; SD = sexual dysfunction; SF= sexual functioning.

**Table 2.** Summary of the participant characteristics for the female KTx recipient sample in each study.

No.	Study	N (female KTx)	Participant Age			Ethnicity/R eligion	Relationship Status	Additional Transplant Information	Pre-Transplant Dialysis	Post KTX duration
			Mean	SD	Range					
1	Toorians, et al. (1997)	27	38.9	10.3	20-60	Dutch	89% partner; 11% single	-	66.6% HD 33.3% PD	Range 1-7 years Mean 4 years
2	Diemont et al. (2000)	99	42.5	11.3	20-65	Dutch	-	-	-	-
3	Muehrer et al. (2006)	65	53.8% aged 41-50	-	18-50	American	62.5% married; 84% regular sexual partner	-	-	54% 5 years or less
4	Ozdemir et al. (2007)*	33	36	11.2	18+	Turkish	65.3% married; 34.7 % single	61.2% LD 38.8% C	Mean 1.5 years dialysis	Mean 4.2 years
5	Basok et al. (2009)	20	36.35	8.55	18+	Turkish	-	-	-	-
6	Filocamo et al. (2009)	39	36	5.9	18-45	Italian	100% stable heterosexual relationships	-	100% HD 6months +	1 year
7	Noohi et al. (2010)	79	49.5	1.8	-	Iranian	100% married	1 <sup>st</sup> KTx	-	6 months – 5 years
8	Kettas et al. (2010)	21	35.04	9.6	21-53	Turkish Islamic religion	100% married	1 <sup>st</sup> KTx 71.4% LD 28.6% C	85.71% HD Mean duration 3.38 years	Mean 2.29 years



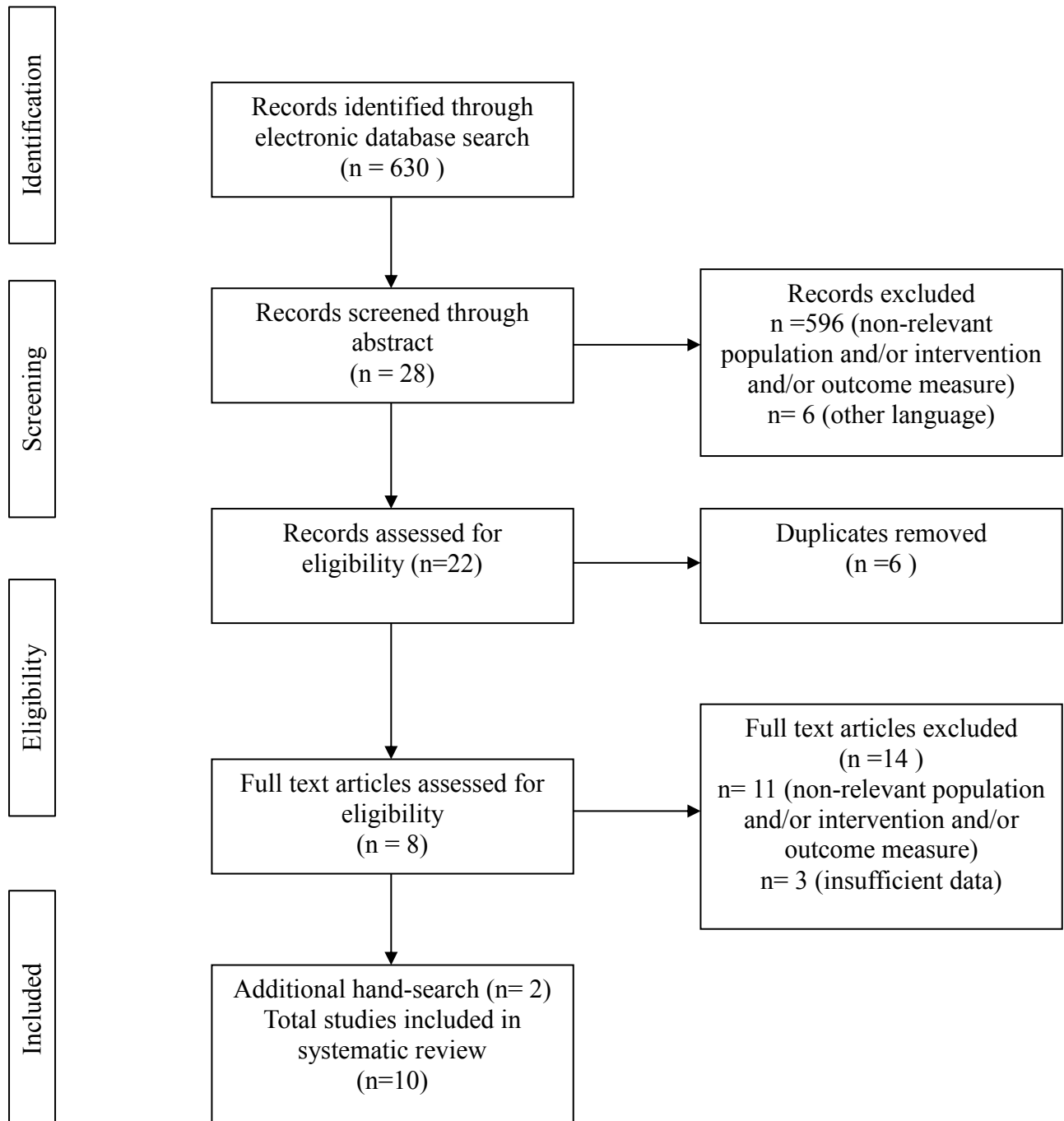
No.	Study	N (female KTx)	Participant Age			Ethnicity/Religion	Relationship Status	Additional Transplant Information	Pre-Transplant Dialysis	Post KTX duration
			Mean	SD	Range					
9	<b>Koca et al. (2012)</b>	33	37.3	7.0	18+		100% sexually active	-	Mean 3.2 years dialysis	Mean 3 years
10	<b>Kucuk et al. (2013)</b>	100	41.08	10.13	-	Turkish Muslim	93% married; 3% single; 3% divorced; 1% spouse died	66% LD 34% C	77% HD; 12% PD; 11% pre-emptive Mean duration 3.49 years	Mean 6.45 years

Note. \* = participant characteristics are male and female sample combined no information on female only information; SD = Standard Deviation; LD = Living Donor; C = Cadaveric; HD= Haemodialysis; PD = Peritoneal Dialysis

**Table 3.** Identification of the additional variables collected and analysed in each study.

No.	Study	Mental Health variables				Clinical variables			
		Socio-demographic	Depression	Anxiety	Self Esteem	QOL	Hormones	Chronic co-morbid illnesses	Kidney function
1	Toorians, et al. (1997)	X	X	X	X	X	✓	X	X
2	Diemont et al. (2000)	✓	X	X	X	X	X	X	X
3	Muehrer et al. (2006)	X	X	X	✓	X	✓	X	✓
4	Ozdemir et al. (2007)	✓	✓	X	X	X	X	X	X
5	Basok et al. (2009)	✓	X	X	X	✓	✓	✓	X
6	Filocamo et al. (2009)	X	✓	X	X	X	✓	X	X
7	Noohi et al. (2010)	X	X	X	X	X	X	X	X
8	Kettas et al. (2010)	✓	✓	X	X	X	✓	✓	X
9	Koca et al. (2012)	✓	✓	✓	X	X	X	✓	X
10	Kucuk et al. (2013)	✓	X	X	X	X	X	X	✓

Figure 1. PRISMA Flow diagram displaying process of study identification.



## **Paper 2: Empirical Paper**

## **Exploring the Experiences of Living Donors in Kidney Transplantation**

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## **Qualitative Health Research (QHR)**

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## **Abstract**

This study explored the lived experiences of living non-couple donors who have donated kidneys to relatives for transplantation. Six individuals volunteered to take part in semi-structured interviews which were analysed using an interpretative phenomenological approach. Three themes evolved from the data; “I’ve got to be the donor”; “I don’t remember signing up for this, I thought it would be a doddle”; and “The transplant process is harder for the recipient.” Complexities in the decision making process were revealed. Some donors experienced significant and in some cases ongoing problems. Despite most of the donors reporting difficulties during the process, they were found to minimise problems due to a fear of preventing the transplant from going ahead or increasing feelings of guilt for the recipient. This appeared to contribute to the donors’ experience of a lack of care and support during the donation. Clinical implications and future research recommendations are discussed.

**Key words: donor, kidney, transplant, qualitative, interpretative phenomenological analysis (IPA)**

## Introduction

End stage renal disease is the final stage of chronic kidney disease when kidneys no longer function sufficiently to maintain life. Following kidney failure, patients require renal replacement therapy in the form of dialysis or kidney transplant. Transplants are the preferred treatment as life expectancy is generally increased, quality of life improved (QOL) and it is more cost-effective than dialysis (Landreneau, Lee & Landreneau, 2010; Tonelli et al., 2011; Poyntz, Lusuardi, & Price, 2010). In comparison to deceased donors, kidneys from living donors have been found to be slightly superior with improved patient graft and survival rates (Johnson, Bradbury, Martin & Neuberger, 2014).

The number of living donors in the UK has risen from 463 in 2004 to 1098 in 2013 (Johnson et al., 2014). Live donation accounts for one in three kidney transplants in the UK (National Health Service Blood and Transplant [NHSBT], 2014).

Through the strategic plan of NHSBT, the Department of Health requested that the living donor programme in the UK be increased by 20% by 2017 (NHSBT, 2012). In order to achieve this, there has been a focus on optimising transplant activity from living donors. If these targets are reached the number of living donors will increase significantly and therefore research involving them is vital.

Previous research has addressed the psychological impact of transplantation for recipients. Although transplants improve physical functioning and overall QOL in recipients (Burra & De Bona, 2007; Liem, Bosch, Arends, Heijenbrok-Kal & Hunink, 2007), improvement on psychological QOL has been found to be minimal or reduced in comparison (Landreneau, Lee & Landreneau, 2010; Overbeck et al., 2005). Prihodova et al., (2010) investigated the predictors of health related QOL in recipients following a kidney transplant and found psychological distress to be the best predictor of poor QOL.

Research into donors has produced mixed results. Clemens et al. (2006) conducted a systematic review including studies from America and European countries (one UK-based study). They found the majority of donors experienced no depression or anxiety and either no change or an improvement in the relationship between the recipient and donor. Some donors had increased self-esteem following donation. However, the studies included in the review were all quantitative in nature and the results for the 'majority' of participants were emphasised. They commented that in some studies a small number of donors had experienced difficulties post-donation. These included relationship separation and divorce, family conflicts, body image issues, feeling ignored and unappreciated, guilt, depression and anxiety. Although the number of cases was small, the identification and management of these individuals is of importance, particularly with the current UK strategy to increase live donation. More recent quantitative studies, mainly outside of the UK, continue to focus on the benefits to donors (e.g. Rodrigue et al., 2014; Clemens et al., 2011).

Tong et al. (2012) carried out a qualitative synthesis looking at the motivations and experiences of living donors. Their review highlighted the complexity of donating and the impact on donors' identity, role and relationships. Six UK studies were included in the synthesis with differing outcomes. Franklin and Crombie (2003) and Crombie and Franklin (2006) found there were psychological, social and cultural risks within the live donation process. Gill and Lowes (2008) used thematic analysis to explore the transplant process with both donors and recipients in the UK. Their study included 11 recipient-donor pairs, eight of which were married couples. The study found the donors derived 'immense personal satisfaction' with no detrimental impact on the relationship between themselves and the recipient. Analysis of the brother-sister pairing found variation in the decision making process, however this was not explored further. No unsuccessful transplants were included in the study. Another paper detailed the couples' experience and reported feelings of grief, loss,



suicide and depression (Gill & Lowe, 2009). Rana and Akoh (2010) collated postal questionnaires and found living donors to be generally satisfied with the donation process and likely to recommend it to others. The remaining two studies were carried out in the 1960s and 1980s and due to the advancements in treatment (see Davis & Delmonico, 2005) these studies were deemed unsuitable for discussion.

In light of the inconsistencies in previous research it was deemed beneficial to conduct a more in-depth qualitative study. The inclusion of both recipient and donor in the Gill and Lowe (2008) study might have prevented donors from sharing their genuine experience and therefore focus in this study was solely on the donor experience. Many participants in previous studies consisted of couples therefore the current study focused on other pairings to see whether there is any impact on their relationship that may not be understood in the same way as a romantic relationship. Lastly, this study looked to include participants who experienced both successful and unsuccessful transplants.

### **Study Aims**

The aim of this study was to explore in depth the perceptions, meanings and experiences of living non-couple donors who have donated kidneys to relatives or friends for transplantation. A focus on donors' experiences of the donation process had not previously been researched in North Wales despite three renal services covering a large geographical area. The study aimed to increase understanding of donors' experiences and highlight possible clinical implications in light of the expected increase in live kidney donation. Additionally the project aimed to help develop services, information and support for donors.

## Methods

### Design

This study adopted a cross-sectional qualitative design guided by an Interpretative Phenomenological Analysis (IPA) approach (Smith, Flowers & Larkin, 2009). IPA questions how individuals make sense of their personal and social world and seeks to gain insight into the meanings that events and experiences hold for people. IPA was deemed the most appropriate qualitative methodology due to the aim of exploring the personal meaning attached to the experience of being a kidney donor. The focus on the subjective as opposed to objective experience is essential in IPA and is what defines its ‘phenomenological’ nature.

Idiography is an important aspect of IPA as there is emphasis on gaining greater depth at an individual level, hence the smaller sample size compared to quantitative research. The participants play an important role in guiding the research process and outcomes. The aim is to explore their experiences resulting in a ‘bottom up’ process as opposed to applying rules, guidelines or theories in a ‘top down’ approach. The aim is not to provide a conclusive explanation of the experiences of all donors, rather it seeks to represent the possible responses to kidney donation by exploring the experience of relevant cases.

### Recruitment

Participants were recruited from two sites within Betsi Cadwaladr University Health Board (BCHUB)<sup>2</sup>. A fairly homogenous sample is required when using IPA (Smith et al., 2009) and because each of the participants had been through the process of kidney donation the sample was considered to be homogenous. Participants were recruited using a protocol by transplant specialist nurses (TSNs) between February 2015 and September 2015.

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<sup>2</sup> N.B. Pre and post donor care was provided by BCHUB however the procedure for each of the participants took place outside of BCUHB in other NHS establishments.

The criteria were:

**Inclusion:**

- Individuals who have donated a kidney to a recipient who is not their spouse/ partner (i.e. siblings, parents to children, adult children to parents, and friends).
- Adults (18 years +)
- No restrictions on gender and time since donation
- All participants to have received care from the National Health Service (NHS) within Betsi Cadwaladr University Health Board.

**Exclusion:**

- Individuals who have donated a kidney to a partner/ spouse
- Non-fluent English

Two TSNs each randomly selected ten living donors from their databases to contact. A telephone protocol was provided to ensure that individuals were not coerced to take part in the study. Donors who expressed interest in participating were sent further information in the post by the TSNs to maintain confidentiality. The information included an opt-in form to complete and return to the primary researcher (L.R.) should they wish to do so. Six participants were recruited which was considered an appropriate size for IPA (Smith & Osborn, 2003).

**Participants**

Four females and two males participated with an age range from early 20s to early 70s. Five participants had donated to their adult child and one had donated to their parent. All

participants lived in North Wales. The time since donation ranged from three to eleven years. Participants have been assigned pseudonyms to ensure anonymity.

### **Data Collection**

Individual interviews were conducted by L.R. with initial time spent discussing the limits of confidentiality, the interview process and building rapport with participants. Interviews were guided by a semi-structured schedule (see Appendix 1) as recommended by Smith and Osborn (2003). The purpose of the schedule was to guide the interview, however the priority was to gather data regarding the lived experience of the participant and therefore information which seemed pertinent to them was explored in more detail. Five participants were interviewed at home and one in a community hospital therapy room. Interviews were audio recorded, transcribed verbatim and analysed sequentially. Field notes were recorded during and after interviews regarding participants' non-verbal behaviour and the researcher's initial thoughts. The interviews ranged from 39 to 63 minutes. A protocol regarding risk for participant and researcher was followed and adhered to for each interview.

### **Data analysis**

IPA involves the identification of themes and then uses the researcher's interpretation of the information gathered to expand on these themes. IPA recognises that whilst a researcher attempts to understand how an individual makes sense of their experiences, this is complicated by the researcher's own preconceived values and ideas. Therefore the process of understanding is that of interpretation. The researcher is engaging in a 'double hermeneutic' as they are "trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003; pp. 51). Time and effort was allocated before, during and after analysis for the researcher to contemplate and reflect on her own thoughts and feelings regarding the research topic and process.

As recommended by Smith et al. (2009) the first stage of analysis involved reading and re-reading the transcripts several times in order for the researcher to become immersed in the data. A line-by-line analysis of each interview transcript was undertaken with descriptive, linguistic and conceptual commentary added. This led to abstract concepts being identified which were continuously compared to each other to develop emergent themes. Once themes had been identified for each transcript, through a process of abstraction, the researcher looked for commonalities and differences both within and between transcripts resulting in the development of super-ordinate themes. See Appendix 2 for a sample of analysis.

### **Quality**

This study applied a quality framework outlined by Yardley (2008; see Table 1). The use of a reflective diary was helpful for the researcher to recognise the context in which the research was being carried out and her impact on the analysis within that context. The researcher made an effort to recognise her own subjectivity during the process in order to try and maintain a focus on the original data. Input from another member of the research team (B.P.J.) enabled validity checks during the analysis process.

### **Ethics**

Ethics approval was gained from Bangor University School of Psychology Ethics Committee (see Appendix 3) and granted by North Wales NHS Research Ethics Committee (see Appendix 3). The research project was also subject to site-specific NHS R&D approval after the full review.

### **Findings**

Three super-ordinate themes each with sub-themes emerged from the data. Tables 2 and 3 provide a summary of the themes and example quotes.

## 1. “I’ve got to be the donor”

**Moral Imperative.** Five participants donated to their child. Some donors initially described the decision making process as being straight forward, without hesitation, with an “automatic” decision to donate to their child. When asked about his decision to donate, Robert said: “No, didn’t even think about it really.” The donors appeared to have no choice with regards to donating to their relative. Linda explained that this was not something she would do if it were not for her child: “You’re putting yourself in that position that you wouldn’t have done, you wouldn’t have been giving somebody a kidney [unless it was your child].” Linda reflected an awareness that she would not choose to go through with the donation if it were not her child, however her role as a parent meant she had to. The moral obligation, particularly as a parent to go through with this process for their child was apparent. Several of the parents spoke about their responsibility describing it as their “job” or the “natural thing to do.” Despite the moral imperative, some were able to speak openly about their “hesitation” regarding the donation and fears about the operation. Linda described a “slight hesitation” to donate due to being fearful about the procedure. For others it seemed more difficult to verbalise their concerns about themselves. Alison tried to convey that there was no reluctance to donate however she struggled to express the words:

There was no...no, you know what I am trying to say, I knew X (daughter) had to have a kidney so there’s no question, I was, you know, I was gonna do it and my husband was, yeah... (swallowing, holding back tears).

Discussing the decision making process was difficult for Alison and she was tearful throughout. She reported there was “no question” however it seemed that although she had come to a logical conclusion, she was struggling emotionally to accept this decision.

Describing how her husband was also willing to donate indicates her beliefs about their role as parents. The perceived moral duty as a parent to donate meant Alison had to mask any concerns about herself and focus on her child. It seemed in situations where a child is in need of a kidney, there was a lack of choice and freedom to make a decision for the donors.

**Sacrifice.** Alison described her duty to sacrifice anything for her child stating: “You’d do anything for your children wouldn’t you?” There was an expectation of parents that it was their duty to sacrifice anything for their children. Linda described using a process of self-talk to convince herself to go through with the donation:

[I] went home and then I saw [son] and I thought yes I can, yes I can, come on, you’ve had your life, you’ve done all the things you’ve want to do, come on, you can do this, so I did.

Linda speaks of the sacrifice she was making in order to give her son “life”. She recalls reflecting that she has had her “life” and now her duty is to give life to her offspring.

**Historical Context.** Mark was the only participant to donate to a parent. He spoke of his desire to want to donate and having to convince his parent to accept his kidney. Mark actively volunteering to donate meant the decision to go through with the procedure was placed with the recipient. Through further discussion it was revealed that Mark’s parent had previously received a kidney before from another family member. He discussed the process for them and how that impacted his approach to donation:

I knew my [family member] had done it and my [family member] is really hardcore, er she’s like Margaret Thatcher kind of thing, she’s really posh

and so if she did it in the 70's and then it was a big thing, like she had her ribs removed and stuff, dead hard core and I just remember thinking if she can do that then like it's no big deal.

Mark describes his family member as being “hardcore” and his perception was that his donation would be easier due to medical advancements. The context of another family member donating previously and being “stoic” during the donation seemed to result in an expectation on himself to donate and a requirement for him to cope effectively throughout the process. Similarly, Robert's child had received a kidney previously. Both Mark and Robert minimised the donation describing it as “no big deal” and “nothing.” This may have been their way of demonstrating their masculinity given the previous donors were female. It seemed their histories increased their sense of duty and expectation to cope well.

**Societal Expectation.** In addition to their own beliefs regarding donation, there was evidence of healthcare professionals' expectations of parents. For Joan the decision to donate to her child was taken by a consultant:

I just remember this appointment going to the appointment and I wasn't even sort of asked or anything about donating at that time but he, basically when I came out he said, “oh its erm its down to you really, he's gotta have a living donor, if he has this, you will be t-the donor you see” and I sort of didn't think about...I walked out and do you know what, I was in shock, I was thinking I hadn't gone in there with the intention of being the donor and I just totally, I just burst into tears.



The decision was taken away from Joan as she was his mother and therefore expected to donate. Joan later explained that she was able to come to the “logical conclusion” that it would be her. Joan appeared able to cognitively conclude that she should donate however emotionally it was difficult for her to process, which resulted in shock, distress and fears about the donation. The expectation as a parent was reflected back in some of the interviews whereby individuals asked whether the researcher would donate. Robert asked: “You know anybody would do it wouldn’t they, you would do it, have you got children?” Robert is clear that his views are expressed by everybody and therefore anyone with children would be expected to do the same thing.

The decision to donate is far more complex than might be assumed. The process may involve emotional distress, internal conflict and a pressure to do what is morally expected. This raises the question of who is advocating on behalf of the donors at this time, issues of informed consent, and how this process impacts on donors’ abilities to cope and adjust following donation.

## **2. “I don’t remember signing up for this, I thought it would be a doddle”**

Despite two of the donors reporting relative ease during and following the donation, all of them reported some difficulties.

**Loss.** There was a sense of loss throughout the process which differed for each individual. Mark tried to make sense of the experience of going into hospital healthy and becoming unwell:

Unless you’ve done something like that, you don’t know what it feels like to be healthy and then wake up feeling ill, ‘cause normally you go into hospital feeling ill and wake up feeling better so to do that the other way around it’s quite an odd experience.

He appears eager to express that his experience was unique and that others are not able to identify with it unless they have been through it. Mark's use of the word "odd" may indicate that he struggled to make sense of his experience. The "normal" experience in hospital whereby you go in unwell and health is restored is starkly juxtaposed with his experience of going in and losing his health. Sheila described a similar experience of loss of health and strength during the process.

Why didn't you ask the question, you know you're normally such a confident woman, why didn't you do that or why didn't you demand it or why didn't...it's like when you have a baby and, bit vulnerable, and you don't demand things as if you're healthy and strong.

She draws a connection between the donation process and her experiences of giving birth and described a sense of vulnerability. She experienced a loss of confidence and was unable to express her needs or wishes during the process. Joan, who described herself as being "scared" and a "big baby", echoed this vulnerability. Referring to herself as a baby, Joan indicated a need to be looked after and protected during the process. The loss of strength, health and control for some donors resulted in feelings of vulnerability during the donation process which may prevent individuals from requesting support as they would do in other circumstances. Linda stated:

[Husband] said I sat for nine days doing nothing and that's not me, I've never sat for nine days and done nothing never, all the time I just sat there and then I'd sit in the chair there [points to chair] and then I'd move there [points to another chair] but I would hobble around because of it felt like I'd got a concrete block, that's how it felt, that whole section [frames side of body with hands] nothing, there was no feeling, nothing

She begins by describing an overall loss of functioning, being unable to carry out activities in her home as she usually would. Linda recalls information through what her husband has told her, suggesting a possible disconnection from herself at that time. It seemed she was unable to relate to herself as she described her behaviour at that time as “not me”. The use of the word “concrete” suggested a heaviness of the “block” she experienced inside of her. This description encapsulates her experience of being physically weighed down and unable to move during that time. She contrasts this physical, tangible experience of an object inside her with the feeling of emptiness and loss. It seemed her loss of self after the donation resulted in an inability to relate to herself at that time.

**Physical impact.** All donors reported a physical impact. Two described feeling uncomfortable following the operation, however this was expected and they found the recovery to be fairly quick. For others there was unexpected pain and additional difficulties. Alison spoke of being surprised at how long it took to recover: “I thought, oh I’ll be out in about two days, I was still in bed by Thursday I hadn’t got up at all, I was really ill, really ill.” The repetition of “really” emphasises how unwell she felt post-operatively.

Mark recalls the physical challenges once he returned home from hospital: “Just the physical like just really painful to get in and out of bed that was just a nightmare and all that kind of stuff and getting upstairs was sore and all that kind of stuff.” His description of the experience as a “nightmare” reflects an unpleasant or perhaps frightening time for him. Mark had described his desire to leave hospital and recover quickly. This expectation may have been due to the historic context of the other family member’s “easy” recovery. He went on to reflect that pushing himself to recover quickly may not have been helpful: “I think in retrospect maybe I pushed myself a little bit too fast maybe I should have stayed just one night in hospital extra.” Mark seems to have awareness that his physical recovery may have

needed more time than expected and having the extra support in hospital would have benefited his recovery.

**Adjustment.** The emotional impact of donating was discussed with most of the donors. Some experienced minimal difficulties throughout the donation process and encouraged others to donate. Robert stated: “[I] would tell anybody, just go ahead and do it.” Others spoke of the challenges of donating. Mark spoke about the ability to prepare physically but being unable to prepare emotionally: “It’s hard, it’s you know your, emotionally I don’t think you really can prepare for it to be honest, the actual, not the all the mental stuff, just the physicality of it.” He describes the process as “hard” and goes on to say he had prepared for the physical impact however perhaps was not prepared for how mentally challenging the donation would be.

Alison also recognised the contrast between her physical and emotional recovery. When asked whether she felt different following the donation she replied: “No, not physically, maybe mentally” [R: how mentally?] more sensitive, for some reason (tearful), I dunno...but not physically, I’m ok, back to normal.” She became tearful following her description of being more sensitive following the donation but then appears to reassure herself by focusing on physically how she is back to normal.

There seemed to be a marked point in time for some of the donors who spoke about the differences before and after donation. It was speculated and confirmed by Shelia that this may have been a trauma reaction: “It’s difficult to know, it’s quite strange when something traumatic happens to your life you think about life pre, date [hits table] and after [hits table] that date, it’s quite strange that.” Sheila spoke of the donation as being a “traumatic” event that happened to her life leaving her feeling split between two time periods. This was similar for Alison who reported the experience as still feeling real despite the time that had passed.

She stated: “it’s [number] years ago and it’s still real.” It seemed that some donors had been unable to emotionally process the experience around the time of the donation and the emotional impact continued to be experienced years after donation.

In addition to the difficulties adjusting emotionally following donation, Linda described problems with body image: “I didn’t feel that whatever was going on the body was not adjusted to it.” Her description of “the body” highlights a disconnection from herself at that time. Linda found it difficult to adjust to the removal of her kidney. Speaking about the wound she stated: “Couldn’t touch it, couldn’t look at it... it didn’t belong, that piece didn’t belong.” There was a strong feeling that it didn’t belong and a sense that she felt uncomfortable in her own skin. She described the impact this had on her relationship with her husband:

It’s that invasion I think, all that poking and prodding and yeah erm I went through a stage I couldn’t stand X (husband) anywhere near me, nobody no kissing no cuddling, no sex, no nothing, nothing for a whole year I think it’s been, or was.

She described the process of donating as an “invasion”, conveying a sense of a lack of control over her body and a feeling of unwanted intrusiveness. She was unable to tolerate any physical contact for a significant period following the donation. At the end of the extract she states “it’s been, or was” which suggests although there may have been improvements over time she continues to struggle with accepting what has happened and the changes to her body. There appeared to be frustration when asked to comment further on the feeling of invasion as she pointed to her head and said “they don’t tell you about that” referring to the lack of consideration for the mental and emotional impact of donating.

This theme captures the physical and emotional difficulties experienced by the donors during the donation process and following the operation. Loss of health, functioning and sense of self during the donation and difficulties adjusting following were experienced by them.

### **3. “The transplant process is harder for the recipient”**

**Dismissive of self and needs.** Despite the emotional, mental and physical impact for the donors detailed in the previous theme, it was apparent that the donors were dismissive of their own difficulties and need for support. Their attention was clearly focused on the recipient throughout the process. Two of the participants downplayed the operation and donation describing it as “nothing”. Similarly some donors dismissed complications following their surgery. Alison stated: “I had a bit of complication after the surgery.” Followed by: “well it was just internal bleeding.” There appeared to be a need to minimise their difficulties in relation to the recipient with the use of “just” and “a bit”. Shelia recalled it being “all about him [recipient]” with a belief that the process was more difficult for the recipient, stating: “it was harder for him isn’t it, harder for him wasn’t it, bless him.”

There appeared to be a constant focus on the recipient and a disregard for themselves during the donation.

I didn’t really think about me after that it was all just, you know, getting him through it really and erm..I never thought about me at all to be honest it was all just focused on him and I can’t can’t say I thought...can’t really think of anything- Joan

The donors themselves viewed and rejected their needs as unimportant. Some donors were critical of their difficulties and reported a requirement to cope independently. In a discussion with Alison regarding accessing support for feeling overwhelmed by her emotions,

she stated: “I haven’t talked to anyone about it, ‘cause I just feel silly.” Similarly, Linda described herself as “ridiculous” for struggling to adjust post-operatively.

The process of minimising problems, dismissing their own needs and focusing on the recipient may have been reflective of their role (i.e. being a parent). The donors appeared to take responsibility to ensure that the transplant went ahead as planned and therefore they were reluctant to share any concerns through fear this would delay the process. Mark stated: “I think because also it might be as my mum had waited for so long I just wanted to make it as easy as possible for it, I didn’t want anything that I said to hold anything up.” Linda recalled a similar experience: “I remember thinking I’ve got a sore throat but I can’t say anything to anybody...I didn’t want to delay anybody or delay anything.”

There seemed to be an awareness of the recipient having feelings of guilt in relation to their loved one donating to them. Shelia spoke about her child not wanting her to donate to him: “I mean I could understand why he was like that with me ‘cause of the guilt, I could understand that.” It seemed that this understanding of the recipient’s feelings of guilt led to a desire to appear “fine” in order to minimise any worry or guilt for the recipient.

There appeared to be a drive for the donor to present as “fine” initially to enable the process to go ahead as quickly and easily as possible. Following the donation there is a need to continue this presentation in order to reduce any feelings of guilt or worry for the recipient.

**Lack of support.** Most of the participants described feeling overlooked by healthcare professionals and their family. As discussed above, it is possible that the donors minimised their difficulties or did not express them at all. This appeared to result in an underlying assumption from both the donor themselves and others that the recipient was more important and therefore required more care and attention.

They didn't have a place for me...when we got there on the Sunday evening they had a place for [son] on the on the renal unit but they didn't have a place for me so they put me on...the elderly [ward]. -Linda

Linda expressed feeling scared as she felt no one was looking after her or knew why she was there which resulted in her not being able to sleep the night before. Alison described a similar feeling of being "forgotten about" and she recalled feeling like "they didn't give me much attention." Several donors reported a sense of pressure to recover and leave the hospital quickly following the donation. Alison recalled the hospital staff being "determined to get me out of bed" and felt she was dismissed when she reported feeling unwell: "They weren't listening to me, I I told them I wasn't feeling well...they tried to get me out of bed and I was pfff on the floor."

The expectation from donors and healthcare professionals that recovery would be quick and uncomplicated may have led to the difficulties experienced by some following donation. Linda recalled a focus from her family and healthcare professionals on her physical recovery. She summarised their attitudes as: "As long as you look alright that's fine." There appeared to be a focus from healthcare professionals on the donors' physical recovery and a disregard for their emotional experiences.

Linda discussed an interaction with a male consultant who she felt did not understand her difficulties regarding body image. She gained weight following the donation and believed it was due to water retention. She mentioned this to the consultant who she described "poo poo'ed it a bit." Linda expressed her frustration about the physical changes not being discussed prior to the donation and consequently being unprepared for them: "He [consultant] never said anything about that."



Following donation Mark also described being surprised at the interactions with healthcare staff. Although not sure what to expect, he felt the follow-up checks were brief:

I think when I went for the six month check I think, I think I was a bit surprised at how like not a check it was really if that makes sense...He looked at the scar and then he said “yeah that’s fine” and that was it really so I dunno what I expected.

Despite not knowing what to expect he recalled feeling dismissed and unimportant during the check, with a focus on the physical recovery of the scar.

### **Discussion**

This research aimed to explore the experiences of living donors in North Wales. Previous quantitative studies have reported positive outcomes for donors such as increased self-esteem and improvements in relationships (Clemens et al., 2006). Qualitative studies have highlighted the complexities of donating a kidney with some individuals experiencing psychological difficulties. This study echoed these mixed results with some individuals reporting minimal post-operative difficulties whereas others described significant problems in relation to being a donor.

This study highlights the challenges involved in the donor decision-making process within a family. The donors spoke of their responsibility as a parent or child to donate to their loved one despite having reservations about the process. Russell and Jacob (1993) suggest potential donors are in a ‘no-win’ situation as they may regret the decision not to donate or, if they donate, may regret the loss of an organ or not having the opportunity to decide with no pressure. Eggeling (1999) found that although donors wanted to help family members, there was a sense of obligation in the process. A recent study has found that feeling morally obligated to donate was a predictor of depressive symptoms following donation (Jowsey et

al., 2014). However, some of the individuals in the current study described the automatic decision to donate with no moral dilemma. This was described by Machado (1998) as being a spontaneous feeling of doing what is evidently right. Crombie and Franklin (2006) conclude that the parent-child relationship is more predictable than other relationships as the donation is seen as “a natural action within the framework of kinship obligations” (p.209). The majority of donors in this study were parents and some spoke of the donation being the natural thing to do.

Despite the transplant procedure being known as more painful for the donor than the recipient (Crombie & Franklin, 2006), our study found the donors themselves to be dismissive of the process. Donors masked their physical, emotional and mental difficulties due to a fear they would prevent the donation or add to the recipient’s guilt. Previous research has reported on the presence of guilt for recipients due to accepting a donation from a family member (De Groot et al., 2012; Schipper et al., 2014). It is thought that the donors keep silent in order to protect their loved one and that relationship. This appeared to be reinforced by their perceived lack of care from family members and healthcare professionals. A lack of care has been reported as a contributing factor for post-donation depression (Sharma & Enoch, 1987). Some donors in this study reflected on going into hospital ‘healthy’ and this may have also contributed to them feeling unable to ask for support and why they were given little medical attention.

Following donation some of the participants experienced difficulties with adjustment. They spoke of the contrast between physical and mental recovery which is often overlooked in post-donation medical follow up as the focus is solely on physical recovery. Donors appeared better adjusted to the physical aspects compared to the psychological aspects of donation. It is hypothesised this is due to better preparation by healthcare staff for the physical outcomes of donating. This study was consistent with previous research in that

donors were found to experience feelings of loss (Andersen et al., 2007) and may have a worse perception of their own general health following donating (Tellioglu et al., 2008). One participant spoke of ongoing difficulties with body image - an important area that is currently lacking in research. In contrast, some participants experienced no difficulties following donation and went on to recommend others to follow in their footsteps. This contrast is apparent in previous research (Tong et al., 2012) and may be explained by the success of the donation, a quicker recovery and individual differences.

### *Limitations and Further Research*

A limitation of this study is the lack of variety in the relationships between donors and recipients. The aim was to recruit non-couple donors including siblings, friends and altruistic donors, however as the recruitment was randomised within the target population the participants were mainly parent-child relationships. That said, parent-child donations are important to understand because they form a large proportion of donors (NHSBT, 2014). However, further research may look to include non-blood relations in order to look for similar and differing themes.

This study was cross-sectional and therefore a donor's experience was that of one time point following donation and their accounts were based on memories. Further research may look to do a longitudinal design in order to explore the changes throughout the process in more detail and capture the experiences of living donors before, during and after donation.

Further research is required to understand the predictors of psychological difficulties following donation in order to assist healthcare professionals in their assessment and identification of individuals who may be more at risk.

### *Clinical implications*

This study highlighted the potential difficulties for some living donors throughout the transplant process. The decision to donate to a family member is complex. The familial dynamics involved appeared to heavily influence an individual's motivation to donate and this may impact on a donor's freedom of choice. Therefore, in order to gain informed consent, this process requires further consideration and guidance for donors. Previous suggestions of 'donor advocates' (Tong et al., 2012) who are independent from the recipient assessment team may enable potential donors to speak to somebody who is not involved in the donation process.

There appeared to be frustration from donors regarding the lack of recognition of the emotional impact of donating. Information and preparation regarding the potential emotional difficulties may be useful to bridge this gap. Information from this research may be utilised to better inform donors of the potential psychological impacts of donating with the aim to better prepare potential donors. It is hoped that better preparation of the psychological aspects of donating will enable donors to better adjust to potential difficulties. Improving access to psychological support prior to, during and following the donation process is likely to prevent some of the difficulties in adjustment experienced by some donors in this study.

A number of barriers were apparent which may prevent a donor sharing their concerns throughout the process. Increasing healthcare professionals' awareness of potential barriers for donors to report difficulties and access support is essential for them to adequately manage families under their care. Enquiring about emotional coping and recovery as opposed to solely physical aspects of care may result in donors sharing more information. Awareness of the donors' fears of preventing the transplant if they share concerns may allow clinicians to offer reassurance and promote openness of emotional experiences during the process.

## *Conclusion*

This study explored the experiences of living non-couple donors and found: complexity in the decision-making process; psychological difficulties during and following donation for some individuals; and a perception from donors that there was a lack of support during the process. Additional information and further preparation during the assessment of donors is required. Access to psychological support and independent advocates in addition to raising clinicians' awareness of the barriers that prevent donors sharing difficulties may help to prevent problems following the donation. It is hoped that this research demonstrates the complexities of kidney donation to a family member and can be utilised to raise awareness in the field of renal transplantation. Further research is required to understand other donor-recipient relationships and to identify individuals who may be more at risk of experiencing psychological difficulties during donation.

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## **Journal Statement Requirements**

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The Author(s) declare(s) that there is no conflict of interest

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**Table 1. Quality Framework: Characteristics of good qualitative research (adapted from Yardley, 2000)**

Principal	Description
Sensitivity to context	<p>Theoretical: Extensive grounding in the philosophy of the approach adopted.</p> <p>Relevant literature &amp; empirical data: Awareness of the relevant literature and previous relates empirical work.</p> <p>Sociocultural setting: Awareness of the socio-cultural setting of the study (e.g. the normative, ideological, historical, linguistic and socio-economic influences on the beliefs, objectives, expectations and talk of participants and researcher themselves).</p> <p>Participants' perspectives: The design of the study should incorporate consideration of the general and specific effects of the researchers' actions and characteristics (e.g. gender)</p> <p>Ethical issues: Careful consideration of the participants at each stage of the design, analysis and reporting of the study.</p>
Commitment and rigour	<p>In-depth engagement with topic: Prolonged engagement with the topic to be researched.</p> <p>Methodological competence skill: Development of competence and skill in the methods used and immersion in the relevant data.</p> <p>Thorough data collection: The completeness of the data collection and the interpretation (e.g. addressing all variation and complexity observed, undertaking analysis at several levels).</p> <p>Depth/breadth of analysis: This may include gathering data from a number of sources or using "triangulation" of data analysis.</p>
Transparency and coherence	<p>Clarity and power of description/argument: Clarity and contingency of the description and argumentation. The function of the story is not to describe but to construct a version of reality.</p> <p>Transparent methods and data presentation: Detailing every aspect of the data collection process and the rules to code data. Presenting excerpts of the textual data for readers to discern patterns identified during the analysis.</p> <p>Fit between theory and method: The 'fit' between the research question, the philosophical perspective adopted and the method of analysis and investigation undertaken.</p> <p>Reflexivity: Openly reflecting on how the researchers assumptions, intentions and actions may have affected the product of the research investigation.</p>
Impact and importance	<p>Theoretical (enriching understanding): Drawing on empirical data to present a novel, challenging perspective, which opens up new ways of understanding a topic.</p> <p>Socio-cultural: Consideration that <i>all</i> our speech and actions arise from a particular social context, serve some social purpose and have some social effects. Awareness of individuals experiences being altered by research which contributes to a change in the way <i>we</i> think or talk about health.</p> <p>Practical (for community, policy makers, health workers): Emphasis on providing a close 'fit' between research and practice.</p>

**Table 2. Super-ordinate Themes, Sub-themes and descriptive summaries**

Super-ordinate Theme	Sub-theme	Descriptive Summary
<b>“I’ve got to be the donor”</b>	<i>Moral Imperative</i>	Describes the lack of choice for donors due to the moral duty they experience as a parent or child to donate to their loved one.
	<i>Sacrifice</i>	Captures the donors’ experience of sacrificing their own needs for the recipients.
	<i>Historical Context</i>	Describes how individuals’ histories and the context around the donation impacted their responses to their loved one needing a kidney.
	<i>Societal Expectation</i>	Discusses the donors’ experiences of the expectations of others regarding parent/child donation.
<b>“I don’t remember signing up for this, I thought it would be a doddle”</b>	<i>Loss</i>	Conveys the donors’ loss of health, functioning and sense of self during and following the donation process.
	<i>Physical Impact</i>	Captures the donors’ expectations and reality of the physical impact of donating.
	<i>Adjustment</i>	Outlines the difficulties in adjusting that donors experienced following donation.
<b>“The transplant process is harder for the recipient”</b>	<i>Dismissive of self and needs</i>	Describes how donors’ are dismissive of the procedure and their need for support during and following the donation. Their focus is on the recipient. The donor presents as ‘ <i>fine</i> ’ in order to ensure the process goes ahead and to prevent guilt for the recipient.
	<i>Lack of Support</i>	Captures the donors’ experience of healthcare professionals, family and society. Donors reported feeling unsupported by healthcare professionals during and following the donation.

**Table 3.** Themes with Example Quotes

<b>Super-ordinate Theme</b>	<b>Sub-theme</b>	<b>Example Quote from Individual Transcripts</b>
<i>“I’ve got to be the donor”</i>	Moral Imperative	<p><b>Linda:</b> You’re putting yourself in that position that you wouldn’t have done, you wouldn’t have been giving somebody a kidney</p> <p><b>Alison:</b> Something I had to do (breath out) er I was quite pleased that it to be honest I think it was er (stumbling) I was glad it was me and not my husband”</p> <p><b>Shelia:</b> That’s your job, the good and the bad</p> <p><b>Joan:</b> I just burst into tears and am thin- (surprised raised voice:) ‘oh my god I’ve gotta be the donor’</p> <p><b>Robert:</b> I just you know if it was for my next door neighbour then well hang on that’s that’s different isn’t it but for your son, or your daughter or your wife or your brother or your sister I would just I would do it</p> <p><b>Mark:</b> I just felt you know I had to just do it</p>
	Sacrifice	<p><b>Shelia:</b> It’s your son isn’t it, he shouldn’t be there, [it] should be me not him</p> <p><b>Joan:</b> I just basically said to him you know, X (son) is my first priority and you know, second place” [in reference to her partner]</p> <p><b>Alison:</b> You’d do anything for your children wouldn’t you?</p> <p><b>Linda:</b> [I] went home and then I saw [son] and I thought yes I can yes I can come on you’ve had your life you’ve done all the things you’ve want to do come on, you can do this, so I did</p> <p><b>Linda:</b> I don’t think anybody wants to die do they?</p>
	Historical Context	<p><b>Mark:</b> I dunno like maybe it was because my [family member] had done it and she was fine when it was far more hard core</p> <p><b>Robert:</b> Because he’d had one before and that worked, you just assume it’s going to work</p>

Super-ordinate Theme	Sub-theme	Example Quote from Individual Transcripts
<p><i>“I don’t remember signing up for this, I thought it would be a doddle”</i></p>	Loss	<p><b>Mark:</b> Unless you’ve done something like that, you don’t know what it feels like to be healthy and then wake up feeling ill, cause normally you go into hospital feeling ill and wake up feeling better so to do that the other way around it’s quite an odd experience.</p> <p><b>Shelia:</b> Why didn’t you ask the question, you know you’re normally such a confident woman, why didn’t you do that or why didn’t you demand it or why didn’t...it’s like when you have a baby and, bit vulnerable, and you don’t demand things as if you’re healthy and strong.</p> <p><b>Joan:</b> I’m a big baby when it comes to me.</p> <p><b>Linda:</b> I used to hobble around trying to stand up straight, didn’t do a lot, couldn’t peg out washing, couldn’t Hoover, not for three months</p> <p><b>Alison:</b> I had to have blood and that was quite disappointing because I used to donate blood before and I can’t now, so that’s one thing that’s really upset me.</p>
	Physical Impact	<p><b>Alison:</b> I thought oh I’ll be out in about two days, I was still in bed by Thursday I hadn’t got up at all, I was really ill, really ill.</p> <p><b>Mark:</b> Just the physical like just really painful to get in and out of bed that was just a nightmare and all that kind of stuff and getting upstairs was sore and all that kind of stuff.</p> <p><b>Shelia:</b> waking up for the first time, pain free, amazing [clicks fingers] just like that, it felt [clicks fingers] like that, erm..and I thought god this is easy, this is easy.</p> <p><b>Joan:</b> [the wound] was really sore.</p> <p><b>Robert:</b> you were in pain but for what I’ve done what the hell its only gonna be few, only gonna be a few days.</p>
	Adjustment	<p><b>Mark:</b> It’s hard, it’s you know you’re, emotionally I don’t think you really can prepare for it to be honest, the actual, not the all the mental stuff, just the physicality of it.</p> <p><b>Shelia:</b> I was healthy but maybe mentally I wasn’t, you know, bit all over the place maybe</p> <p><b>Alison:</b> No, not physically, maybe mentally [R: how mentally?] more sensitive, for some reason [tearful], I dunno...but not physically, I’m ok, back to normal.</p> <p><b>Linda:</b> I don’t think I’m quite the same person either...I don’t know if it’s in my head cause I think perhaps I shouldn’t be, but I don’t think I am the same person.</p>

Super-ordinate Theme	Sub-theme	Example Quote from Individual Transcripts
<p><i>“They didn’t give me much attention”</i></p>	Dismissive of self and needs	<p><b>Alison:</b> I had a bit of complication after the surgery.  <b>Joan:</b> When I woke up I did erm pass out, I can’t remember why they said, and I had to have oxygen but it was, erm..it was just one of those things after.  <b>Shelia:</b> I hope he’s ok and I wish he could see me now because he’s worried about all this and I’m fine!  <b>Mark:</b> I think because also it might be as my mum had waited for so long I just wanted to make it as easy as possible for it, I didn’t want anything that I said to hold anything up.  <b>Linda:</b> I remember thinking I’ve got a sore throat but I can’t say anything to anybody and I was scared to say that I’d got a sore throat but I think it was just anxiety, I didn’t want to delay anybody or delay anything.</p>
	Lack of support	<p><b>Alison:</b> I felt there wasn’t a ward just for the donors, it’s it’s mixed so er...that’s the only thing I did feel they, they didn’t give me much attention.  <b>Linda:</b> [Consultant] said ‘you should be out of here, you shouldn’t be here’  <b>Mark:</b> He looked at the scar and then he said “yeah that’s fine” and that was it really, so I dunno what I expected.  <b>Shelia:</b> I mean when you watch Holby City [laughs] it’s quite funny really because she gave a kidney to her mum I think it was, and it was just one blood test and off she went!</p>

## Appendix 1: Interview Schedule

### Interview questions for Donors

There are 6 areas to include in the interview listed below. The initial question will be asked and further questions are listed to prompt the researcher if necessary (i.e. if participant is not forthcoming with information). It is hoped these questions will not be required as the initial questions will facilitate the discussion. Although listed in an order, the researcher will be flexible and may not need to ask questions if the topics are initiated by the participant.

**1. Initial Question – Please can you talk me through the decision making process prior to donating?**

*(Prompt questions only to be used if needed)*

- How did the situation arise for you to be asked/ offer to donate?
- How did you make the decision to donate? What factors did you consider?
- What emotions did you feel in the decision making process?
- How long did the decision making process take for you?
- Was there any barriers/ obstacles which made the process difficult? What helped you overcome these barriers?

**2. Initial Question – Please can you talk me through your experience during the transplant?**

- How were you prepared for the operation?
- How did the operation go?
- What were the problems/ complications during the transplant, if any?
- How did you feel immediately before the operation? Immediately after the operation?
- How long did it take to recover from the operation?

**3. Initial Question – How were things for you following the transplant?**

- What emotions did you feel following the transplant?
- How did the operation have an impact on your life?
- Were there any problems or difficulties following the transplant?
- Was there anything about the process that surprised you?

**4. Initial question- What is the relationship between yourself and the recipient? What has been the impact on your relationship through the transplant process?**

- Whose suggestion was it for the transplant?
- How was your relationship affected during the decision making process?
- How has the relationship changed at all following the transplant?

**5. Initial Question –What was your experiences of the services throughout the process?**

- What was your experience of the transplant service prior to the transplant?
- What, if anything, do you think could have helped when making the decision?



- During the transplant what contact did you have with the service, if any?
- Following the transplant what contact with the transplant service, if any?
- What would change about your experience with the transplant service, if anything?

**6. Initial Question – How has the transplant process impacted the way you think or feel about yourself?**

- Have you noticed that you feel different about yourself since the process?

## Appendix 2: Data Analysis Example

Emergent Themes	Original Transcript	Initial Notes & Exploratory Comments
<p>Trauma Loss of identity Illness/ loss of health Numbness-lack of feeling vs heaviness Feeling different</p> <p>Disgust -Body Image Disconnection from self Emptiness – loss Adjustment Physical changes Lack of understanding from consultant Others - Dismissive Making sense of experience Using medicine/ logic to make sense</p>	<p>R: When you talk about recovery, just so I know what you mean by it?</p> <p>P: Erm, (breath out) X (<b>husband</b>) <b>said</b> I sat for nine days doing <b>nothing</b> and <b>that's not me</b>, I've <b>never</b> sat for nine days and done nothing <b>never</b>, I'm and all the time I can- just sat there and then I'd sit in the chair there (points to chair) and then I'd move there (point to another chair) but I would <b>hobble around</b> because of it felt like I'd got a <b>concrete block</b> that's how it felt, that whole section (frames side of body with hands) <b>nothing</b>, there was <b>no feeling, nothing</b></p> <p>R: Right</p> <p>P: Erm... <b>couldn't touch</b> it, <b>couldn't look</b> at it, couldn't...didn't have a shower for ages cause I wanted it to heal but when it had healed <b>couldn't stand touching it</b> to wash it, it <b>it didn't belong</b>, that <b>piece didn't belong</b>, didn't want to look at it either so I don't know what that's about (small laughter/ slight despair) but it just felt if anybody said <b>felt like a concrete</b>, carrying a concrete block, its <b>heavy and numb and nothing, didn't belong</b> erm ... also I've <b>put on weight</b> but that might be my age see as well so erm I like I felt like it was water retention, and I I said that to [Consultant] and <b>he's a man</b> isn't he so he <b>poo poo'ed it a bit</b> erm but I didn't feel that whatever was going on <b>the body was not adjusted to it</b>, does it take that two years to get adjusted to having one, after both my kidneys worked fifty percent, some work thirty some work seventy</p> <p>R: Ah ok</p>	<p>Initial Notes &amp; Exploratory Comments</p> <p>Refers to her husband informing her, not able to remember herself, trauma. 'not me'- identity, not able to recognise herself, mismatch, not able to relate to herself at that time. Specificity of '9', repetition, duration. 'Hobble'- illness related word, feeling old, unable to do anything, weak, restricted, loss. Metaphor – 'concrete block', heavy, stuck, ugly. Contrast of physical heavy object and feeling of 'nothing', empty. Body language expressive – pointing, framing.</p> <p>Repetition – couldn't, unable, impossible, disconnection. Disgusted with wound, not showering- not washing-not taking care of self. 'Piece' description of body, jigsaw, not fitting. Don't know – confusion, remains unable to make sense of her experience. 'Carrying' - weighed down, burden, numbness, nothing, loss, sadness. Not 'belonging' – rejection, unable to accept, realisation, adjustment. Contradiction - heavy-nothing. Changes to physical appearance – weight gain, heaviness, changes, trying to make sense. Consultant- dismissive, gender – not able to understand, not heard, lack of recognition, support. 'the body' – disconnect from her body, not belonging. Unable to adjust to the removal of her kidney. Trying to make sense of the science, why she isn't able to adjust, accept.</p>

<p>Loss of kidney function Inability to function Physical vs emotional aspects Adjustment Future impact on use of healthcare services</p> <p>Invasion – Trauma Impact on relationships Ongoing difficulties Body image Intimacy Adjustment</p>	<p>P: Both of them <b>worked fifty percent</b> and were <b>equal in size</b> erm the reason they took the left one was because it had a small kidney stone in it so they gave that to X (son) cause of the condition of his disease <b>so my body has now lost fifty percent</b> hasn't it of...<b>whatever it does</b> filtering everything so...no I used to <b>hobble</b> around erm <b>trying to stand up straight</b>, didn't do a lot, <b>couldn't</b> peg out washing, <b>couldn't</b> Hoover, no for three months. I <b>couldn't stand X (husband) coming near me</b> I just did not want anybody to touch that section (framing side of body) the thought of having to go to hospital even to the dentist, it it's not something I like doing anymore, cause I <b>don't want to be poked and prodded</b> erm</p> <p>R: And why is that?</p> <p>P: It's that <b>invasion</b> I think, all that poking and prodding and yeah erm I went through a stage I <b>couldn't stand X (husband) anywhere near me</b>, nobody no kissing no cuddling, <b>no sex, no nothing, nothing</b> for a whole year I think <b>it's been or was</b></p>	<p>Loss of kidney function, trying to understand her difficulties with recovery. Regret? Unsure, confusion of biological aspects. Repetition of 'hobble', unable to stand straight, loss of functioning, daily activities. The 'thought' of going to see healthcare professional, distress. Description focuses on physicality of procedure, not wanting to have contact with medical settings is associated with loss of control, having things done to her. Clear information regarding her needs – not wanting physical contact. Sensitivity.</p> <p>'Invasion' – unwanted, experimented on, coercion, lack of control. Invasion into her life, privacy, impact on relationship. Disgust with her body, rejection, traumatic experience –strong emotion 'couldn't stand', impact on intimacy. Difficulties with body image? 'Been or was' – ongoing difficulties, still affected by emotions, not fully adjusted.</p>
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R= Researcher; P= Participant

**Note.** This table displays an extract from a transcript (middle column) alongside initial notes and idea as an immediate reaction to the data (right hand column). This led to ideas being incorporated resulting in emerging themes (left hand column).

### **Appendix 3: Ethics Submission Documents**

- 1. IRAS Form**
- 2. Research Protocol**
- 3. Participant Information Sheet**
- 4. Opt-in Form**
- 5. Consent Form**
- 6. Nurses Telephone Protocol**
- 7. NHS REC Approval Letter**
- 8. R&D Approval Letter**
- 9. Bangor University Approval**

### **Paper 3: Contributions to Theory and Practice**

## **Contributions to theory and practice**

The aim of this final paper is to integrate the findings from the literature review and empirical study in order to consider their impact both in research and clinical fields. Both papers are centred around the transplant process and the impact on recipients' and donors' quality of life. The literature review focused on the impact on sexual functioning in female recipients following a kidney transplant (KTx), whereas the empirical paper was concerned with the donors' experience of the transplant process. Previous research focuses on the physical aspects of donating and receiving a KTx with positive results (Burra & De Bona, 2007; Liem, Bosch, Arends, Heijenbrok-Kal & Hunink, 2007; Clemens et al, 2011). Therefore, the focus of these two papers was to address the more psychological aspects of receiving and donating a kidney. Kidney transplantation is regarded as the gold standard in regards to renal replacement therapy (Lee & Tang, 2007) as it is associated with lower mortality and quality of life (Tonelli et al., 2011). Living donation is slightly superior to cadaveric (deceased) donation with improved patient graft and survival rates (Johnson, Bradbury, Martin & Neuberger, 2014) and therefore UK government strategy aims to increase living donation (NHSBT, 2013). With that in mind it is important to understand all aspects of the transplant process for both the donor and the recipient in order to assist in informing services how they can best support individuals. The remainder of the paper is divided into three sections; 1) contributions to theory and recommendations for future research; 2) clinical implications; and 3) personal reflections on the research process and outcomes.

### **1) Contributions to Theory and Future Research**

The literature review focused on one specific aspect of quality of life in female recipients; sexual functioning. Previous research has neglected this area due to its complexity. The literature review highlighted several methodological issues with the studies such as small sample sizes, inappropriate use of measures and lack of control over potentially confounding

variables such as age and co-morbidities. Prevalence rates varied across studies and with the methodological issues it was difficult to draw conclusions from the findings. Future research must address these limitations and aim for studies with methodological rigour.

The majority of the studies in the literature review were carried out in predominantly Muslim countries. The sexual practices and traditions of people in predominantly Muslim cultures will differ from those in more liberal Western cultures and therefore the findings cannot be generalised. Noohi et al (2010) touched on the difficulties for the females in their study to talk about sex due to cultural and religious issues. Sex and sexuality is viewed differently depending on the culture and social constructs of a society. For example, in some African countries where the desire for children is very high, sexuality is linked closely with fertility and sex is viewed as a means to create life. This differs hugely from Western cultures whereby the desire for children is less and contraception is used to control fertility resulting in sex being viewed as free, open and conceptually separate from fertility (Caplan, 2013). Cross-national studies have found that Muslims and Hindus have more conservative sex-related attitudes than Christians (Finke & Adamczyk, 2008). Other research has found that Muslims are less likely to have premarital sex compared to Christians (Addai, 2000, Agha, 2009). These differences will shape the sexual attitudes and behaviours of individuals and therefore results cannot be generalised across cultures. There is lack of research regarding female sexual functioning following a KTx in Western cultures and so future research needs to address this gap. It is necessary for future research to include more information on participants' religious and cultural backgrounds in order to understand the relationship between beliefs, attitudes and sexual functioning in female KTx recipients.

The review highlighted that problems with sexual functioning may persist following KTx. The nature of the problems and factors impacting sexual functioning is unclear and therefore current methods of measuring outcomes using quantitative methodologies is

insufficient. One study (Muehrer, Keller, Powwattaa & Pornchaikate, 2013) included qualitative methods that highlighted difficulties which were not included in sexual functioning measures (e.g. decreased energy levels, body image issues). This highlights the usefulness of using inductive qualitative methods to reveal underlying causes of problems versus more deductive quantitative tools. There appears to be a need for more qualitative research as currently little is known about the nature and contributing factors of sexual dysfunction. Initial research has revealed the complexity of female sexual dysfunction and therefore exploratory methods are required before large scale quantitative methods can proceed.

Identifying prevalence rates in a population has its difficulties due to participant subjectivity and other factors which can result in inaccurate outcomes. This was demonstrated in the empirical paper that found donors struggled to express their difficulties through fear of preventing the transplant and/or increasing any guilt for the recipient. It is possible on a questionnaire that donors' responses may not capture this outcome. Whilst quantitative methods can be useful, the use of skilled interviewing techniques to explore donors' perceptions, thoughts and emotions is likely to reveal complexities that cannot be achieved through quantitative methods. Although findings from qualitative research are now more likely to be included in healthcare practice and policy (Green & Thorogood, 2013), there has been a focus on demonstrating the 'usefulness' of such research to society. There has been a movement towards mixed methods, particularly in the healthcare sector due to the complexity of problems researchers are often faced with (Doyle, Brady & Byrne, 2009). Future research may look to combine methodologies to gain the benefits of both.

In both of the papers the impact of transplantation on body image was raised. For recipients it was raised in Muehrer et al's (2006) study as a potential reason for difficulties with sexual functioning. There are very few studies addressing body image following KTx in



recipients. Beer (1995) indicated that there are sexual fears associated with body image changes in KTx recipients. A study by Limbos, Chan & Kesten (1997) explored sexual functioning, body satisfaction and quality of life among lung transplant recipients and found their biggest concerns to be related to body satisfaction describing concerns with weight gain, facial changes and hair growth. Engle (2001) discussed the impact of immunosuppressant medication and their indirect effect on sexual dysfunction due to unwanted side effects which may include increased appetite, weight gain and hair growth. These side effects may impact women's perception of their bodies and could lead to changes in perceived sexual desirability. Yagil et al (2015) investigated associations between body image, psychological distress and quality of life in transplant recipients. They found higher levels of body image satisfaction was associated with a decrease in several quality of life domains and an increase in psychological distress in KTx recipients. It has been suggested that recipients' inability to incorporate their new kidney into their self-image may result in rejection of the kidney (Severino, 1980); however this finding has not been empirically supported. Yagil et al (2015) hypothesise that intervening with recipients to increase their body image satisfaction increases their quality of life, which may in turn enhance recovery and adherence.

In the empirical study one participant spoke in detail of on-going difficulties regarding body image following her donation. The donor discussed the physical changes due to her organs adjusting into the space where the kidney had been removed. She explained how this had resulted in her stomach protruding and created lumps meaning she felt uncomfortable and was unable to wear certain clothes. A systematic review into the psychosocial health of living kidney donors (Clemens et al., 2006) summarised ten studies which had addressed body image. Similarly to the findings of this empirical paper, whilst the majority of donors did not notice any meaningful change in their appearance, attractiveness

or self-esteem, there were a minority of donors who perceived themselves as less attractive, with decreased self-esteem and difficulties in relation to their scarring.

Research into body image during and following transplant for recipients and donors is limited. Further research is needed to investigate the risk factors for the development of body image difficulties in kidney donors and recipients. There is research to suggest body-image cognitive behavioural therapy (Jarry & Cash, 2011) is effective in changing negative body image in a variety of medical conditions, however organ transplantation is unique as the process results in an addition or removal of an organ and therefore may require more specific interventions.

The empirical paper highlighted the complexity of the relationship between donor and recipient in the transplantation process. A previous study by Gill and Lowes (2008) used the gift exchange theory (Mauss, 1990) in an attempt to understand donor and recipient's experiences. Donating a kidney was described as the 'gift of life' (Gerrand, 1994; Deguchi, 2002) as it is not only a gift of an organ but one of 'life' itself. Gill & Lowe (2008) found gift exchange theory provided a logical explanation of the transplant process, however in their qualitative study all of the donors found the decision to donate to be voluntary and managed the process with relative ease. In the current study some of the donors expressed difficulty with making the decision to donate, with most viewing the donation as a moral duty. Being obliged to donate a kidney would not be classed as voluntary and therefore would not be seen as a gift (Godbout & Caille, 2000). Although some of the principles of gift exchange theory could be mapped onto the donation process, the process of giving and receiving a kidney appears more complex than previously thought.

The two papers have highlighted the difficulties of researching donors' and recipients' experiences due to a lack of anonymity. Research into female sexual functioning remains

difficult due to the bias in volunteer participation (Strassberg & Lowe, 1995) and the current empirical paper highlights the difficulties for donors in being able to share their true thoughts and feelings. Future research may look to include technology which would enable individuals to partake in studies anonymously.

## **2) Clinical implications**

Both the literature review and the empirical paper highlight difficulties for the donor and recipient in the transplant process. Health psychology is relatively new in the renal medicine field and therefore guidance, practice and policies have mainly been concerned with medical practice and physical recovery from a KTx. In the empirical study, the donors' spoke of the focus on physical recovery with them often feeling ignored or unable to discuss psychological difficulties with healthcare professionals. As the focus has historically been on the physical recovery, there may be hesitation from nurses and doctors to approach psychosocial aspects of recovery such as sexual functioning due to feeling uncomfortable or unqualified to treat patients with sexual dysfunction (Phillips, 2000). Previous research has found reluctance for healthcare professionals to assess and treat problems with sexual function. A survey of sexual concerns among a sample of organ transplant recipients found that 67% had received no information regarding sexual functioning post-transplant (Hart et al., 1997). Similarly, a study by Schover, Novick, Steinmuller & Goormastic (1990) found that only 35% of women reported they were given information on sexual functioning following a KTx despite 70% of the sample stating that they would have liked to receive information. Screening, assessment and treatment of sexual functioning needs to be a priority for renal professionals in order to raise the awareness and improve sexual functioning for their patients.

The empirical paper highlights the difficulties that donors have expressing concerns or emotional distress prior to donating through fear of preventing the transplant from going

ahead. Some of the donors spoke about being given information regarding the physical aspects of the donation but reported feeling unprepared emotionally. Throughout the interviews most of the participants described the difference between the physical and emotional aspects of the donation and the lack of opportunity to share any concerns with clinicians who were also caring for the recipient. Raising the awareness of these barriers with healthcare professionals through training may help to identify donors who may require additional time and support prior to donating. As the process of deciding to donate appears more complex than first assumed, it may be helpful to introduce ‘donor advocates’ who are independent from the healthcare professionals to enable donors to speak openly prior to donation. A recent feasibility study (Dew et al, 2013) used motivational interviewing to explore ambivalence in donors. The one-site randomised control trial assessed individuals at 6 weeks and 3 months following donation. Individuals who were given motivational interviewing interventions had a significant reduction in ambivalence, significantly less physical symptoms, lower rates of fatigue and pain, and shorter recovery times compared to a group who received standard care and a group who received health education. In regards to psychological outcomes the intervention group had significantly less anxiety and fewer unexpected family related problems compared to the two other groups. There were no differences on the depression measure, how they felt about donating or relationship quality. There appear to be some benefits to providing an intervention to donors in order to improve psycho-social outcomes, however further research on a larger scale is required to confirm such findings.

Following donation it is important to identify and support those individuals who experience psychological difficulties. Some of the donors in the empirical study reported a view that they should be able to cope and were therefore unable to ask for help from the transplant team. Increasing the awareness of the professionals who have contact with donors

about this barrier may result in a more thorough review following donation. Highlighting services that may be available to donors, such as psychology, may encourage donors to access such services which otherwise they may not have been aware of. Transplant clinics may also look to use screening tools to identify individuals who may require further support during and following donation.

Since the introduction of the biopsychosocial model (Engel, 1977), the role of psychology in medical settings has been recognised and applied. Clinical health psychology now has a body of theories, evidence and intervention strategies (see Hunter, Hunter & Kessler, 2014). The benefits of psychology services in renal settings in the UK has been recognised. In 2002 the British Renal Society (BRS) recommended a minimum of one clinical psychologist per 1000 renal replacement therapy patients in order to meet the needs of the renal services (BRS; 2002). Increasing the awareness of psychological services within renal settings is essential in order for donors and recipients to get additional support if needed. Interventions from the third wave therapies such as Mindfulness Based Cognitive Therapy and Acceptance and Commitment Therapy have the potential to alleviate the stressors that arise whilst receiving or donating a kidney. It is important for psychologists to provide information, education and consultation to healthcare professionals working within renal service so they are able to encourage potential service users to access support when needed.

Feedback and guidance from service users may help in understanding how best to meet their needs. Chamney (2014) details the advantages of renal services collaborating with service users' and their carers' to improve the education and training of nurses in the UK over a four-year period. The National Service Framework for Renal Services (Department of Health, 2004) recommends that organisations need to access feedback to ensure services are

developed and improved to meet the needs of the people who access them. The benefits of collaborating with service users is outlined by Towle et al (2010):

*“There is great potential to promote the learning of patient centred practice, inter-professional collaboration, community involvement, shared decision making and how to support self-care” (p. 64).*

The research presented in this current thesis suggests there are improvements that can be made in relation to donor and recipient care and well-being. Acquiring service user feedback to understand how best to support donors and recipients will help to shape and develop services in line with their needs.

### **3) Reflections**

The empirical paper adopted IPA methodology as the aim was explore the personal meaning attached to the experience of being a kidney donor. Reflection is an essential element of IPA as there is the double hermeneutic whereby I, as the researcher, was trying to make sense of the participant making sense of their experience. The data was collected and analysed in my context and therefore I had to acknowledge my thoughts and feelings about the area of interest and how my interaction with participants may be shaped by both the participants and my socio-cultural worlds. I utilised several methods of reflection during the process. Prior to beginning the research I attended an IPA training event where I was encouraged to reflect on and record my experience of the research topic. I continued to do this at several stages of the research and was able to recognise the change in my knowledge base, perceptions and feelings over time. During supervision I engaged in reflective practice and was able to acknowledge differences between myself and my supervisors’ thoughts, feelings and interpretations of the data. I regularly attended an IPA peer supervision group along with four other researchers where I had opportunities to engage in more formal reflective practice.

Alongside the entire process I kept a reflective diary which provided further opportunity to gain awareness of my thoughts and feelings during the interviewing, analysis and writing up processes. Although there is not opportunity to discuss all of the themes that arose during reflection I have detailed what I believed to be the most poignant areas below.

I held a naïve position prior to beginning recruitment due to my lack of experience with individuals who had donated or received transplants. I recognised I have always had an interest in the idea of an individual being able to help another via donating an organ, however my lay opinion was that it would be a quick, simple and uncomplicated process. I had the view that following a kidney transplant, the recipient would be ‘cured’ forever and the donor would derive immense satisfaction from being able to help a loved one. My awareness of the complexities of donating arose once I began a clinical placement in a renal psychology service, at a similar time to when I began interviewing. My knowledge increased hugely during this time and I spent time reflecting on how my attitudes, thoughts and feelings towards donors and recipients was evolving. I had to maintain awareness of these changes in order to remain open and unbiased during each of the interviews. I was aware of the changes to my thinking following the use of a reflective diary and therefore I had to ensure that during later interviews that was not led by this new knowledge and remained open to each participant. Being on placement in the renal psychology service was useful as it allowed me to immerse myself in the data during the analysis and gain further insight into the world of kidney transplantation.

Most of the interviews consisted of a parent donating to an adult child and I was aware of my age being similar to that of most of the recipients who the participants donated to. I feared this may have had an impact on their ability to share any difficult experiences as they may have had a desire to protect me as they did with their adult child. I was also aware of my position as an employee of the health board and how this may have prevented

participants from being open and honest about their experiences. I spent time prior to the interview describing my role, experience and limits of confidentiality to try to gain participants' trust and build rapport. I was mindful to gain a balance of a formal, yet relaxed atmosphere in order for participants to be able to both be open and to feel contained if sharing difficult information. The framework of IPA along with the structure of the interview schedule allowed me to remain focused and maintain confidence during the interviews. The data gathered included a range of topics which contained highly emotive and sensitive information which suggests participants were able to be open and honest about their experiences. Participants felt able to openly share their disappointment, frustration and critique of the services they received care from which demonstrated they had understood my role and the limits of confidentiality. Some of the participants were tearful during their interview, further evidencing that they felt comfortable to share difficult experiences with me.

The interviews were focused on individuals who had donated to relatives (parents or adult children) which led me to reflect on my own family situation and how I would have reacted and coped in a similar situation. I gained a deeper awareness of my personal relationships, values and morals in relation to the research topic and how these were impacting my interpretations of individuals' experiences during each stage, particularly during analysis. Some of the participants enquired to whether I had children or not and whether I had experience of the donation process. I felt it was important to be honest in these situations, in order to be respectful and maintain rapport. I spent time reflecting on the context and motivations of the individuals who had asked these questions which was incorporated into the analysis.

All of the participants appeared grateful for the opportunity to share their stories. Some reported they appreciated being able to share their experiences as they had not had the chance to do so before. Through reflection of these processes it became clear that I felt



strongly about sharing each of their stories to ensure their voices were heard. I felt passionate about representing each of their experiences which became difficult during the writing up. I felt frustrated that I was not able to include all of the content from the analysis and this made the writing process extremely difficult.

The donors were enthusiastic about wanting to help others who might be in their situation in the future and following the interviews expressed an interest in taking part in further research. I was concerned this drive to want to help other people would deflect them from being able to share their experiences honestly. It was hoped that clear and simple explanation of the research objectives prior to the interview alongside actively engaging participants through questioning their personal experiences would maintain focus. The participants were aware that I was a university student and therefore I was aware they may have been motivated to try to help or please me. I was aware that participants would typically begin by answering questions and trying to gauge or ask whether their answers were appropriate. However gentle reassurance and a focus on listening and leading from their responses quickly led to participants relaxing and sharing stories from their experience.

I was aware that I was conducting research specifically in Wales, however I was not able to conduct interviews in Welsh. I felt guilty for not being able to provide the means for individuals to speak in their first language. Although there were no recruitment difficulties, this may have prevented some individuals from volunteering to take part. There were some Welsh speakers included in the study, with one participant being first language Welsh. Although all of the participants were able to express themselves excellently in English during the interview, I wondered whether they would have described their experiences differently in their preferred language.

I am currently on a clinical psychology training programme in which interviewing, effective communication skills and reflective practice are crucial. The training programme enabled me to have the confidence to manage any highly emotive or difficult situations and therefore I felt encouraged to explore these areas with the participants further. I was aware at times that I had the urge to enter into ‘therapist’ mode with the participants and therefore I had to remain focused during the interviews to maintain my role as a researcher. At times this resulted in frustration as I felt the need to provide information, support and knowledge from a clinical position, therefore I had to remain mindful during the interview to remain focused on the research objectives. Where appropriate, individuals were informed they could be referred onto psychological services following the interview, which for some participants they were not aware of. The lack of awareness for the support systems available to donors surprised me. However, in the context of the findings from this study it was understandable given that donors had been dismissive of their own needs. This further strengthened my passion for the donors’ experiences to be heard and acknowledged in the hope that services can develop with a greater awareness of donors’ psychological needs.

I was supervised by two consultant clinical psychologists who currently work in renal services. The use of supervision to reflect on my interpretations on the data was extremely useful. The reassurance from two professionals working in the field enabled me to feel confident at each stage of the process and provided confirmation that my findings made sense in the context of a renal psychology service. Being on placement in the renal service allowed me to have discussions with other healthcare professionals regarding the research which helped shape my understanding of the service. I was aware that I had some concerns regarding my findings and how they would impact services. I was mindful that I wanted the donors’ voices to be heard, however I did not want the findings to be critical of services. Discussions with my supervisors and careful thought during the write up process was

required in order to effectively communicate the findings. Continual reflection on the research objectives and aims and remaining close to the data helped to keep my focus.

## **Conclusions**

This study has highlighted the complexities in the transplantation process for both the donors and recipients. There is currently a lack of research into the psychosocial aspects of donating and receiving a kidney. Further higher quality research is required to understand the issues and raise awareness of the difficulties for individual following transplantation. The aim of this research was to inform, raise awareness and shape renal services and it is my hope this research will help to accomplish those aims.

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body-image dissatisfaction among kidney-transplant recipients. *Psychology, health & medicine*, *20*(8), 955-962.



## **Word Count**

### **Main Substance of thesis:**

Thesis Title and Abstract:

Word count: 264

Paper 1: Literature Review

Title page word count: 80

Word Count without tables, figures and references: 7894

Paper 2: Empirical Study

Title page word count: 85

Word Count without tables, figures and references: 6908

Paper 3: Contributions to Theory and Practice

Word Count without tables, figures and references: 4368

**Total of the main substance of thesis: 19,606**

### **Tables, figures, references and appendices:**

Paper 1: Literature Review

References: 1789

Tables, Figures and Appendices: 1574

Paper 2: Empirical Study

References: 981

Tables, Figures and Appendices: 3034

Paper 3: Contributions to Theory and Practice

References: 951

## 10. Research Protocol

### Research Protocol

#### Project title

The Experiences of Living Donors in Kidney Transplantation

#### Background

End stage renal disease (ESRD) is chronic kidney failure requiring patients to receive renal replacement therapy. Transplants are the preferred treatment for patients with ESRD as they offer a better life expectancy and quality of life than dialysis (Landreneau, Lee & Landreneau, 2010). Kidneys used in transplantations can come from living donors or deceased donors, known as cadaveric transplants. The success rate for transplants is better from living donors compared with transplants received from a cadaver with improved patient graft and survival rates (Johnson, Bradbury, Martin & Neuberger, 2014).

The first live kidney transplant took place in 1960 (Hamilton, 1994) and since then there has been an increase in the number of live donations. In the last 10 years the numbers of living donors has risen from 463 in 2003 -2004 to 1098 in 2012-2013 (Johnson, Bradbury, Martin & Neuberger, 2014). The latest figures from 2012-2013 show a 6% increase in the last year making live donation account for 1 in every 3 kidney transplants performed in the UK (National Health Service Blood and Transplant (NHSBT) 2013).

Through the strategic plan of NSHBT, the Department of Health (DoH) has requested that the living donor programme in the UK to be increased by 20% by 2017 (NHSBT, 2012). The plan to increase the numbers of living donors includes optimising transplant activity from living donors to enable further expansion in live donation, increasing transplant activity from non-directed altruistic donation and facilitating the growth in other forms of live donation e.g. encouraging pair pooled donations. Paired donations are when a potential donor and an incompatible recipient can join a list with others in the same situation with the hope that an exchange of kidneys between them leads to compatible living donor transplants. This recent development to enable more transplants will further increase the number of live transplantations in the coming years.

Previous research has addressed the psychological impacts of transplantations in individuals who receive a kidney transplant. Although kidney transplants have been found to improve physical functioning and overall quality of life in recipients (Burra & De Bona, 2007; Liem, Bosch, Arends, Heijenbrok-Kal & Hunink, 2007), improvement on psychological quality of life have been found to be minimal or reduced in comparison ((Landreneau, Lee & Landreneau, 2010; Overbeck et al, 2005). A study in Slovakia (Prihodova et al, 2010) investigated the predictors of health related quality of life in recipients following a kidney transplant and found psychological distress to be the best predictor of poor quality of life following a transplant. A further study in the Netherlands found that objective health appeared to have an indirect effect on subjective psychological distress (Schulz et al, 2012) suggesting that although kidney transplants offer better physical wellbeing, individuals may have difficulties with the psychological impacts following the transplant. Due to the health concerns with recipients they continue regular contact with services following the transplant

procedure and therefore it is thought that psychological difficulties may be recognised and treated.

Research into donors appears to have produced more straight forward results. A systematic review of studies (Clemens et al, 2006) conducted in America and European countries (only one study was based in the UK) found the majority of donors experienced no depression or anxiety, no change or an improvement in the relationship between the recipient and donor and some had an increase in self esteem following the transplant procedure. However as the studies in the systematic review were quantitative in nature the results for the 'majority' of participants were emphasised. The systematic review reported that in some of the studies a small number of donors had experienced significant difficulties following the transplant procedure. For example; relationship separation and divorce; family conflicts; body image issues; feeling ignored and unappreciated; feelings of guilt; feeling depressed and anxious; and donors reporting that they had felt like they had given up something for nothing in return. It is important to note that the difficulties were found in a small number of cases, however how these individuals are identified and managed following the procedure is of great importance. Similarly to systematic review most of the recent research, mainly outside of the UK, report the benefits of donating a kidney (e.g. Clemens et al, 2011), however much of this research has been quantitative. This may be insufficient for this area of research as quantitative research isn't able to provide an understanding of donors attitudes, perceptions and experiences through their evaluation of outcome measures. It is therefore important to explore this fairly new field of health psychology in a qualitative manner.

Gill & Lowes (2008) carried out a qualitative study in the UK that explored the kidney transplantation process with both donors and recipients. Their study used a phenomenological approach alongside a framework of gift exchange theory. Their study included 11 pairs, 8 of which were husband and wife couples. In relation to the experiences of donors, the study found that they derived 'immense personal satisfaction' with no detrimental impact on the relationship between themselves and the recipient. However, the study did not include analysis from 1 of the 11 couples whose transplant was unsuccessful. A further observation from the study is that they found a variation in the decision making process when analysing the only brother - sister pairing, however, the study did not explore further to understand what the indecision in the case was about.

In light of the previous research it is thought to be beneficial to build on previous findings and to carry out a qualitative study in North Wales, where there has not been any previous research into the experience of living donors. It is thought that the inclusion of both the recipient and the donor in the Gill & Lowe (2008) study may have had an impact on information collected. In addition, by focusing specifically on the experiences of the donors, without the inclusion of the recipient, the accounts of the transplant process may be different as participants will be aware that the researcher will not be speaking to the recipient of the transplant and therefore may feel able to express any negative experiences. As the majority of participants were husband and wife pairs in the previous qualitative study, the current study will focus on other pairings such as relations and friends to see whether there is any impact on their relationship that may not be understood in the same way as in a romantic relationship. Lastly the proposed study will include all of the information gathered from participants in both successful and unsuccessful transplants.

In summary, the rationale for the current study is that there are rising numbers of live transplants taking place in the UK and little is known about how non-couple living donors experience transplantation. A focus on donors' experiences of the transplant process has not been researched in North Wales despite there being 3 renal services covering large geographical area. It is important to become aware of the experiences of donors in order to inform provision of care, information, advice and support for donors.

### **Research question**

The aim of this study is to explore in depth the perceptions, meanings and experiences of living non-couple donors who have donated kidneys to relatives or friends for transplantation. The study aims to increase understanding of donors' experiences and highlight possible implications in light of the planned increase in live kidney donation. In addition the project may help to develop services, information and support for donors in North Wales Renal Services and elsewhere.

### **Methods**

#### **Participant Criteria**

*Inclusion Criteria:* Individuals who have donated a kidney to a recipient who is not their spouse/ partner (i.e. siblings, parents to children, adult children to parents, and friends).

All participants will be adults over 18 years. There will be no restrictions on gender and time since donation.

*Exclusion Criteria:* Individuals who have donated a kidney to a partner/ spouse.

The research study is adopting a qualitative approach and therefore the target sample size for this study will be 5-8 participants in order to analyse the perceptions and understandings of living donors in great detail. The sample is homogenous as each of the participants have been through the same process of donating a kidney.

#### **Participant recruitment**

Recruitment of participants will take place via Renal Transplant Specialist Nurses in North Wales Renal services. Three Transplant Specialist Nurses (TSN) from Bangor Renal Unit, Wrexham Maelor Renal Unit and Glan Clwyd Renal Unit have been contacted and have expressed interest in the study. Previous discussions with TSNs have found there are approximately 50 living donors across the two services who are in contact with the TSN's on an annual basis. There is approximately 30 of these living donors who would meet criteria for this study. The TSN's have initially agreed to contact relevant patients from the criteria specified above on the researcher's behalf in line with data protection and research ethics guidelines. Living donors from two of the units (Wrexham and Glan Clwyd) will be contacted initially and if more participants are required then living donors in Bangor will be approached. The participants will be randomly selected by the TSN's from a list which they have on their records (e.g. selecting every other name or taking names out of a hat). The TSN's have regular

contact with the living donors (minimum once per year) and therefore the procedure for recruitment will involve the TSN's contacting suitable participants via telephone to inform them of the study. A telephone protocol will be provided for nurses to follow to ensure individuals do not feel pressured take part in the study. Information packs will be posted to provide further information regarding the study. If individuals are happy to proceed they will be asked to complete the opt-in form and send this to the researcher. Once received the researcher will contact the participants via telephone.

### **Design and Procedures**

A qualitative approach has been adopted for this study as it aims to understand and explain how the individuals included in the study make sense of their world and experiences. Qualitative studies are particularly useful when exploring areas that are not well understood in order to generate information about the 'what', 'how' and 'why' of a particular field (Green & Thorogood, 2013). As health psychology is a fairly new area of research it is thought that it will benefit from the more explorative qualitative methods as opposed to quantitative approaches (Green & Thorogood, 2013).

Participants will be asked to take part in an interview with the researcher at times, dates and locations convenient for them, for example, at their home address or in a room at they have been in contact with. The interviews can take place either at hospital site or in participants own home and will last for approximately 1-2 hours. All interviews will be audio recorded on a digital recorder and transcribed by the researcher. The interviews will be semi structured with a few key themes to prompt discussion. The themes will focus around the donors' experience of the transplantation process, before, during and after the procedure. Potential areas of exploration include:

7. The decision making process pre-transplant
8. Donors' experiences of the services throughout the process
9. The impact on the relationship between donor and recipient
10. Donors' experiences following the transplant

### **Measures**

Some demographic information will be collected such as age, gender, donors' relationship to recipient and time since transplant procedure. No psychometric measures will be administrated in the study.

### **Data management and analysis**

Data Management:

The data collected from the participants will be kept in line with Bangor University policies and procedures. Audio data will stored on a digital recorder and kept in a locked briefcase. Transcripts of interviews will be stored in password protected documents and each participant will be assigned an identification number to ensure data is anonymised. Word documents will be kept on an encrypted USB stick. All of the

data will be deleted following the completion of the project in line with Bangor University procedures.

#### Data Analysis:

In order to analyse the data, Interpretative Phenomenological Analysis (IPA) will be used (Smith, Flowers & Larkin, 2009). IPA asks questions about how individuals make sense of their personal and social world and seeks to gain insight into the meanings that events and experiences hold for people. IPA involves the identification of themes and then uses the researcher's interpretation of the information gathered during the interview to expand on these themes. IPA recognises that whilst a researcher attempts to understand how an individual makes sense of their experiences, this is complicated by the researcher's own conceptions and therefore the process of understanding is that of interpretation.

#### **Diversity**

The sample will be defined by the individuals available for the project through the TNS. It is hoped that the study will include a range of participants in terms of their demographics and time since donation.

The research project will take place in North Wales and therefore it may include Welsh speaking individuals. All written information will be translated and available in Welsh. As the researcher is not a Welsh speaker the interviews will be conducted in English. If there are any issues resulting from this they will be addressed with the individual and supervisors.

#### **Risk Assessment**

##### Risks to participants:

BCUHB Confidentiality procedures will be adhered to at all times during the study. The interviews are likely to involve participants talking about highly personal and sensitive information and therefore may elicit difficult emotions in participants. This will be discussed with each individual prior to interview in order to allow an open discussion of any difficulties that may arise during the interviews. If the individuals experience distress during interview the researcher will allow space for this to be worked through together and for a decision to be made on how to manage the risk. The researcher will ensure she is aware of useful contact numbers for participants to be given if required. Both of the researcher's supervisors are a consultant clinical psychologist who work across the three services that participants are being recruited from and therefore participants can be referred, with their consent, into the psychology service for additional support during or following the study if required.

##### Risk to researcher:

Interviews may take place in participants' homes or in settings where the researcher is lone working. The researcher will follow the BCHUB lone worker policy. This will be discussed with supervisors prior to beginning the interview process to confirm details

of how contact will be made between researcher and a base before and after the interviews.

### **Feedback**

All participants will be asked whether they would like to have feedback on the main results of the research project. Participants who opt-in to receive feedback will be provided with written feedback following the completion of the project.

### **Data storage**

All participant information will be stored on an encrypted USB stick will be anonymised through the use of personal identification numbers and password protected. The audio recordings will be deleted following completion of the project and any written information will be kept in a locked filing cabinet at the researcher's base. Following completion of the project all data will be deleted in line with Bangor University Policy and Data Protection Legislation.

## **11. Participant Information Sheet**

### **Information Sheet**

**Title of Project:** The Experiences of Living Donors in Kidney Transplantation

We would like to invite you to take part in our research study. It is important for you to understand why the research is being done and what it will involve before you choose to take part. Please read the information sheet and if you have any questions please call 01745 445 655 and one of the research team will get back to you.

#### **Research Team**

Lucie Rutter, Trainee Clinical Psychologist

Dr Beth Parry-Jones, Consultant Clinical Psychologist

Dr Paul Gardner, Consultant Clinical Psychologist

You can also speak to your specialist transplant nurse who informed you of this project who can access further information for you if needed.

Section 1 tells you the purpose of this study and what will happen if you decide to take part. Section 2 gives you more detailed information about the guidelines of the study.

Please ask if anything is not clear.

#### **SECTION 1**

##### **What is the purpose of the study?**

Previous research has looked into the experiences of people who receive a kidney through transplantation. Other studies have looked at the experience of people who donate kidneys, however this research has mainly been with couples e.g. husband and wife. Only a few studies have looked at the experiences of 'non-couples' and none of this research has been done in North Wales.

The aim of this study is to explore in depth the experiences of living non-couple donors who have donated kidneys to relatives or friends for transplantation. The study aims to increase understanding of donors' experiences and may also help to develop services, information and support for donors in North Wales Renal Services and elsewhere.

This study will form part of a Doctorate of Clinical Psychology thesis for Lucie Rutter, who is studying at Bangor University. Lucie is being supervised by Dr Beth Parry Jones and Dr Paul Gardner, who are both Consultant Clinical Psychologists working in Renal services across North Wales.

##### **Why am I being invited to participate?**

We have asked the specialist transplant nurses to approach individuals who have donated a kidney to a recipient who is not their spouse/ partner (i.e. siblings, parents to children, adult children to parents, and friends). There is no time limit on when you donated the kidney. The study requires a maximum of 8 people to take part.



**Do I have to take part?**

No. It is entirely up to you to decide whether or not you want to take part in the research. You are able to withdraw from the study at any time without giving a reason. If you do decide that you don't want to take part or decide to withdraw at any time it will not affect the care you receive from the Renal Service.

**What will happen if I decide to take part?**

If you do decide you want to take part please fill in the 'opt-in form' and send using the stamped addressed envelope. Following this Lucie will contact you to arrange a time and place to meet for an interview, e.g. can be at home or in a clinic. You will be asked to read and sign a consent form before the interview takes place (please find a copy of this form attached).

The research will involve meeting with Lucie and talking about your experiences of donating a kidney. You will be asked some short questions regarding your age, time since transplant and your relationship to the person you donated to. Following this Lucie will invite you to talk openly about your experiences of the transplant process and life since. The research questions have been designed by the research team and approved by Bangor University and Betsi Cadwaladr University Health Board. Lucie will be using a digital audio recorder in order to keep a record of the interview.

The interview will take place at a date, time and location that best suits you and will last approximately 45-90minutes. It is important for the interview to take place in a location which is comfortable for you and also where it is quiet and private so the interview is confidential and there are no interruptions. There will be opportunity to take breaks during the interview if needed.

It is important to be aware that there are no right or wrong answers to the questions in the interview and you do not have to answer any questions if you don't want to.

**Will private information be kept confidential?**

Everything you discuss with Lucie will be kept confidential within the research team. However, if you share any information which raises concern about your safety or the safety of another person then Lucie will speak to you about this further. Depending on the concerns raised it may be that confidentiality has to be broken and the information shared with other people.

Direct quotes, i.e. specific information you have shared during the interview may be used in the report. However, the research team must follow strict guidelines to ensure nothing you say can be linked to you in the final report. The interviews will be transcribed and any identifiable information will be changed or removed to avoid identification when the study is submitted to Bangor University and later published.

**What are the possible risks or disadvantages of taking part?**

This study is hoped to not cause any distress however it is possible that you may find it difficult to talk about your experiences. The interview may include speaking about potentially stressful and upsetting experiences that you have been through. Lucie is a Trainee Clinical Psychologist and has the skills to manage difficult emotional responses.

If you do feel distressed by any of the questions you do not have to respond and can stop the interview at any time.

It is important to make you aware that although Lucie is a Trainee Clinical Psychologist she is not able to help you with any difficulties following the interview. However if you or Lucie think you need further support following the interview Lucie will be able to direct you to the appropriate services if this is helpful. This could include a referral to the Renal Clinical Psychology Service in North Wales or a referral to you GP.

Not all of the information from your interview will go into the final report as it is hard to represent all of the individuals who take part in the study. If there are some parts that are not included this does not mean that the information was not important.

### **What are the possible benefits of taking part?**

You may not benefit directly from taking part in the study, however you may find it helpful or enjoyable to share your experiences. You may also find it beneficial to be part of a scientific study that aims to understand the experiences of people who have donated a kidney for a transplant. You can be sent a copy of the results of the study when it is completed which you may find interesting. In addition it is hoped that the study may provide insight and potentially benefit others who go through the donation process.

### **Expenses**

If you would like the interview to take place in the hospital, there is up to £15 available to cover any travel expenses.

### **What happens after the research?**

Following your interview you will not be asked to do anything else and your care will continue as usual. If you would like to receive information about the results this can be sent to you following completion of the study.

### **Welsh Language**

Although all of the information about the study will be provided in English and Welsh, the interview has to take place in English as unfortunately Lucie does not speak Welsh.

## **SECTION 2**

### **What will happen if I don't want to carry on with the study?**

You can decide at any time to withdraw from the study. You will be assigned a personal identification number and therefore if you wish to remove your information from the study following the interview you can.

### **What if there is a problem?**

If you have any concerns about taking part in this study, you should speak to the research team who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can contact:

For an NHS complaint:                      Concerns Team

Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW

Email: [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)

Tel: 01248 384194

For a University complaint:

Hefin Francis (School Manager)

School of Psychology

Adeilad Brigantia

Penrallt Road

Gwynedd LL57 2AS

Email: [h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)

Tel: 01248 388339

### **Where will the research study be presented?**

This project forms part of a thesis for a professional Doctorate of Clinical Psychology and will be submitted to Bangor University. It will also be presented at the annual stakeholders meeting for the North Wales Clinical Psychology Programme. The results will be submitted for publication in at least one journal for other professionals to read. The results may also be presented at conferences such as the British Renal Society annual conference.

### **What will happen to the recordings of what I have said?**

The recordings will be kept on a digital recorder in a locked briefcase. The recordings will be deleted as soon as they have been transcribed. The transcripts will be kept on an encrypted USB stick which means that only the research team will be able to access the transcripts. The research team may wish to access the data for further research following this study however you will be asked whether you agree to this before this happens. The transcripts will be destroyed 5 years after the study has been completed.

### **Who is funding the research?**

The research team are all employees of Betsi Cadwaladr University Health Board. The University of Bangor is providing any funding needed to conduct the study.

### **Who has reviewed the study?**

All research in the NHS is looked at by independent groups of people to protect your interests. This study has been reviewed and allowed to commence by Bangor School of Psychology Ethics and Governance Committee, the Research and Development Internal Review Panel for BCUHB, and the North Wales Research Ethics Committee – West.

### **Further information and contact details**

If you have any further questions or require more information before deciding whether to take part please contact Lucie Rutter via email or telephone:

[Psp2e1@bangor.ac.uk](mailto:Psp2e1@bangor.ac.uk) or 01745 445 655.

Thank you.

## 12. Opt-in Form

Centre Number:

Study Number:

Patient Identification Number:

# Opt-in Form

**Title of Project:** The Experiences of Living Donors in Kidney Transplantation

**Name of Researcher:** Lucie Rutter, Trainee Clinical Psychologist

Thank you for considering to take part in this research project. Please read the items below and tick the boxes if you agree to be contacted. Please leave your contact details and signature at the bottom and use the stamped addressed envelope to send this form back to Lucie Rutter. Once received, Lucie will contact you to discuss the next stage of the research.

1. I have read and understood the participant information form.
2. I am happy for Lucie to contact me via the contact details I have provided below.
3. I understand I can contact Lucie to discuss the research further.
4. I understand that I can opt-out of the project at any time.

### Contact Details:

Name:

Telephone (home):

Telephone (mobile):

Signature.....

Date.....

### Further information about the study

If you have any further questions or require more information about this study please contact: Lucie Rutter via e-mail [psp2e1@bangor.ac.uk](mailto:psp2e1@bangor.ac.uk)

**Complaints:** Any complaints concerning the conduct of this research should be addressed to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57 2AS

### 13. Consent Form

Centre Number:      Study Number:      Patient Identification Number:

#### CONSENT FORM

**Title of Project:** The Experiences of Living Donors in Kidney Transplantation

**Name of Researcher:** Lucie Rutter

Please put your initials in the box if you agree to the following statements:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information and could contact Lucie to ask any questions.
2. I understand that my participation is voluntary and that I am able to withdraw at any time without giving any reason, without my past, current, or future medical care or legal rights being affected.
3. I understand that specific quotes may be included in the final report, however these will be carefully selected to ensure that I cannot be identified through these.
4. I agree for the interview with me to be recorded.
5. I understand all information stored on a computer will be anonymised and any information that is stored will be kept in a locked filing cabinet at the researcher's base.
6. I agree for my GP to be informed of my participation in this study
7. I agree to take part in the above study.

Name of Participant: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Signature: \_\_\_\_\_

#### Further information about the study

If you have any further questions or require more information about this study please contact: Lucie Rutter via e-mail [psp2e1@bangor.ac.uk](mailto:psp2e1@bangor.ac.uk)

**Complaints:** Any complaints concerning the conduct of this research should be addressed to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57 2AS.

## **14. Nurses Telephone Protocol**

### **Telephone Protocol**

**Project title:** The Experiences of Living Donors in Kidney Transplantation

Script for potential participants.

**Hi....,**

**I am calling to let you know that an information pack regarding a research project has been sent out to you. The researchers contact details are included in the pack if you wish to take part but you don't have to. If you are not interested please discard the pack. Participation is completely voluntary and will not affect any aspect of your care from the renal service. I have been asked to inform you of the information pack but I am not involved in the study so I will not know if you decide to take part or not.**

**Thank you**

If the potential participant would like more information please share with them that the researcher is interested in talking to people who have donated a kidney to discuss their experiences. They are able to find full details in the pack once it arrives. Please do not discuss any further information with potential participants at this stage.