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The 'Gift' of Life? Individual and Family Perceptions of Organ Donation

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Abstract

This Large-Scale Research Project (LSRP) investigated the experiences and beliefs of families and individuals regarding organ donation.

Paper One reports a systematic review of qualitative literature involving bereaved families who were approached about organ donation at the end-of-life of their relative. The review aimed to understand the implications of the decision at least six-months after the bereavement. Fifteen studies were included in the review and were critically appraised using a quality appraisal tool. A meta-ethnographic approach yielded three themes: *An ongoing relationship with the donor*; *The psychological impact of the decision*; *Support in grief*. The findings are discussed in relation to the complicated grief literature.

Paper Two reports a mixed-methods study, which utilised the Self-Regulation Model of Illness and Interpretative Phenomenological Analysis. People living with chronic kidney disease and pre-dialysis were surveyed (n=31) and interviewed (n=8) about their illness and treatment beliefs and experiences regarding pre-emptive living donor kidney transplantation. Responses suggested illness perceptions and treatment knowledge inform treatment preferences. Four master themes emerged from the qualitative analysis (*My Kidney and I*; *Co-constructing Decisions*; *A Kidney Shared as a Problem Solved?*; and *Navigating the Unknown*), which described the complexity the option of living donation may present to people. A desire for enhanced self-management information to delay illness progression was found.

Paper Three provides a critical appraisal of the strengths and limitations of the LSRP and the wider implications of the findings, including areas for future research. Dissemination approaches and consideration of competence development from the work undertaken are also discussed.

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Abstract

Purpose

The unexpected death of a relative can lead to families being approached by healthcare staff with an organ or tissue donation request. This review aimed to identify, appraise and synthesise the extant qualitative research into the longer-term experiences of grief and adjustment to loss in such families.

Method

A systematic search of the literature identified fifteen studies utilising qualitative methodologies which met the criteria for the review. A qualitative appraisal tool was used to assess quality, and a meta-ethnographic approach facilitated data extraction and synthesis.

Results

The quality of the studies was predominantly moderate to high, with variance regarding reference to researcher reflexivity and theoretical frameworks. Three master themes arose from the data extraction and synthesis process: *Ongoing relationship with the donor*; *The Psychological impact of the decision*; and *Support in grief*. The consequences of donation decisions may not be clear at the time of request.

Conclusions

The synthesis illustrated the importance of post-bereavement follow-up for both consenting and non-consenting families, and the value of making donation intentions known. Further research is required exploring the post-bereavement experiences of families from countries operating presumed consent.

Keywords: *post-bereavement; complicated grief; organ donation; meta-ethnography*

Introduction

The global demand for organs and tissue for transplantation exceeds availability, with many initiatives aiming to improve the supply, such as increasing the deceased donor pool (Saidi & Hekazii-Kenari, 2014; NHS Blood & Transplant (NHSBT) (2013). Approximately 6,500 people in the UK require a transplant (NHSBT, 2018), with 16.5% dying while waiting (Neuberger, Trotter & Stratton, 2017). Wales is the only nation in the UK to have adopted a presumed consent model to organ donation, with the aim of increasing cadaveric donation rates (Noyes & McLaughlin, 2017; Rithalia et al., 2009).

The family of a dying or deceased potential donor has significant influence in determining donation outcomes. In the UK, 38% of donation requests are rejected (Neuberger et al., 2017) and over 500 families refused donation in a six-year period, despite their relative opting-in to the system (NHSBT, 2016). Many countries operating presumed consent adopt a 'soft' approach (McCartney, 2017), whereby the relatives of the deceased continue to be consulted (Douglas & Cronin, 2015; Shaw, 2017; Rosenblum et al., 2011), to ensure ethical and person-centred practice (National Institute for Health and Care Excellence [NICE], 2011).

Requests for donation may occur following unexpected circumstances, such as sudden illness or injury, resulting in the brain or circulatory death of a relative. As organ retrieval must be achieved within specific timeframes for the organs to be useable, consenting to donation can mean the donor is quickly taken from their family to surgery following the removal of life-support. When tissue is requested following an unexpected instant death, decisions are required within 24-hours of a relative's death. Requests are therefore made to families under tremendous psychological strain, shock and denial (Eckenrod, 2008; Moraes & Massarollo,

2008), and while their relative appears alive due to life-support equipment while being described as clinically dead. The overload of factual and sensory information can compromise attention and information processing, further complicating decision-making and sense-making (Eckenrod, 2008).

Both non-consenting and consenting families can experience dissatisfaction regarding decision outcomes, with between 27% (Burroughs, Hong, Kappel & Freedman, 1998) and 52% (Morais et al., 2012) of non-consenting families regretting their decision, compared to up to 10% of donor families (Rodrigue, Cornell & Howard, 2008). Post-bereavement satisfaction with regards to the decision is predicted by knowing the deceased's preferences, feeling the decision was not hasty, and a sense of certainty at the time of decision-making (Rodrigue et al., 2008; Morais et al., 2012). While reasons for refusal have been explored, such as denial of brain-death (Ghorbani et al., 2011); not knowing the relative's preferences (Siminoff & Lawrence, 2002), poorly communicated requests (Birtan et al., 2017); religious beliefs (Ghorbani et al., 2011) and emotional exhaustion (Vincent & Logan, 2012), the consequences of the decision for families has received limited attention, especially for minority ethnic groups (Morgan, Kenten & Deedat, 2013).

Approaching relatives with donation requests can be challenging for healthcare professionals (Orøy, Strømskag & Gjengedal., 2013; De Groot et al., 2014), due to concerns over causing further distress and complicating the bereavement process for families (D'Alessandro, Peltier & Phelps, 2008; Cleiren & Van Zoelen, 2002), and over mis-judging the timing for a request, which can impact on decision outcomes (Anker & Feeley, 2010). Intensive care staff may receive little feedback regarding relatives' satisfaction with their decision due to insufficient aftercare support (De Groot et al, 2014).

Grief is a concept difficult to define, with experiences varying between people, cultures and time. Broadly, grief is the emotional reaction to having lost someone significant through death (bereavement) (Stroebe, Hansson, Schut & Stroebe, 2008), which most people process without severe difficulties (Bonanno et al., 2002). Approximately 7-10% of all bereaved people (Kersting, Braehler, Glaesmer & Wagner, 2011) experience grief which does not heal or recede with time¹. While there is a lack of agreed terminology (Carmassi, Bertelloni & Dell'Osso, 2017), such grief is characterised by significant and enduring separation distress, preoccupation with the deceased, disbelief, anger and avoidance over the loss, detachment from others and features of traumatic distress (Stroebe, Schut & Stroebe, 2007), and diagnostically must last for at least six months (Prigerson, Vanderwerker & Maciejewski, 2008). The risk factors for prolonged grief include traumatic and unanticipated deaths, unpreparedness for death, close emotional bonds to the deceased, and the deceased being younger (Keesee, Currier & Meimeyer, 2008; Lobb et al., 2010).

Grief responses can be understood through various theories and models, which can guide the design and delivery of grief interventions (Hall, 2014). Stroebe & Schut's (1999) Dual-Process Model is a particularly comprehensive and influential cognitive-stress model of grief (Lund, Caserta, Utz, & de Vries, 2010), whereby grief is proposed as a process of oscillation between loss-oriented or restoration-oriented coping. The model proposes that grief reactions become complicated as a result of extreme confrontation or avoidance of either mode of coping. The Continuing Bonds Model (Klass, Silverman & Nickman, 2014), and the Task Model (Worden, 1992/2009) similarly emphasise the importance of understanding factors

¹ This review will use the terms 'complicated', 'complex', 'persistent', and 'prolonged' interchangeably to describe such chronic grief.

such as the circumstances of the bereavement, culture, and the strength and nature of attachment with the deceased to help understand individual differences in coping with grief. Such conceptual frameworks typically emphasise that adaptive coping strategies lead to a reduction of the negative impact grief has on psychosocial functioning (Stroebe et al, 2007); the importance of both letting go of bonds and holding onto the attachment (Stroebe, Schut & Boerner, 2010); and the process of meaning-making to form healthy continuing bonds with the deceased (Neimeyer, Burke, Mackay, van Dyke Stringer, 2009).

Quantitative research has yielded inconsistent results regarding the relationship between donation decisions and the grief process, often focusing on early grief (e.g. Stouder et al., 2009). Cleiren & Van Zoelen, (2002) found decisions neither helped or hindered grief in the first six-months after the loss, although this timeframe is within that of normal acute grief processes. Conversely, Merchant et al (2008) found consenting to donation may have a beneficial effect on the grief process, three-months to five-years after bereavement.

Complicated grief was reported in 46% of relatives of deceased donor relatives (Soriano-Pacheco et al., 1999) 13-months post-bereavement, although grief was defined as requiring psychological or pharmacological intervention.

Research on families who have been affected by donation has predominantly focused on experiences of stress and coping when considering consent, and modifiable factors that influence decision-making (Simpkin, Robertson, Barber & Young, 2009). There has been less attention on the longer term psychological impact of donation decisions following the unexpected death of a relative. A longitudinal study of organ donation requests in intensive care settings (Kentish-Barnes et al., 2018), reported complicated grief as high as 51% for donor and 67% for non-donor families. While these differences were not significant, only the

first nine months post-bereavement were assessed, whereby families may still be processing acute grief. A scoping review (Chandler, Holland & Shemie, 2017) examined the literature and research on the psychological impact of donation requests for families, with the aim of developing best-practice guidance for end-of-life conversations. As a scoping review, it did not aim to synthesise the results, nor comment on the quality of the data.

A narrative review by Dicks, Northam, Boer and van Haren (2017), examined all available research, literature, reports and commentary to elucidate families' experiences of donation in their entirety, from before the request to post-bereavement follow-up. The review generated a grief theory-based framework for facilitating meaning-making for families and provided a foundation for considering bereavement in organ donation contexts. However, reviewing the literature in its entirety with minimal exclusion criteria has limitations, including interpretation and reporting bias and issues regarding research quality (Gough, 2015).

A qualitative systematic review conducted in 2012 (Ralph et al., 2014), explored the experiences of all families affected by a donation request, including those bereaved following a relative's terminal illness. The review explored the donation request, decision-making processes, and attitudes towards donation post-bereavement to help improve healthcare practice when making requests. The authors emphasised the need for emotional support, privacy, and adequate time for information to be explained, understood and considered during the decision period.

Summary and Aims

Internationally, policy-makers are focusing on increasing deceased organ donation, which can mean families in highly stressful situations are increasingly being approached to consider

donation. Healthcare professionals are also concerned that such requests create additional burden for families. Knowing more about the longer-term appraisal and impact of donation decisions is therefore of interest.

The aim of this review is to identify, quality appraise, and synthesise the main themes and conclusions from existing qualitative research exploring grief, and to summarise what is known about the longer-term experiences of donation decisions. It is intended that this review will inform the development of person-focused healthcare interventions and research, to help ensure families are as satisfied as possible with their decisions. The review aims to extend knowledge gained from the reviews of Dicks et al (2017) and Ralph et al (2014) through its specific focus on synthesising qualitative studies into the impact of donation decisions at least six months after an unexpected bereavement.

Review question: How do organ and/or tissue donation decisions of families of brain-dead or circulatory-dead relatives influence adjustment to loss at least six-months post-bereavement?

Method

Methodology

The review utilised meta-ethnography (Noblit & Hare, 1988), a well-developed and widely used qualitative methodology, whereby key concepts from the relevant literature are systematically compared and synthesized (Hannes & Macaitis, 2012; Campbell et al., 2011). A higher level of abstraction is developed through moving from the translation of the cases to a translation of interpretations (Toye, Seers, Tierney & Barker, 2017). The process is interpretive, similar to the methodologies of the studies being synthesised, whereby the whole is greater than the sum of its parts (Britten et al., 2002).

Search Strategy

The review followed the seven steps suggested for meta-ethnography (Table 1).

Table 1
The meta-ethnography process (Noblit & Hare, 1988)

Step	Description
1	Getting started: Formulation of the research question.
2	Deciding what is relevant to initial interest: Studies are identified through defining inclusion criteria for literature searches. Studies can be quality appraised.
3	Reading the studies and data extraction: Becoming familiar with the studies and identifying and extracting the themes and concepts relevant to the research question.
4	Determining how the studies are related: The relationships between concepts and themes from each paper are considered.
5	Translating the studies into one another: Themes are compared between papers in a process similar to constant comparison methodology.
6	Synthesising the translations: The translations are interpreted to develop 'third-order' concepts.
7	Expressing the synthesis: Presentation of findings.

Steps one and two involved identifying the research question and identifying relevant studies through defined inclusion criteria (Table 2), which were distinct from those of previous reviews (Dicks et al., 2017; Ralph et al., 2014). While an exhaustive search was completed, such searches are not specified as necessary in meta-ethnography (Noblit & Hare, 1988) as it does not aim to summarise available knowledge in its entirety (Toye et al, 2017).

Research databases MEDLINE, PsycINFO, Embase, CINAHL and Web of Science were searched from October 2017 until March 2018. Search terms were clarified by a librarian, and terms included: (bereavement OR grief OR “psychological impact”) AND (families OR relatives OR “next of kin”) AND (“organ adj3 don*” OR transplant*) AND (“end of life” OR ‘deceased*’ OR “brain death”). Due to the anticipated small evidence base, search restrictions with regards to time period or study design were not applied to capture the full body of research relevant to the question.

As qualitative approaches can both overlap and vary in epistemology and methodology, all available qualitative research utilising a range of approaches were considered for the meta-ethnography provided they used qualitative techniques for data collection, data analysis and interpretation (Sandelowski & Barroso, 2003, p.154). Mixed-methods designs and methodologies such as content analysis were considered for inclusion if the qualitative methodology could be separated from the quantitative elements of the study (Centre for Reviews and Dissemination, 2009); through reviewing the study aims, analysis and interpretation of themes; and through discussion with the research team.

Table 2
Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Studies exploring the experiences of next-of-kin who were approached to donate a relative's organs, at least six months after the request.	Studies exploring decision making.
Studies involving the unexpected death of a relative (brain or circulatory death).	Studies focusing more on the donation request experience rather than the post-donation experience.
Solid organ and/or tissue donation request at the time of a relative's death.	Studies that focused on the perspectives other than next-of-kin (e.g. clinicians).
Studies using qualitative methodology.	Studies involving a terminal illness (e.g. cancer).
Studies with primary or secondary focus on post-bereavement experiences rather than the decision-making process.	Studies using quantitative methodology.
Peer-reviewed journal publications.	Mixed-methods studies with minimal focus on the qualitative component.
	Studies not published in English.

Databases were individually searched and combined for duplications to be removed using Excel. Inclusion and exclusion criteria facilitated the identification process and reference lists of full-text articles reviewed for potential inclusion were scanned for further references. Figure 1 presents the results of the search and selection process, in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) standard (Moher, Liberati, Tetzlaff & Altman, 2009).

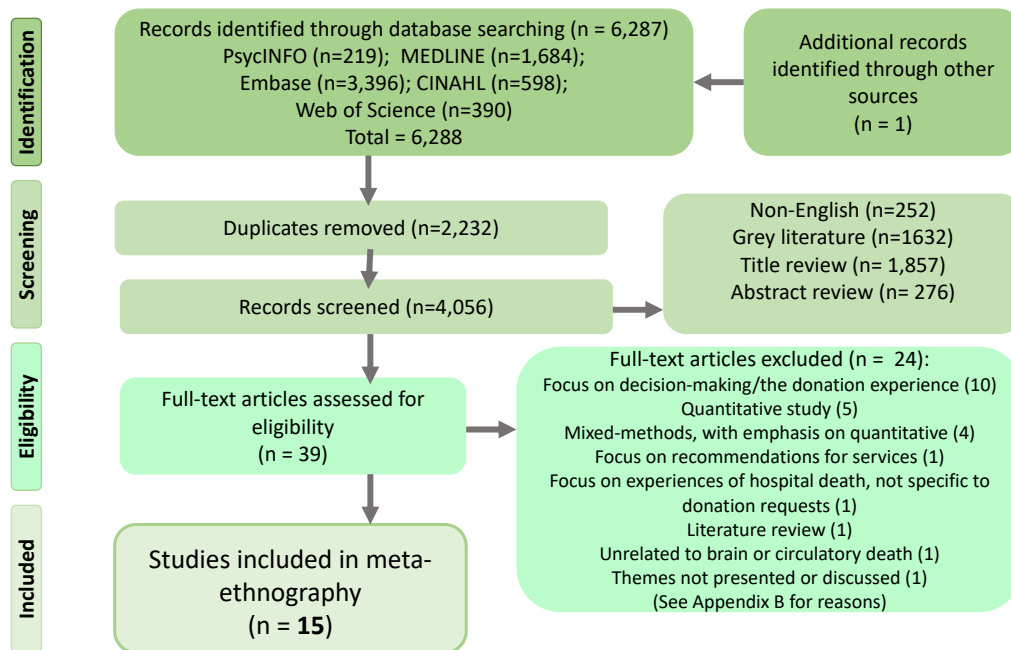


Figure 1: PRISMA (Moher et al, 2009) flowchart detailing search strategy

Study Characteristics

The search strategy identified 6,288 studies, of which 15 met the inclusion criteria for the synthesis. Table 3 (page 15) describes each study to contextualise the interpretations for the meta-ethnography (Britten et al, 2002). Appendix B provides the details of the 24 articles that were assessed in full but were excluded from the review due to not meeting the study aims. The studies explored the experiences of 411 adults, with participant numbers ranging from 2 to 107, the higher number reflective of a mixed-methods longitudinal study (Hogan, Coolican & Schmidt, 2013). Articles were published between 1992 and 2018, with the majority of studies being conducted since 2005, perhaps indicative of the increasing recognition of the challenges for families in reaching organ and tissue donation decisions and interest in how to optimise this process to improve long-term well-being. The age range of the deceased was four months (Hoover, Bratton, Roach & Olson, 2014) to eighty years (Walker & Sque, 2016).

Six studies involved consenting and non-consenting donor families, and nine studies included consenting families only, including one study exploring unsuccessful donation (Taylor et al., 2018). Total consenting relatives (n=368) far outnumbered non-consenting relatives (n=43). Three studies were conducted six-twelve months post-bereavement (Hogan et al., 2013; Shih et al., 2001; Walker & Sque, 2016), with the remaining studies extending beyond twelve-months up to seven years (Bellali & Papadatou, 2006). Fourteen studies explored solid organ donation, five of which also made reference to tissue donation requests. One study focused exclusively on tissue donation requests (Hogan et al, 2013).

Thirteen studies were cross-sectional designs and two were longitudinal designs (Hogan et al., 2013; Sque, Long & Payne, 2005). Hogan et al. (2013) utilised content analysis of written responses rather than an interview method. Two other studies analysed written responses (Tymstra et al.,1992; Walker & Sque, 2016) to accommodate participants' preferences. The included studies represented nine countries, none of which were operating presumed consent: USA (4), UK (4), Greece (1), Switzerland (1), Canada (1), Iran (1), Taiwan (1), China (1), Netherlands (1).

Data Extraction and Synthesis

Steps three to six of meta-ethnography involve a comparative and systematic synthesis of the selected studies. Each paper was read repeatedly to identify and extract key concepts and themes relevant to the research question, forming the primary data for the meta-ethnography. A list of key themes was generated to consider the relationships between the studies (Noblit & Hare, 1988) (Appendix C). As time limits had not been applied to the search, the papers were read in chronological order, to ascertain how experiences within organ transplant processes may have evolved.

These ‘first-order’ (the original respondents’ terms) and ‘second-order’ (the original authors’ interpretations) conceptual categories were translated across studies, grouped into themes, and translated to develop a ‘third-order’ of interpretation (Britten et al, 2002). Original papers were reviewed to ensure that the essence of the original findings remained preserved (Campbell et al., 2011). This process of reciprocal translation, akin to constant comparison, developed a ‘line of argument’, to help understand the themes identified in the meta-ethnography (Toye et al, 2017).

Table 3

Summary of the characteristics of included studies

Study	Country	Study aims	Sample size	Participant details	Reason for death	Data collection	Analysis method
Bellali & Papadatou (2006)	Greece	To investigate donor (organ and tissue) and non-donor parents' experiences, following the brain death of their underage child, and the impact of decisions on their grief process.	22	11 consenting parents (aged 32-51) and 11 non-consenting parents (age 31-51). 8 were couples. Donor children (n=7) aged 2-16 (mean=10); Non-donor children (n=7) aged 3-16 (mean=9). Time range since death: 8-80 months (mean=40)	Brain death (13 head injury; 1 CNS disease)	Semi-structured interview ranging 60 to 200 minutes (mean = 2 hours).	Grounded Theory
Haddow (2005)	Scotland	To explore donor relatives' beliefs about the death and the bonds with the deceased	19	Relatives of 15 donors aged 18-55+. Kinships: spouse; parents; sibling; child; aunt. Deceased ages ranged 15-55+. 10 donors had a donor card. Post-donation period: 8-36 months.	Brain death.	Semi-structured interviews (1-3 hours), focusing on views on death and the deceased's body.	"Qualitative data analysis"
Hogan, Coolican & Schmidt (2013)	USA	To describe family members' experiences of grief 6 months after tissue donation	107	Bereaved adults (ages not reported) who authorised tissue donation. 82% women, mostly Spouses (46%) and mothers (23%). 92% white. 6 months post-death.	Traumatic sudden death; cardiac arrest (67%); accident (20%)	Part one of a 5-year longitudinal study. Written responses to two open-ended questions exploring the loss and meaning of the donation.	Qualitative content analysis of written answers
Hoover, Bratton, Roach & Olson (2014)	USA	To describe organ donor and non-donor parents' experience of grief, following circulatory death of their underage child.	13	13 parents from 11 consenting families and 2 non-consenting families. Child's age ranged from 4 months to 16 years (mean=7.5yrs). Time range since death: 1 to 4.5 years (mean=2.7 years)	Circulatory death. All but one died suddenly from non-chronic causes.	Structured Interview (average 82 mins donor parents; 59 mins nondonor parents).	Constant Comparative Analysis

Study	Country	Study aims	Sample size	Participant details	Reason for death	Data collection	Analysis method
Kesselring, Kainz & Kiss (2007)	Switzerland	To explore experiences of relatives related to an organ donation request	40	31 consenting and 9 non-consenting relatives to 33 individuals. Five donations were unsuccessful. Relatives included parents (38%), partners (33%) and children (15%), aged 20-79yrs. Ages of the deceased ranged 4-78 years (mean=39). Range since death 6-17 months (mean=11).	Brain death: Stroke (15); brain injury (12); suicide (2); long term illness (1) other (3)	Interview lasting 1-3 hours.	Grounded Theory
Maloney (1998)	USA	To describe the experiences of loss, coping and healing in two donor families.	2	A donor mother and donor father from two different families following the death of their children (age 15 and 16)	Brain death due to a traffic accident and suicide.	Case study. Interview implied.	Not stated
Manuel, Solberg & MacDonald (2010)	Canada	To decrease barriers to donation.	5	Females over age 19 who consented to donation. Post-donation period: 6-36 months	Brain death: Head injury; sudden illness	Unstructured interviews (45 minutes)	Thematic Analysis
Manzari et al., (2012)	Iran	To explore families' experiences of an organ donation request following brain death within a specific cultural context	26	14 consenting and 12 non-consenting families. The deceased were aged 12-52 and 75% male. Kinships included parents, children, spouses and siblings. Time since death: 6-18 months	Brain death: Accidents (19), convulsion (1), haemorrhage (3), unknown (1)	Unstructured in-depth interviews (1-3 hours)	Qualitative Content Analysis
Shih et al., (2001)	Taiwan	To explore the impact of the decision to donate a relative's organs and/or tissue on family life.	22	10 men, 12 women age 25-56. Types of kinship: Parents; sister; spouse. Donors were age 19-42. Six months post-loss.	68% victims of an accident; 23% heat attack; 9% unknown	25 semi-structured interviews (40-60 minutes)	Grounded Theory
Sque, Long & Payne (2005)	UK	To identify the impact of hospital care related to donation in grief.	49	46 consenting and 3 non-consenting relatives. Time since death: up to 26 months.	Sudden death: brain-death.	Longitudinal study. Interviews at 3 time-points; Use of Grief Experience Inventory; Beck Depression Inventory.	Comparative thematic approach

Study	Country	Study aims	Sample size	Participant details	Reason for death	Data collection	Analysis method
Sque & Payne (1996)	UK	To describe the totality of relatives' organ donation experience.	24	16 families who consented to multi-organ donation. Relationships to donor were: parents, child, wife and daughter in law. Donors age range:0-56 years. Average 15months post-donation.	Brain death: cerebral haemorrhage (7); head injury (4); cerebral anoxia (3); result of illness (2)	Semi-structured interviews (1.5-2 hours)	Grounded Theory
Taylor et al. (2018)	USA	To characterise the experiences of family members following unsuccessful donation	15	15 family members of 12 potential donors. Potential donors aged: 18-64 years. Respondents: Parents' spouses; siblings; child; aunt. Range since loss: 6-60 months.	Circulatory death and serious brain damage: e.g. stroke (5); head injury (2)	Open ended interviews	Qualitative Content Analysis
Tong et al., (2006)	China	To explore the perceptions and needs of cadaveric organ and tissue donor families, following donation	13	One member from 13 donor families. Kinship: spouses; parents; children and sibling, aged 26-56. Donors were aged between 12-62 years, 11 were male. Range since loss: 7-48 months.	Sudden and unexpected death, brain death: e.g. Accidents (7)	Semi-structured interviews	Thematic Content Analysis
Tymstra, Heyink, Pruijm & Slooff (1992)	Netherlands	Exploring the experiences of bereaved relatives following an organ donation request.	11	Five consenting and six non-consenting family members. 12-24 months post donation.	Cerebral haemorrhage and brain injuries from traffic accidents.	Interviews, either face to face (9), telephone (1), and a written response (1)	Not stated
Walker & Sque (2016)	UK	To identify the perceived benefits of organ and tissue donation for grieving families who experienced end of life care.	43	21 male/22 female members of 31 consenting families. Relationships: parent; spouse; child; sibling; step-relative; uncle. Donors ages: 17-80years; 52% over 60. Post-loss: 6-12months (mean=7)	Brain death (12), circulatory death (18); 1 unknown.	30 semi-structured interviews: face to face (26; 12 involved 2 family members); telephone (4) and 1 written response.	Qualitative Content Analysis

Quality Appraisal

The use of quality criteria for meta-ethnography research has been debated (Toye, et al., 2014), and there is not currently agreement for what makes a study suitable for synthesis (Campbell et al, 2011). Quality appraisal tools for qualitative literature have also been found to produce inconsistent judgements (Dixon-Woods et al., 2007). However, quality control systems can be useful to ensure the quality, trustworthiness and transferability of each study's findings when synthesising the translations. The use of quality appraisal can also help develop the confidence of policy-makers and practitioners regarding the findings (Attree & Milton, 2006) and has increased in popularity (Hannes & Macaitis, 2012).

The quality of included papers was assessed using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018), which comprises of 10 questions relating to issues of validity, credibility and relevance. The checklist was used to help ensure a structured approach in considering the merits of each included study, rather than an exclusion tool, as recommended by the authors (CASP, 2018) and the wider literature (Sandelowski & Barroso, 2007). To allow for comparison of quality, a rating system of 0-2 was developed for each of the 10 items, with a higher score indicating a study's greater potential contribution to the synthesis (Chenail, 2011). Two screening questions in the checklist were completed before data extraction to ascertain the relevance of continuing with the article (CASP, 2018), and the remaining questions were completed following data extraction to reduce bias throughout the process. While all studies were retained for the current review, outcomes of the critical appraisal process were taken into account when reviewing findings.

To maintain quality control, peer review of four of the included papers was undertaken once the author had appraised all studies (NICE, 2012). The peer reviewer completed the CASP

checklist, and the papers and findings were discussed as advised by the CASP authors. Whilst judgements broadly concurred, a few slight differences were noted and resolved through using the prompts included in the CASP tool to facilitate discussion. Discussions were also held within the supervision team regarding quality control.

Results

The results of the quality appraisal of the fifteen included studies are shown in Table 4, and the utility of the findings for the meta-ethnography will be discussed in the results and discussion sections. Appendix D presents the appraisal findings in full.

Table 4
CASP quality appraisal results of the included studies

Study	Aims	Methodology	Design	Sampling	Data	Reflexivity	Ethics	Analysis	Findings	Value	Score
Bellali & Papadatou (2006)	2	2	2	2	1	0	2	2	2	2	17/20
Haddow (2005)	2	2	1	1	2	2	2	1	1	1	15/20
Hogan et al. (2013)	2	2	2	1	2	0	2	2	2	2	17/20
Hoover et al. (2014)	2	2	1	2	2	1	2	2	2	2	18/20
Kesselring et al. (2007)	2	2	1	1	1	0	2	2	1	1	13/20
Maloney (1998)	1	2	1	0	0	0	0	1	1	1	7/20
Manuel et al. (2010)	2	2	1	1	1	0	1	1	1	2	12/20
Manzari et al. (2012)	2	2	1	1	2	2	2	2	2	2	18/20
Shih et al. (2001)	2	2	2	1	2	2	0	2	2	2	17/20
Sque et al. (2005)	2	2	2	2	1	1	0	1	2	2	15/20
Sque & Payne (1996)	2	2	2	2	2	2	1	2	2	2	19/20
Taylor et al. (2018)	2	2	1	2	2	1	2	2	2	2	18/20
Tong et al. (2006)	2	2	1	2	2	1	2	2	2	2	18/20
Tymstra et al. (1992)	2	2	0	2	2	0	1	0	1	1	11/20
Walker & Sque (2016)	2	2	2	2	2	1	2	2	2	2	19/20

The quality of each study ranged from quality ratings of 7/20 to 19/20, with eleven of the fifteen studies scoring above 15, suggesting the majority of studies were of high methodological quality. Although lower scoring studies were not excluded from the synthesis, the meta-ethnography utilised the CASP scores to determine the extent to which single and collective evidence informed the synthesis and subsequent recommendations (Toye et al., 2013), with findings from higher scoring studies being assigned more weight.

All studies provided a rationale for the research and relevance to practice, although this was not always contextualised by the literature (Maloney, 1998) or a theoretical grounding. The rationale for selecting qualitative methodology was not always clear, with nine studies providing limited rationale, or no rationale (Tymstra et al, 1992). Reporting of method, sampling, design and analysis was variable, including a failure to state epistemological positions. Six studies did not refer to the researcher's role in the qualitative process, which could have influenced the reporting of results.

The majority of studies reported on ethical considerations, with three exceptions (Maloney, 1998; Shih et al., 2001, Sque et al., 2005). Tymstra et al. (1992) did not state analysis method, and four studies inadequately stated their method, making appropriateness of analysis difficult to judge. One study did not evidence themes with quotations (Sque et al., 2005). Discussion of limitations and the relevance to psychological theory and practice was variable. Bellali and Papadatou (2006), Hogan et al. (2013), Sque and Payne (1996) and Walker and Sque (2016) made particularly explicit links to theories, including grief, attachment and decision-making when reporting their interpretations.

The themes from included articles were similar, allowing for reciprocal translation (Britten et al., 2002), as opposed to refutational translations. Table 5 presents the twelve translations that were developed from the key concepts; the number of categories that contributed to their development; and three lines of argument that were developed. These lines of argument annotate the experiences of families who experienced an organ donation request: The ongoing relationship with the donor; The psychological impact of the decision; Support in grief. The themes will be presented with narrative examples and original quotations.

Table 5
Summary of the main themes

Translated concepts: Subordinate themes	Number of codes	Contributing papers													Line of argument: Superordinate themes		
		Bellai & Papadatou (2007)	Haddow (2005)	Hogan et al. (2013)	Hoover et al. (2014)	Kesselring et al. (2007)	Maloney (1998)	Manuel et al. (2010)	Manzari et al. (2012)	Shih et al. (2001)	Sque et al. (2005)	Sque & Payne (1996)	Taylor et al. (2018)	Tong et al. (2006)		Tymstra et al. (1992)	Walker & Sque (2016)
A less final death	13	✓	✓	✓			✓	✓	✓			✓	✓			✓	
Honouring the life and wishes of the donor	15	✓		✓	✓		✓	✓	✓	✓		✓	✓	✓			
The need for meaning	18	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	
Social visibility	5		✓				✓		✓	✓			✓	✓			
Post-traumatic growth	18	✓		✓			✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Causing harm in life; causing harm in death	20	✓	✓		✓	✓		✓	✓	✓			✓	✓		✓	
Spirituality	7		✓			✓			✓	✓				✓			
Emotional distress	15	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
The legacy on grief	14	✓								✓		✓	✓	✓	✓	✓	
The support system: approval and privacy	21				✓		✓		✓	✓		✓		✓	✓	✓	
The impact of the donation request	13	✓			✓	✓			✓		✓			✓	✓		
The donation outcome	21	✓	✓		✓		✓	✓	✓	✓		✓	✓	✓	✓		

‘A less harsh road, a less final death’: An ongoing relationship with the donor

‘The bittersweet miracle’: Psychological impact of the decision

‘It’s not gratitude I want, it’s support’: Support in grief

Expressing the Synthesis

“A less harsh road, a less final death” (Sque & Payne, 1996, p1366): An ongoing relationship with the donor

Across all studies, families spoke of the impact of their decision on their ongoing relationship with the deceased, including a need to have the life of the deceased validated. Donation could maintain ongoing bonds to the donor relative, which denied the finality of death.

“It (the donation) comforted me because although my child was buried, I was telling myself that he is still alive. What mainly helps me is to know that his heart is still beating” (2-year-old boy’s donor mother)

Bellali & Papadatou (2006) p.893

“It would be wonderful to have somebody living on with part of [donor] living...just having those same 2 words in the same sentence, ‘Our dead son’s organs are living’. That’s a big thing”. (unsuccessful donor parent)

Taylor et al. (2018) p.406

Such ongoing attachment with the donor was perceived to provide solace in grief, such as easing suffering, although Bellai and Papadatou (2007) found parents who sought their child within the recipient to be at increased risk of experiencing complex grief. Donation was an opportunity to make sense of the sadness, allowing the life and death to have meaning and purpose, a concept appearing in 12 studies, including all with high quality CASP ratings. The knowledge of saving another person’s life and providing hope to another family was a highly reported theme, and failure of the donation was perceived to worsen the loss and be a wasted opportunity.

“They give their organs to somebody else so that they can have the gift of life and what they give to us is almost not an easy road in grief but a different road through grief... it’s filled with the joy of knowing good has come out of his death...It is a tremendous thing, it ripples out to hundreds of people” (Donor father)

Sque & Payne (1996) p.1366

“...hearing from the family just how it helped them, I think that almost lessens your pain, and lessens your grief... because he wasn’t able to donate, I... it’s harder for my children and I”
Taylor et al. (2018) p.406

Ten of the studies reported comfort in grief through honouring the wishes of the donor, and through allowing attributes, such as compassion and selflessness to live on. Comfort was still largely reported in non-consenting families if this decision matched that of the deceased (e.g. Tymstra et al., 1992). For some, comfort was experienced from an internal recognition of honouring the donor’s preferences or values, while public awareness of the donor’s contribution was important for others. Some families imagined what their relatives’ preferences might be based on their character in life, and donation was experienced as an unexpected opportunity that could unify the deceased and the living.

“I’m glad we had a chance to do the right thing” (wife of a donor)
Hogan et al. (2013) p.185

However, distress was reported, up to seven years after the loss, by perceived failures to honour the wishes of the donor.

“I know that Eleni would have wanted me to donate her organs. This is typical of her character. Sometimes I think that I should have done it, but if she was a mother she would have understood why I could not do it” (12-year-old non-donor mother)
Bellali & Papadatou (2006) p.894

“It was not possible for me to change my decision. Maybe it was better to agree with donation, especially because he was satisfied with it...I fear his soul is annoyed because of my decision”
Manzari et al. (2012) p.662

'The bittersweet miracle' (Maloney, 1998, p.346): Psychological impact of the decision

The second theme describes the impact of the decision for families in grief, the title referring to the potential for life to rise out of a situation of sacrifice. Findings were variable, with some families viewing the donation and the grief as separate processes.

"It neither helped, nor hindered me"
Bellali & Papadatou (2006) p.893

Findings captured Sque and Payne's (1996) theory of 'dissonant loss', whereby the donation legacy provides comfort, but is insufficient to ease suffering (Bellali & Papadatou, 2006; Hoover et al., 2014; Manzari et al., 2012; Walker & Sque, 2016). These findings are supported by the high quality of the articles (CASP rating: 17-19/20). Some families were resentful that the donation request had been made (Tymstra et al., 1992; Haddow, 2005), disclosing added uncertainty in grief over the decision, although these studies were of moderate quality (CASP rating: 11-15/20). Consenting families who experienced non-donation perceived a more intense grief than anticipated through being denied a sense of accomplishment, and felt guilt for letting down potential recipient families (Hoover et al., 2014; Taylor et al., 2018), although some found comfort in their meaningful intentions (Taylor et al., 2018).

Features of prolonged grief were reported up to seven years (the maximum timeframe from the included studies) after the loss in consenting and non-consenting families, such as feeling anger, rage, despair, guilt and regret (Bellali & Papadatou, 2006; Manuel et al., 2010; Tong et al., 2006; Tymstra et al, 1992), and traumatic flashbacks of the hospital experience (Kesselring et al., 2007). When the deceased were younger, enduring emotional suffering was

evident regardless of decision (Bellali & Papadatou, 2006; Hoover et al., 2014; Manuel et al., 2010). Shih et al. (2001) also found consenting families to experience significant emotional turmoil, including suicidality in the first six-months following bereavement. Although variable and under-represented, those who declined donation appeared to experience the most regret across studies over the lost opportunity to save a life.

“I wish I could go back in time and agree with the donation”
Manzari et al. (2012) p.662

Concern about causing harm to the deceased, both in life and death, impacted on families, often leading to feelings of guilt rather than regret. Five studies of varying quality (CASP rating:13-19/20), reported additional distress in grief, over concerns the decision to donate had denied the chance for recovery, and that their decision had caused the death (Bellali & Papadatou, 2006; Kesselring et al., 2007; Manzari et al., 2012; Taylor et al., 2018; Walker and Sque, 2016). All studies included families at least 12-months post-bereavement.

“I barely survived it... I have asked myself 100 times if he was really dead or if we killed him by consenting”
Kesselring et al. (2007) p.215

Some families, however, felt donation gave them extra time with their relative and witnessed that recovery was unlikely (Manuel et al., 2010). Seven studies identified concerns about harm to the donor after death. Concerns included harm to body integrity (Haddow, 2005; Hoover et al., 2014; Kesselring et al., 2007; Shih et al., 2001; Taylor et al., 2018; Tong et al., 2006; Walker & Sque, 2016), with a desire to maintain an optimal image of the relative. This was particularly apparent, in relation to feelings of guilt and shame, when the deceased were younger.

“I’ve always felt very sorry that we said ‘yes’ ...I can’t bear the idea that they still cut up his body, while he was so proud of it” (Mother of 20-year-old donor)
Tymstra et al. (1992) p.143

“...not even so long ago it flashed in front of me that his body, which I’d lain with, touched and stroked, wouldn’t have looked the same. That he would have scars. That he would be cut” (Mother of donor).
Haddow (2005) p.102

Reasons for refusing donation included a desire to protect the relatives’ body from further trauma, especially as many relatives had sustained traumatic physical injuries (Bellali & Papadatou, 2006; Hoover et al., 2014; Walker & Sque, 2016). The sense of violation seemed to change in grief:

“But you know, we had her remains cremated so it’s all, I mean, I don’t know”
Hoover et al. (2014) p.108

In grief, donation decisions were evaluated against spiritual, superstitious or cultural norms, often resulting in concerns of causing harm in the afterlife (Kesselring et al, 2007; Shih et al., 2001; Tong et al, 2006). However, donation was also an opportunity to help the relative in the afterlife (Manzari et al., 2012; Shih et al., 2001), and provide the remaining family with solace and deeper spiritual connections (Manzari et al., 2012; Shih et al., 2001; Tong et al., 2006). An inability to honour a donor’s wishes was also perceived to cause harm to donors after death through being denied the chance to counteract the adversities experienced in life.

“[he] always struggled with self-esteem...and I thought this [organ donation] could be, finally something he’d be really proud of” (Mother of unsuccessful donation)
Taylor et al. (2018) p. 405

Donation was also perceived to reduce the emotional pain anticipated in grief, with eleven studies (eight with CASP ratings over 17/20) reporting personal positive change following the adversity. In these studies, donation was perceived to ease grief, evoke a sense of tranquillity and retain some sense of normality (Bellai & Papadatou, 2007; Manzari et al.,

2012; Manuel et al., 2010), especially when relatives were satisfied decisions were aligned to the donor's preferences (Tymstra et al, 1992; Walker & Sque, 2016). Donor families often went on to become advocates for donation, and described reformed priorities, such as an appreciation for life, a focus on the achievement of donation rather than death, closer family relationships and a reduced focus on material objects (Bellai & Papadatou, 2007; Shih et al., 2011; Walker & Sque, 2016). Personal growth was also evident for non-consenting relatives.

"It's made me...able to accept the bereavement...I think if we hadn't done that, the donor system, I think there'd be a big hole and I think the whole process would be more painful"
Walker & Sque (2016) p.77

"I feel that I've matured and become more resilient" (Non-consenting father to 3-year-old)
Bellai & Papadatou (2007) p.904

***"It's not gratitude I want, its support"* (Maloney, 1998, p.342): Living with the loss**

The third theme incorporates factors that appear to help or hinder loss processing in families who experienced a donation request. Stories emerged across studies related to the information quality and timing of the donation request. Through reading the studies in chronological order, it was apparent that healthcare services have responded to the need for well-timed, accurate and clear information regarding brain-death and donation. Both consenting and non-consenting participants in Tymstra et al.'s (1992) study experienced regret and confusion over their decision, attributing this to bad timing and vague explanations about brain-death.

"If they had approached me differently at that time, I might have agreed. I think it's a pity it went the way it did, because they are in desperate need of donor organs"
Tymstra et al. (1992) p.143

Participants of Kesselring et al. (2007) and Hoover et al.'s (2016) study found comfort in their decision to donate, reflecting on the value of the time, information and psychological

support that was offered alongside the request. However, many remain confused and uncertain about their choices.

“My son could donate his organs, but why could people not donate to him?”
(Tong et al., 2006) p.28

Recent studies continue to illustrate the difficulty for families to process such information in such emotionally desperate situations. Confusion was found to continue in grief regarding the difference between coma, brain-death and circulatory death (Bellali & Papadatou, 2006; Taylor et al., 2018; Tong et al., 2006), which increased over time (Sque et al, 2005), and contributed to concerns of harms to donor, as described in theme two. Non-consenting families could regret their decision, but acknowledged they were too overwhelmed at the time to fully comprehend their choices (Bellali & Papadatou, 2006). A high-quality paper found clear conversations, with space for psychological support at the time of request were found to help manage the dissonance in grief, guilt and negative family feedback (Manzari et al., 2012).

“I was very upset, but I thought they (extended family) don’t know the difference between coma and brain death. We had done the right thing and they were wrong”
Manzari et al. (2012) p.661

Making sense of the decision in grief appeared to be linked to the attitude displayed by the staff at the time of the request and the clarity of information provided (Tong et al., 2006). An organ-focused approach rather than a person-focused approach had the potential for additional conflict in grief (Kesselring et al., 2007).

“We clearly said no to organ donation but the MD said ‘You have a healthy child, with a healthy heart and lungs, but he is brain dead...his healthy organs could be very useful to somebody else”
Kesselring et al. (2007) p.215

Support systems, particularly wider family responses to donation decisions, influenced grief. Approval from family and friends at the time or after the decision went some way to alleviating feelings of doubt (Shih et al., 2001; Tong et al., 2006), although many viewed discussing the donation request as an extra burden, potentially causing family disagreement and generating demoralization and shame (Manzari et al., 2012). Some families coped by concealing the request and decision from the wider family (Shih et al., 2001; Tong et al., 2014; Tymstra et al., 1992). Support and praise from outside the family related to a decision to donate emphasised the significance of the donation, as described in theme one, and connecting with other families who had been affected by donation was valued (Hoover et al, 2014). However, many donor families felt isolated, with little professional or psychological support in their particularly unique grief (Shih et al, 2001; Sque & Payne, 1996; Tong et al, 2006).

“It’s not gratitude I want, its support services...I’m living with feelings not only because my son is dead, but because others are alive because of him”
Maloney (1998) p.342

A common theme for consenting families was the outcome of the donation, even up to seven years post-donation (Bellali & Papadatou, 2006). A desire for knowledge of the outcome was perceived to provide comfort in grief and confirm the value of the donation, as described in theme one. Outcome information differed depending on the policies of the country, but included thank you cards or letters from the transplant team (Sque & Payne, 1996; Walker & Sque, 2016) or the recipients (Hoover et al., 2014; Tong et al., 2006) and meeting the recipient and their family (Manzari et al., 2012). Overall, knowledge of the outcome and the wellbeing of the recipient was often more important than an opportunity to meet the recipient (Haddow, 2005; Manzari et al, 2012; Sque & Payne, 1996; Tong et al., 2006). In some

instances, the outcome remained unknown, which caused additional strain (Tymstra et al., 1992; Bellali & Papadatou, 2006, Shih et al, 2001).

“It was important to know and be sure that the transplant had been successful. Although the operation results were not related to us, my mind was always busy with the result”
Manzari et al. (2012) p.660

While Bellali & Papadatou (2006) found some families regarded the outcome as unimportant and as holding little influence over grief, Hoover et al. (2014) found families experienced disenchantment when they learnt their child donated organs to an older adult.

“I would hope that it would be like a, you know, a 30-year-old or something, not a 60 or 70-year-old people. And that’s what kind of hurt me”
Hoover et al. (2014) p.108

Discussion

The review aimed to provide insight into the development of grief over time for bereaved families who were approached with an organ and/or tissue donation request. A systematic search of the literature identified fifteen qualitative studies published between 1992 and 2018, which were quality appraised using a qualitative checklist (CASP, 2018). A meta-ethnography approach (Noblit & Hare, 1988) facilitated the translation and synthesis of the studies to create a line of argument through three super-ordinate themes: An ongoing relationship with the donor; The psychological impact of the decision; Support in grief.

The meta-ethnography suggests the option of consent to donation is a complicated and life changing experience for bereaved families involved in reaching any decision outcome. Donation decisions can provide meaning to the life and death of the deceased relative, which can offer solace and hope for families’ post-bereavement, especially if the wishes of the

deceased and bereaved are fulfilled. The synthesis found donation could change the emphasis from death, to a focus on the joint achievement of the donor and the bereaved. However, grief following a donation request may be a contradictory experience of peace alongside doubt, and psychological harms can be experienced in the months and years post-bereavement. The consequences for families are not obvious at the time of the decision and may depend on the availability and provision of support in grief following a donation request. Families indicated family and friends, religious and cultural beliefs, recipient outcome information and professional support as factors influencing the processing of grief.

Risks of complex grief increase when a death is untimely and in traumatic circumstances (Boelen, 2016; Boelen, De Keijser & Smid, 2015), and responses to loss can be understood through the attachment literature, whereby the relationship style to the deceased may predict the grief response (Hogan et al., 2013; Hogan, Schmidt & Coolican, 2014). The included studies featured families who had experienced the sudden and unexpected loss of a relative, and the deceased included people under age 20 in all studies. The risk factors for prolonged grief were increased in all families, with the potential for difficulty accepting and adjusting to the loss, which was explored from at least six months up to seven years post-bereavement. Theoretical underpinning was lacking in the included studies, with only four papers discussing attachment and grief theory (Sque & Payne, 1996; Bellali & Papadatou, 2006; Hogan et al., 2013, Walker & Sque, 2016).

Sque and Payne's (1996) model of 'Dissonant Loss' suggests donation serves as a defence mechanism against the anguish of death through providing hope and an ongoing attachment with the deceased, in a way that might ease bereavement. While Bellali & Papadatou (2006) suggested donation as a protective factor in parental grief, features of complicated grief were

apparent in parents who sought a permanent attachment to their child through donation. Grief can become complicated when a death is unable to be accepted, (Boelen, Van den Hout & Van den Hout, 2006), which has implications for donor relatives who seek their relative in recipients (Haddow, 2005). The theme 'An ongoing relationship', illustrated variance in donor families' descriptions of the donor's continued existence. For some, the donation was symbolic, whereby the donor's organs lived on, while others described the donor relative as literally living on from their new body. Bellai and Papadatou (2007) found parents who viewed the child as living on in a symbolic sense were better able to grieve their loss. The theme annotates the 'Continuing Bond' (Field, Gao & Paderna, 2006), and how continued inner-connections with the deceased may be adaptive, depending on the relationship in life (Klass, Silverman & Nickman, 2014; Stroebe & Schut, 2005).

Similar to the quantitative research (Cleiren & Van-Zoelen, 2002; Merchant et al, 2008), the synthesis found variance regarding donation decisions and the impact on the grief process. While some families reported the request and the decision neither helped not hindered (Bellai & Papadatou, 2007), others believed donation decisions impacted on the grief process in both consenting and non-consenting families (Manzari et al., 2012; Shih et al., 2001). Such differences may be explained by socio-cultural differences, with Manzari et al's (2012) study emphasising spirituality and religion in managing loss. A minority of families described donation requests to interfere with their grief, creating confusion (Tymstra et al., 1992), unease (Taylor et al., 2018) or regret (Manzari et al., 2012; Bellali & Papadatou, 2006; Haddow, 2005). This was particularly true for parental grief, which could be explained by the strain of coping with the loss alongside the shattering of 'assumptive world' beliefs (Parkes, 1988), through outliving a child (Lichtenthal, Currier, Neimeyer & Keesee, 2010).

Understanding of brain-death was troubling for families in grief, which is similar to findings from a recent longitudinal study (Kentish-Barnes et al., 2018), which found complicated grief was significantly associated with comprehension of brain-death. Differences were not found in grief symptoms between consenting and non-consenting families, however, the study was conducted within the first nine months post-bereavement, which may be premature to categorise prolonged grief. The quantitative component of Hogan et al.'s longitudinal study (Hogan et al., 2014) found grief reactions in consenting families followed a typical process of grief (Hogan, Morse & Tason, 1996), whereby distress decreased over 25-months post-bereavement and personal growth increased. Ongoing attachment to the deceased did not change, and adverse outcomes in bereavement were concluded to be less than those healthcare teams anticipate. However, as with the majority of studies, comparison groups of families who rejected donation were missing, as were families who were not approached to donate.

Critical Appraisal

The review presents an advance from previous reviews (Dicks et al, 2017; Ralph et al., 2014), providing a conceptual synthesis of qualitative research exploring the experiences of families affected by donation using meta-ethnography methodology. It extends Chandler et al.'s (2017) scoping review, which emphasised the importance of the hospital experiences to balance organ requests with a duty to protect families from psychological harm. Consistent with Chandler et al., this review found donation could provide comfort to families, although many felt their pain was the same regardless of the donation decision. The majority of consenting and non-consenting families report satisfaction with their decision, with refusing families reporting more regret than consenting families.

This review incorporated qualitative methods from a range of study designs, although longitudinal designs were few. Studies of non-donor families are grossly underrepresented, which has been attributed to recruitment issues (e.g. lack of contact information), and the challenges and ethical implications of conducting bereavement research (Sque, Walker and Long-Sutehall, 2014). Study participants may have differed in their grief experiences to non-respondents, with the potential for selection bias (Stroebe & Stroebe, 1990). While international demographic profiles were incorporated, Black, Asian and Minority Ethnic (BAME) populations from western countries were poorly represented and research into the impact of donation requests within BAME populations are recommended. Similarly, further research in non-western countries where there may be different socio-cultural norms, healthcare systems and mourning rituals would also enrich and diversify the evidence base.

The inclusion of a quality rating tool (CASP, 2018) helped to evaluate the rigour of the studies and highlight their strengths and limitations. The quality review suggested that the qualitative research quality could improve through clarifying the qualitative method and analysis method employed and describing them in replicable detail. References to researcher reflexivity in the studies were also poor, which could have resulted in biased interpretations and reporting, especially as many studies aimed to improve donation rates. Only four studies were theoretically underpinned, such as Bellali & Papadatou (2006) who applied Hogan et al.'s (1996) grief model to their findings. While qualitative research may aim to develop theory, the use of theoretical frameworks is important in deriving the objectives of the research (Reeves, Albert, Kuper, & Hodges, 2008).

A strength of the review is the use of CASP scores to help assign contribution to the synthesis (Boeije et al., 2013). While CASP scores were used to provide a sense of the rigour of each

paper, in using the meta-ethnography approach, the richness of the data were first examined, and the researcher's interpretation and synthesis of the original findings were qualified with the outcomes of the quality appraisal. Lower scoring papers were used to support a theme only if the theme emerged from papers of moderate to high quality.

Carroll and Booth (2015) question if a final synthesis benefits from the exclusion of studies based on quality, and identified three principal options when conducting qualitative evidence syntheses: 1) omit completing a quality appraisal due to problems of subjectivity, but risk presenting a review with low credibility; 2) use the selected appraisal tool to exclude studies based on specific criteria, although the subjective identification of such criteria may affect the external validity of the review; 3) conduct a quality assessment followed by a post-synthesis sensitivity analysis. This option was selected for the current meta-ethnography as the most risk-averse strategy, through evaluating the relative contribution of studies of questionable merit on the synthesis while also ensuring no studies were excluded.

A post-hoc sensitivity analysis (Boeije et al., 2013) was conducted whereby the two lowest scoring studies by Maloney (1998) and Tymstra et al. (1992), with CASP scores below 12/20, were removed from the synthesis through excluding the evidence from each study for each theme as detailed in Table 5 and Appendix C. While these two studies were not found to contribute any unique themes or perspectives to the synthesis, the similarity in findings between studies of varying quality and utilising different methods are a strength of the synthesis. The exclusion of the lower quality studies based on CASP scores may have minimised the transferability of the synthesis findings, and the two studies in question provided rich narratives and quotations of the experiences of grieving parents, including those who refused donation.

Lower quality scores on the CASP may also be a reflection of focusing on published studies in peer-reviewed journals, which may be constrained by word counts and publication bias and the alignment of the primary studies aims and that of the review (Garside, 2014). It should also be considered that the value of sensitivity analysis in interpretative syntheses, such a meta-ethnography, has not yet been evaluated, and its use in qualitative syntheses is subject to further research (Carroll & Booth, 2015).

Studies ranged over a 26-year period and included varying timepoints (six months to seven years), which could have implications for the findings, for example, due to healthcare practice changes. However, while improvements in donation request practise were observed, family responses related to their grief largely remained consistent. The review illustrated the importance of person-focused rather than organ-focused approaches in donation requests (Kesselring et al., 2007), and the provision of quality information which includes visual explanations of brain-death (Sque et al., 2005). There was also evidence that post-bereavement support remains variable in its provision.

The literature search was exhaustive, although this is not a requirement in meta-ethnography (Noblit & Hare, 1988), with a suggested maximum of forty studies for synthesis (Toye et al., 2014) to ensure robust conceptual analysis (Campbell et al., 2011). A study published June 2018 (Sque et al., 2018) focusing on donor relatives' experiences of decision-making 3-12-months post-bereavement, found themes consistent with those of this meta-ethnography and examples of personal gain in grief through a sense of ongoing connection to loved-ones. As with any interpretative methodology, it is acknowledged that the synthesis provided is only the author's interpretation as a trainee clinical psychologist without familial experience of

donation, and alternative interpretations will be compatible with the same studies (Britten et al, 2002).

Clinical Implications

Healthcare systems are continually aiming to better support donation requests (Jansen, et al., 2011). Non-consent to donation has been linked to poor communication and support during the request process (Kentish-Barnes et al., 2018), and studies continue to illustrate the post-bereavement confusion for non-consenting and consenting relatives about the term ‘brain-dead’ (e.g. Taylor et al., 2018). This uncertainty can increase months and years after the decision (Sque et al., 2005), adding to emotional distress in grief (Stouder et al., 2009), which has implications for informed consent.

Clearly communicated information supported by visual information related to brain-death may ease confusion in grief (Sque et al, 2005). However, information about brain-death and donation may not be as influential on decision-making and sense-making in grief as knowing a family members preference towards donation and healthcare professionals displaying person-focused care (Bellali & Papadatou, 2006; Kesselring et al., 2007).

Support from family and social networks was sufficient for the majority of people following a loss, and professional intervention was not required (Bonanno, Westphal & Mancini, 2011). However, distress during the circumstances of donation requests can limit relatives’ recall of donation information (Siminoff et al., 2018), potentially restricting the ability for sense-making during the bereavement experience. Follow-up support for families could be beneficial to assess coping, and to respond to difficulties and unique challenges in grief that may stem from the stressful circumstances of donation requests. Specialist support may assist

with confronting the loss, providing a narrative for sense-making of requests and decisions, and reconstruct people's 'assumptive worlds' (Boelen, 2016; Calhoun, Tedeschi, Cann & Hanks, 2010; Neimeyer & Wogrin, 2008; Roepke, Jayawickreme & Riffle, 2013). While meta-analysis into grief interventions implies that complicated grief can be 'treated' but not prevented (Wittouck et al., 2011), access to support following bereavement must be available.

Descriptions of posttraumatic growth (Calhoun et al., 2010) in donor and non-donor families, emerged from the synthesis. Descriptions included an appreciation for life, a sense of meaning (of the death) and purpose (advocating donation post-bereavement), enriched spirituality and closeness with others, which may develop through honouring the wishes of the deceased, and identifying personal strengths from enduring the adversity. This indicates the significance of people sharing or registering donation intentions and has implications for countries considering 'enforced' or 'soft' presumed consent systems (McCartney, 2017; Shaw, 2017). Further research into support groups (Shih et al., 2001) for families affected by donation may be useful, as posttraumatic growth may be facilitated through connection with those who had similar experiences (Calhoun et al., 2010).

The review identified an internationally consistent theme of a need for donation outcome information, which varied significantly by country (e.g. Manzari et al., 2012; Walker & Sque, 2016). Outcome information provided solace in grief, although unsuccessful outcomes (Taylor et al., 2018), or unanticipated donor allocation could be distressing (Hoover et al., 2014) and be a lost opportunity for personal meaning-making of the event. Some families wanted contact with donor recipients, in some cases to have a continued relationship with their deceased relative (Bellali & Papadatou, 2006; Tong et al., 2006). While outcome

information may help in grief, healthcare professionals must be alert to ongoing rumination or ‘brooding’ (Boelen, 2016) regarding outcomes, which may complicate grief through intensifying the continuing bonds with the deceased (Eisma et al., 2015).

Further Research

None of the included studies were conducted in countries operating presumed consent; research is required in countries with ‘soft’ and enforced presumed consent legislation. A research briefing evaluating the impact of presumed consent in Wales indicates adjustment challenges for both families and healthcare professionals (Noyes & McLaughlin, 2017). Future meta-ethnographic reviews may focus on sub-populations of bereaved families, such as the perspectives of fathers (Dodd-McCue, Tartaglia & Cowherd, 2007), children and siblings (Sque et al., 2005). Studies which look at the grief process and changes in family members experiences of grief across time will optimise healthcare assistance for those who seek support.

Conclusion

This review has synthesised the extant qualitative literature with families who have experienced an organ and/or tissue donation request between six-months and up to seven-years post-bereavement. These studies highlight that relatives, regardless of decision, may experience grief processes which have yet to be fully understood. Healthcare professionals need to facilitate the process for families, recognising that they may re-frame their decision-making, especially during the follow-up period. Knowledge of relatives’ preferences may have notable influence to support both decision-making and grief, emphasising the value of public campaigns for relatives to express their intentions, even in countries operating ‘soft’ presumed consent, (e.g. NHSBT, 2013).

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“They make it all sound so easy”:
Pre-emptive Living Donor Kidney
Transplantation, Illness Perceptions and Treatment
Knowledge

Prepared in accordance with the author guidelines for the journal, *Psychology and Health*
(Appendix A)

To preserve confidentiality, all names of participants have been changed to pseudonyms

Word count excluding references: 8,000

Abstract

Aim: This study explored perceptions of pre-emptive living donor kidney transplantation (PELDKT) in a pre-treatment population. Its aim was firstly to explore perceptions of illness, knowledge of transplantation and preferences for renal replacement therapy (RRT). Secondly, the study aimed to use qualitative methods to elucidate how people with chronic kidney disease evaluate RRT choices, given Wales has newly adopted presumed consent legislation.

Method: A sequential explanatory design included a survey of 31 people with stage 3b-5 chronic kidney disease to situate the sample for semi-structured interviews with a homogenous sub-sample of 8 participants. The survey included the Brief Illness Perceptions Questionnaire, a living donor transplant knowledge questionnaire, and questions on RRT preferences. Audio-recorded interviews explored experiences of considering PELDKT. Interview data were transcribed and analysed using Interpretative Phenomenological Analysis.

Results: Four master themes emerged from the IPA (*My Kidney and I; Co-constructing Decisions; A Kidney Shared as a Problem Solved?; and Navigating the Unknown*). A desire for enhanced self-management information to delay illness progression was found.

Conclusions: Findings facilitate understanding of the potential psychological challenges and tasks facing people with CKD in pre-RRT. This understanding, along with the psychological theories applied, could help nephrology and transplant teams support patients and their families.

Keywords *Chronic kidney disease, illness perceptions, pre-emptive kidney transplantation*

Acronyms and Glossary of Terms

- | | |
|--|---|
| . Brief Illness Perceptions Questionnaire (B-IPQ) | . Living donor kidney transplant (LDKT) |
| . Chronic kidney disease (CKD) | . Non-directed transplant - <i>a kidney donated by a stranger into the donor pool</i> |
| . Deceased donor kidney transplant (DDKT) | . Pre-emptive living donor kidney transplantation (PELDKT) |
| . Directed transplant - <i>a kidney donated to a specific person</i> | . Renal replacement therapy (RRT) |
| . End Stage Kidney Disease (ESKD) | . Self-Regulatory Model of Illness (SRM) |
| . estimated Glomerular Filtration Rate (eGFR) | |

Introduction

Chronic kidney disease (CKD) is a long-term condition of gradual kidney function decline that is recognised as a serious global health problem (Webster, Nagler, Morton & Masson, 2017). There are five stages of CKD through which kidney function progresses from 'normal' (Stage 1) to End Stage Kidney Disease (ESKD) (Stage 5). Approximately 5-7% of the adult UK population have Stage 3-5 CKD and the number is expected to rise over the next ten years (Kim et al., 2017). Stages of kidney disease are determined by an estimated Glomerular Filtration Rate (eGFR), ranging from 44 (stage 3b) to below 15 (Stage 5).

Renal Replacement Therapies

Although some people prefer conservative management (Johnston & Noble, 2012), as kidney function declines, it becomes necessary for health professionals to assist people to consider Renal Replacement Therapy (RRT), such as dialysis modalities or transplantation.

Approximately 5,000 people with ESKD remain on UK transplant waiting lists (NHS Blood & Transplant, 2018), and depend on dialysis for their survival. Although there is not presently any evidence that transplantation earlier than stage 4 or 5 CKD produces additional benefit (Abramowicz et al., 2016), pre-emptive transplantation (before dialysis) from a living donor is regarded as the most clinically effective option (Abecassis et al., 2007) and is recommended in the UK where possible (Barclay & Burnapp, 2013; Dudley & Harden, 2011).

Reported advantages of pre-emptive living donor kidney transplantation (PELDKT) include: improved graft and life expectancy rates compared to other RRT modalities (Kanellis, 2010); psychological benefits (Gozdowska et al., 2016); maintaining financial wellbeing (Gaston &

Thomas, 2005); avoidance of dialysis (Innocenti et al., 2007); the ability for planned surgery (Kasiske et al., 2002), which could influence health control perceptions (Mitchell, 2007), and lower healthcare costs (Friedewald & Reese, 2012). However, living donor kidney transplantation (LDKT) poses ethical and emotional dilemmas for health professionals and potential recipient-donors dyads (Kanellis, 2010).

Despite demonstrable benefits of pre-emptive transplantation only 10.4% of UK kidney transplants are pre-emptive, 54% of which are from living donors (Bzoma et al., 2016). This can be attributed to nephrologists' difficulty in providing accurate timelines for optimal intervention (Marks et al., 2015), health comorbidities excluding transplantation (Lenihan, Hurley & Tan, 2013) and organ shortages (Neuberger, Trotter & Stratton, 2017).

Attitudes Towards Living Donor Kidney Transplantation

While patient preferences for cadaveric over living donors have been reported (Conrad & Murray, 1999; Gordon, 2001), medical and legislative advances since the millennium have facilitated awareness and preferences for LDKT as a treatment option. Martin (2014) and Kranenburg et al. (2009) found unspoken preferences for LDKT among those on transplant waiting lists, indicating that waiting list presence is not a proxy for preference. Challenges of pursuing LDKT include feelings of indebtedness at accepting a donor (Waterman et al., 2006); the potential for graft rejection (Pradel, Mullins & Bartlett., 2003); family conflict (Gill, 2012); perceived risks posed to donors (Zimmerman et al., 2006); fears of acquiring an unknown donor's characteristics (Bailey et al., 2016); and lack of knowledge (Kranenburg et al., 2007), such as not knowing how to discuss donation with relatives (Barnieh et al., 2011).

Compared to those transplanted after dialysis, pre-emptive transplant recipients experienced greater psychological discomfort and lower acceptance of illness post-transplant (Bzoma et al., 2016). This can be attributed to abstract perceptions of illness and treatment becoming experiential (Meuleman et al., 2017; Leventhal, Brissette, Leventhal, Cameron & Leventhal, 2003), and indicates the importance of creating opportunities for people to evaluate decisions (Morton, Tong, Howard, Snelling & Webster, 2010; Prochaska & DiClemente, 1983), and ill-health in prompting pursuit of LKDT (Hanson et al., 2015).

Studies into attitudes towards LDKT and RRT preferences predominantly explore waiting list or post-treatment populations, who may hold differing concepts of transplantation to pre-RRT populations (Morton et al., 2010). Studies focused on the attitudes of pre-RRT populations towards PELDKT are limited and have poor generalisability to users of UK healthcare systems. Coorey, Paykin, Singleton-Driscoll and Gaston (2009) surveyed pre-RRT and dialysis cohorts, finding concerns held towards PELDKT regarding immunosuppressant medication, financial barriers and perceived harm to donors. Psychosocial complexities associated with identifying and approaching potential donors were also found, consistent with Siegal, Alvaro, Hohman and Maurer (2011).

A systematic review (Hanson et al., 2015) on attitudes towards LDKT, included four studies featuring pre-RRT participants (n=108). Generalisability of the findings to the UK healthcare system was limited as three were conducted in North American healthcare systems (Barnieh et al., 2011; Boulware et al., 2011; Pradel et al., 2003) including one focusing on the African-American demographic (Boulware et al., 2011), and the fourth was undertaken in Australia (Tong et al., 2009). The results have further restrictions regarding applicability, such as reliance on focus groups; inclusion of potential recipients already matched with potential

donors (Pradel et al., 2003); and broadly focused on living with CKD generally (Tong et al., 2009). The review demonstrated little is known about attitudes towards PELDKT in the diverse legislative context of the devolved nations in the UK.

Common Sense Model of Self-Regulation

The application of psychological theory to understanding PELDKT and how decisions about treatment choices are reached is in its infancy. Application of the Theory of Planned Behaviour (Ajzen, 1991) found perceived behavioural control to be associated with behavioural intentions to discuss LDKT with family members in people with ESKD (Siegal et al., 2011). While attitudinal models can be clinically useful to understand treatment decisions and behaviour, they do not fully describe individual representations of a chronic health condition (Dempster, Howell & McCorry, 2015).

Leventhal et al.'s (2003; 2016) Self-Regulatory Model of Illness (SRM) suggests that people's intentions to avoid and treat chronic illness are influenced by dynamic cognitive and emotional representations of the threat of illness. These representations are developed through the information a person has available and their experience of symptoms, and the Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996); the Revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al., 2002); and the Brief-IPQ (Broadbent, Petrie, Main & Weinman, 2006) have been devised and validated for their measurement. The Brief-IPQ has moderate to good associations with the IPQ-R (Broadbent et al., 2006), which has shown construct validity within a CKD pre-dialysis population (Pagels, Soderquist & Heiwe, 2012).

The SRM has been applied to CKD populations (Griva et al., 2009; Meuleman et al., 2017) and illness representations have been found to vary across the CKD trajectory with the potential for modification (Jansen et al., 2013). Systematic review has identified less is known of the applicability of the SRM in pre-RRT CKD populations and how illness perceptions may influence treatment choices (Clarke, Yates, Smith & Chilcot, 2016).

Welsh Context for Kidney Transplantation

In Wales, 41% of kidney transplants were from living donors in 2016-2017 (NHS Blood & Transplant, 2018), which is comparable to 42% worldwide (Hanson et al., 2015). However, 176 people in Wales remain waiting for a kidney transplant, a 20% increase on the previous year (NHS Blood & Transplant, 2018). This is despite UK legislative changes in 2007 allowing “non-directed” donation, enabling the donation of a living donor kidney to a stranger, and the introduction of a presumed consent model for organ donation in Wales in 2015.

There are few studies conducted in the UK healthcare system, and fewer still in the new legislative context of Wales, regarding how pre-RRT CKD populations might consider renal replacement options, specifically PELDKT. Given evidence that some people prefer deceased organ donation, it is also timely to explore the impact the Welsh opt-out system has on people’s attitude formation, especially as other UK nations are considering adopting the presumed consent model (British Medical Association, 2017).

Study Aims and Objectives

Illness representations are associated with health beliefs (Leventhal et al., 2003), which may in turn influence treatment preferences (Hale, Treharne & Kitas, 2007). This study aimed to

elucidate the beliefs held by a pre-RRT population with stage 3b-5 CKD towards pre-emptive living donor kidney transplantation.

Phase One used self-report questionnaires to situate the sample through elucidating perceptions of illness; knowledge about living donor kidney transplantation; illness severity, and pre-emptive living donor transplantation preferences. Phase Two used semi-structured interviews to elicit qualitative data from a sub-sample of respondents and Interpretative Phenomenological Analysis to derive themes concerning:

- The lived experience of people with CKD in considering pre-emptive living donor transplantation and renal replacement therapies in a Welsh context.

Method

Participants

A Welsh NHS nephrology database was searched by the Responsible Clinician to identify those who had stage 3b-5 CKD (eGFR between 10-44) and who were: aged between 18-70; at least 6 months post-diagnosis; and not actively waiting for treatment (pre-RRT). Based on a power calculation, a stratified random sample of 300 people representing the eligible population (n=1,654) was devised, stratified by age to reflect the skewed age distribution in the database. Potential participants who responded to an invitation letter (Appendix E) were sent an information sheet (Appendix F), consent form (Appendix G) and a questionnaire (Appendix H) either in hard copy or via Qualtrics (depending on participant preference). Non-respondents were sent a follow-up reminder after 3 weeks. Reasons for non-participation were not explored.

Ethics

Approval was granted by NHS Research Ethics Committee Fulham and the health board's Research and Development team (Appendix I). Written consent for participation was obtained in both phases of the study. All responses were coded to ensure anonymity.

Sequential Explanatory Design

A sequential explanatory design (Ivankova, Creswell & Stick, 2006) using the '*participant selection model*' (Creswell & Plano-Clark, 2007) was applied, whereby Phase One (questionnaires) helped inform purposive selection for Phase Two (interviews). The design was also pragmatic as it was foreseen that putting sensitive psychometric questions to this population might result in a low response-rate and insufficient power to achieve statistically

robust findings. Priority was given to the qualitative data collection and analysis, a decision influenced by the purpose of the study. The design of the study is displayed in Table 1.

Table 1

Recruitment

Age range (years)	18-29	30-39	40-49	50-59	60-70	Total
Stratified sample invited to participate (Phase 1)	9	18	33	69	171	300
Respondents in Phase 1 (n)	1	4	1	4	21	31
<i>Data Analysis</i>						
Purposive sample invited for interview (Phase 2)	0	0	1	3	10	14
Respondents in Phase 2 (n)	0	0	1	1	6	8
<i>Data Analysis and Integration of Findings</i>						

Phase One – Questionnaire and Situating the Sample

Participants completed four questionnaires (Appendix H), which were returned via freepost or Qualtrics:

The Brief-IPQ

The Brief-IPQ uses a nine single item scale. Cognitive (*identity, timeline, personal control, treatment control, consequences*) and emotional (*emotion and concern*) perceptions of illness, as well as illness *coherence* are assessed on a 0-10 scale. Perceived *causes* of illness are also listed. The validity of the Brief-IPQ has been systematically evaluated (Broadbent et al., 2015), indicating good concurrent and predictive validity and sensitivity to change. The Brief-IPQ has moderate to good correlations with the IPQ-R for concurrent validity (Broadbent et al., 2006). As recommended by Broadbent et al. (2006), the Brief-IPQ was adapted to include the term ‘CKD’ and treatments specific to RRT. Scores on selected domains are reversed, with high scores indicating higher perceived threat of illness.

Beliefs about Living Kidney Transplantation

A ten-item Likert scale on beliefs about living donor transplantation, with a five-point strongly disagree to strongly agree scale (Barnieh et al., 2009). The instrument has demonstrated face and content validity and reproducibility. An eleventh question regarding timing preferences to discuss RRT options was added and analysed separately.

Preferences and Experiences of Discussing RRT

A purpose-designed survey about renal replacement therapy preferences and experiences of discussing PELDKT with relatives or friends.

Socio-demographic Characteristics

Socio-demographic information was recorded for each participant, including age, gender, child status and stage of illness.

Phase One Analysis

Data were analysed using descriptive statistics and outcomes were applied to ‘situate the sample’ (Elliott, Fischer & Rennie, 1999) for Phase Two through enhancing understanding of participant demographics and current attitude towards their health condition and PELDKT.

Phase Two - Semi-Structured Interview

Questionnaire respondents in Phase One provided contact details if they consented to being contacted regarding Phase Two interviews. Individuals were purposefully selected to produce a homogeneous sample and to elaborate on findings through Interpretative Phenomenological Analysis (IPA) (Smith, Jarman & Osborn, 1999). IPA is a pragmatic, idiographic qualitative methodology, allowing in-depth exploration of a person’s life experiences and sense-making

of topics which are emotionally complex (Smith & Osborn, 2015; Tuffour, 2017). IPA allows the use of existing psychological models, and is well suited to health-related research, especially when the phenomenon under study is subjective and relatively understudied (Smith, 2017; Smith & Osborn, 2004; Pietkiewicz & Smith, 2014). Purposive sampling created a sample of potential interview participants in the 40-70 age category, who would consider or who were unsure about PELDKT. Those meeting the inclusion criteria were contacted and if in agreement, face-to-face semi-structured interviews were arranged. Eight individual interviews were conducted, and responses were audio-recorded and transcribed verbatim. Smith, Flowers and Larkin (2009) recommended samples between four and ten participants for doctoral IPA research to recognise the convergence and divergence of data, with emphasis on maintaining an idiographic focus (Hefferon & Gil-Rodriguez, 2011).

Interview schedule questions were framed by the research aims and Phase One findings (Appendix J). The interviews focused on eliciting the participants' lived experiences of CKD, using open-ended stem and probe questions (Willig, 2013) to introduce topics related to PELDKT and deepen respondent' reflections on the personal meaning. A pilot interview was conducted to test the schedule for suitability, whereby minimal changes were required and the interview was included for final analysis. Interviews lasted between 23-56 minutes and took place approximately two months after Phase One at a location chosen by the participants, either their home or a university setting.

Phase Two Analysis

In IPA, a double hermeneutic is created, whereby the researcher attempts to construct in-depth meaning from the participants' own interpretation of a phenomenon (Smith, 2017; Pietkiewicz & Smith, 2014). Interview transcripts were analysed in succession using the

stages described by Smith, et al. (2009) (Appendix K), with the researcher maintaining an openness to emerging themes and patterns from each transcript (Appendix L). Microsoft Word documents were created to record excerpts from the transcripts related to each emergent theme. Initial themes were refined until the super-ordinate themes emerged.

Quality Assurance

In conducting the IPA approach, reflexive bracketing (Ahern, 1999), supervision, and data immersion were utilised throughout the process to identify researcher preconceptions, assumptions and bias (Yardley, 2000). This aimed to best ensure an objective stance and that reporting was grounded in participants experiences (Smith et al., 2009) (Appendix M).

To further ensure reflexivity and theme credibility, a peer and supervisor independently reviewed the emergent themes in a sample of data to verify analysis reliability. A good level of agreement was achieved with minor amendments suggested in recognition of the rigour and robustness of the analysis process (Yardley, 2000). Ethical approval was not requested for respondent validation as an additional quality check, and the value of this practice for IPA has been questioned (Smith et al., 2009) due to the triple hermeneutic it creates. The Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury & Craig, 2007) checklist was also utilised to ensure quality. The researcher is a healthy male trainee clinical psychologist without any known kidney problems, and has no clinical or familial experience of RRT or organ donation, but has experience of family decision-making regarding treatment choices for a chronic health condition. The researcher has not registered a decision relating to presumed consent.

Results

Participant socio-demographic characteristics are presented first, followed by the results from Phase One and Phase Two.

Sample Characteristics

Phase One achieved a 10% response rate and 84% questionnaire completion rate from 31 participants. The sample comprised of 19 men and 12 women with 68% in the 60-70 years category, 11% higher than the representative sample. Participants were predominantly white (97%) which is comparable to the Welsh population (Welsh Government, 2017), and were Stage 3-4 CKD (87%). Demographic information of non-respondents are unknown. Of the eight Phase Two participants, 50% were women, 75% were age 60-70, 75% had stage 4 CKD and all were parents to adult children. Table 2 (page 67) presents participant characteristics in relation to PELDKT preferences.

Phase One: Questionnaires

Treatment Preferences

Table 2 shows 52% of respondents would consider pre-emptive transplantation from a living donor. Two male respondents rejected living kidney donation (50-70 years, eGFR 4 and 5), holding preferences for deceased donation or conservative management to avoid a sense of obligation for graft survival, and a preference to pass away naturally rather than “surviving not living” (Appendix N). All respondents with children under age 18 (n=4) would consider PELDKT, whereas 57% of respondents with children over 18 (n= 23) were either unsure or rejected the option.

Table 2

Sample characteristics and factors associated with pre-emptive living donor transplant preferences

		Pre-emptive living donor transplantation				
		Phase One n=31 n (%)	Yes n=16 (52%)	No n=7 (22%)	Unsure n=8 (26%)	Phase Two n=8 n (%)
Gender	Male	19 (61)	12	4	3	4 (50)
	Female	12 (39)	4	3	5	4 (50)
Age	18-29 years	1 (3)	-	-	1	-
	30-39 years	4 (13)	4	-	-	-
	40-49 years	1 (3)	-	-	1	1 (12.5)
	50-59 years	4 (13)	3	1	-	1 (12.5)
	60-70 years	21 (68)	9	6	6	6 (75)
Marital status	Married	22 (71)	14	6	2	4 (50)
	Divorced/Separated	6 (19)	1	1	4	4 (50)
	Single	3 (10)	1	-	2	-
Child Status	Children under 18	4 (13)	4	-	-	8 (100)
	Children over 18	23 (74)	10	6	7	-
	No children	4 (13)	2	1	1	-
Employment Status	Retired	18 (58)	9	5	4	4 (50)
	Employed	9 (29)	5	1	3	2 (25)
	Unemployed/Unable to work	4 (13)	2	1	1	2 (25)
eGFR	Stage 3	13 (42)	4	4	5	1 (12.5)
	Stage 4	14 (45)	10	2	2	6 (75)
	Stage 5	4 (13)	2	1	1	1 (12.5)
Ethnic Background	White	30 (97)	15	7	8	7 (87.5)
	Asian	1 (3)	1	-	-	1 (12.5)

Table 3 (page 68) presents a descriptive analysis of preferences for pre-emptive surgery for both living and deceased donor sources. Preferences for a living donor were expressed by 52% of respondents compared to 55% from deceased donors, reducing to 26% for living donors should donation be suggested if asymptomatic, compared to 39% for deceased donors.

Table 3
Preferences for pre-emptive kidney transplantation (n=31)

Response	Living Donor Transplantation		Deceased Donor Transplantation	
	Pre-emptive n (%)	Pre-emptive if asymptomatic n (%)	Pre-emptive n (%)	Pre-emptive if asymptomatic n (%)
Yes	16 (52)	8 (26)	17 (55)	12 (39)
No	7 (22)	12 (39)	3 (10)	9 (29)
Unsure	8 (26)	11 (35)	11 (35)	10 (32)

The prevalent preference for RRT was living donor kidney transplantation (Figure 1) when living donor options (blood-relative; non-blood relative; stranger) were combined (32%, n=10), with 8 out of the 10 respondents preferring a kidney from a blood-relative. Reasons included a desire to avoid dialysis and maintain a good quality of life. A preference for transplantation as the initial RRT rose to 58% when including deceased donor transplantation. Dialysis was ranked as the most preferred RRT and the least preferred RRT by equal numbers (n=9, 29% respectively). Avoiding surgery, health complications and prioritising others were stated as reasons for preferring dialysis. Conservative management was the prevalent least preferred RRT (n=10, 32%).

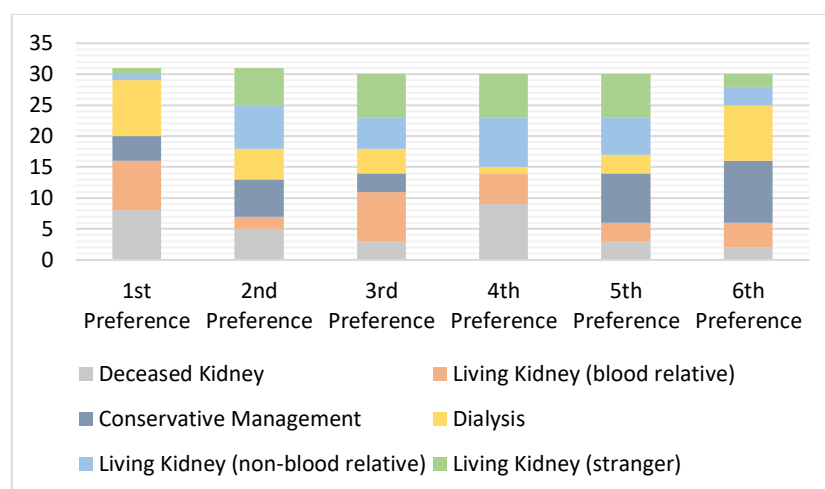


Figure 1
Ranking of Renal Replacement Therapy Preferences
n=31 for preferences 1&2, n=30 for preferences 3-6

Illness Perceptions

The illness representations of CKD and treatment beliefs held by participants are shown in Table 4. All participants anticipated a long duration of CKD, with low personal control and high levels of concern. The majority did not experience symptoms (identity) but felt they had relatively good understanding of their condition. Transplantation modalities (deceased, and pre-emptive living donors) were viewed equally as being helpful treatments, with dialysis viewed as offering less help. Theming of causal beliefs found biology/genetics as the predominant perceived cause, followed by lifestyle and the effects of medical intervention.

Table 4
Illness perceptions and living kidney donor transplantation knowledge in a pre-RRT population

Illness representation*	Total median n=31 (IQR)
Timeline	10 (8.5-10)
Consequences	5 (2-6.5)
Personal Control	7 (5-8)
Treatment Control (DDKT)	2 (0-6)
Treatment Control (PELDKT)	2 (0-7)
Treatment Control (Dialysis)	5 (2-7)
Coherence	4 (1.5-5)
Emotional representation	5 (2-7)
Identity	4 (2-6.5)
Concern	7 (5-9.5)
LKD Knowledge**	
Knowledge	35 (32-39)

*Items are scored on a 0-10-point scale where 10 represents a higher perceived threat associated with CKD. Personal Control, Treatment Control Items, and Coherence were reversed prior to calculation. **LKT knowledge is scored /50.

Transplantation Knowledge

Regarding knowledge about living donor kidney transplantation, 30% (n=9) of participants would prefer to discuss treatment options only when RRT was required, not knowing how to ask someone for a kidney was the largest barrier to pursuing living kidney donation (91%) (Table 5). Further knowledge deficits were identified, including 29% of people not knowing a

friend can donate a kidney in Wales, and 71% of people believing living donor kidney prognosis is not superior to deceased donor kidney.

Table 5
Knowledge of living kidney donation

Item	% who agreed/strongly agreed
In Wales, a family member can donate a kidney to someone with CKD	87% (n=27)
In Wales, a friend can donate a kidney to someone with CKD	71% (n=22)
Kidneys from living donors last longer than kidneys from deceased donors	29% (n=9)
The sooner I get a kidney transplant, the better off I will be	42% (n=13)
People who have a living donor will wait less time for a transplant than those without	52% (n=16)
I understand what living donation means	97% (n=30)
Individuals who donate a kidney are more likely to develop kidney failure themselves	3% (n=1)
Individuals who donate a kidney are more likely to end up with high blood pressure	6% (n=2)
I could tell someone how to contact the living donor programme	42% (n=13)
I know how I would ask someone to donate a kidney	9% (n=3)
I would rather not discuss kidney transplantation until I know I will need RRT	30% (n=9)

Discussion with Relatives

Of the fourteen respondents who had discussed LKT with a relative (Table 6), eight had identified a potential donor, 62.5% of whom would consider PELDKT. Of the people who had not discussed living donation with relatives (n=17) or had not yet identified a donor (n=6), only 9% planned to discuss this in the future. None of the participants reported feeling pressurised to consider a particular treatment.

Table 6
Discussion of pre-emptive living donor kidney transplantation

	Opportunity for directed donation n=31 (%)	Discussed living kidney donation Total n=31 (%)	Donor identified Total n=14 (%)	Intend to discuss (not discussed/ not identified) Total n=23 (%)
YES	17 (55)	14 (45)	8 (57)	2 (9)
NO	14 (45)	17 (55)	6 (43)	10 (43)
Unsure	10 (32)	-	-	11 (48)

Phase Two: Interviews

Phase One analysis suggested preferences regarding PELDKT need to be considered in context of people's relationships, which is not addressed in the SRM, and the challenges for respondents of involving others at this stage in their illness was evident from responses.

Phase Two aimed to extend Phase One findings and explore participants' experiences of CKD and considering RRT in a Welsh context. Of 19 participants who consented to take part in Phase Two, 14 met interview inclusion criteria of not rejecting PEDLKT as an option and being representative of the predominant CKD population (40-70 years-old) to create a homogenous sample. In arranging interviews, two participants did not respond, two were unavailable, one person was hospitalised, and one respondent had unfortunately died. The characteristics of the eight IPA participants who were interviewed are described in Table 7.

Table 7
Characteristics of Phase Two Participants (n=8)

Pseudonym	Age	Ethnicity	eGFR	Consider PELDKT	Discussed	Preference	Quote
Mina	50-59	British Asian	4	Y	Y	DDKT or PELDKT from a stranger. Would not consider from a relative.	<i>"They're [adult children] willing to give theirs...I said no" p.4</i>
Julia	60-70	White British	4	U	N	Conservative management but has not considered options before. Would consider a LDKT if it was essential.	<i>"I wouldn't like to cause any of my loved ones the pain and anxiety of going through a kidney donation" p.12</i>
Owen	60-70	White British	4	Y	Y	PELDKT from a relative but lacks opportunities. Currently waiting for a transplant (pre-dialysis)	<i>"I'd obviously prefer to have a transplant living donor, than go on dialysis" p.24</i>
Carys	60-70	White British	4	U	Y	Would prefer only a PELDKT from a relative but has concerns of the implications.	<i>"Although I know it comes with a lot of problems, I'd feel much happier having the kidney from my own than from a stranger, and especially from a dead person" p.43</i>
Aled	60-70	White British	3	U	N	Conservative management or DDKT. PELDKT is not attractive due to perceived risks to family and the needs of others on the waiting list.	<i>"I was toying with the idea of not to go on the machine and just let it go" p.60</i>
Ian	60-70	White British	4	Y	N	DDKT, but largely unsure. Would prefer not to consider transplantation until it is raised in clinic and can predict the dilemma of a PELDKT.	<i>"Nothing is ever that simple is it? You can't just draw a line and say 'oh, it's black and white and yes or no'" p.80</i>
Vanessa	40-49	White European	3	U	N	Conservative management, but largely unsure. Would consider a PELDKT but not until receiving significant information from the clinic.	<i>"If quality of life got so poor that I couldn't do much then yeah, obviously I'd start looking more seriously at those other options" p.102</i>
Thomas	60-70	White British	5	U	Y	Conservative management or dialysis. PELDKT is not attractive due to prioritising the needs of others.	<i>"I've set myself against kidney replacement, rightly or wrongly" p.116</i>

Nine sub-ordinate themes emerged from the IPA, which were incorporated into four interrelated master themes to represent how participants perceived their experiences (Table 8). Master themes were generated by the researcher, while quotations from respondents were used for subordinate theme titles to communicate the 'essence' of the phenomenon (Tuffour, 2017).

Table 8
Superordinate themes relating to each master theme

	Master theme	Sub-ordinate themes
“in the back of my mind”	My kidney and I	<i>“in the back of my mind”</i>
	Co-constructing decisions	<i>“I’ve always been...”</i> <i>“what does all that mean?”</i>
	A kidney shared as a problem solved?	<i>“Preparing myself mentally”</i> <i>“being beholden to somebody”</i> <i>“I don’t want to put my own priorities ahead of theirs”</i>
	Navigating the unknown	<i>“meaningful conversation(s)”</i> <i>“it’s a distant possibility”</i> <i>“would it or would it have not progressed?”</i>

Examples of presenting qualitative data creatively are increasing (Toye et al., 2014; Chandler et al., 2015), including the use of images (Wiles et al., 2011). A visual representation of the IPA (Figure 2) was created which aimed to capture the phenomenon of being someone pre-RRT and considering PELDKT. Rather than portraying a model, the figure illustrates how the themes interrelate and symbolises the opportunities, barriers, decisions and systems described by the interview respondents.

The picture is reminiscent of the London Underground logo, symbolising the health trajectory journeys being navigated. The same logo is also reminiscent of a ‘no entry’ sign, symbolising the barriers, obstacles and choices which people may face regarding their health condition and treatment decision-making. The horizontal line also represents ‘decisional balance’ (Janis & Mann, 1977) and how people may evaluate the risks of their decisions differently. A crossroads symbolises the multiple directions that may be available to people, and the information that people require to choose a path. Finally, the concentric circles are representative of Bronfenbrenner’s (1979) systems theory, whereby people exist within

family, healthcare and societal systems, which may impact on their experiences and choices. At the centre and in the background is the awareness of the journey and decisions that people may face.

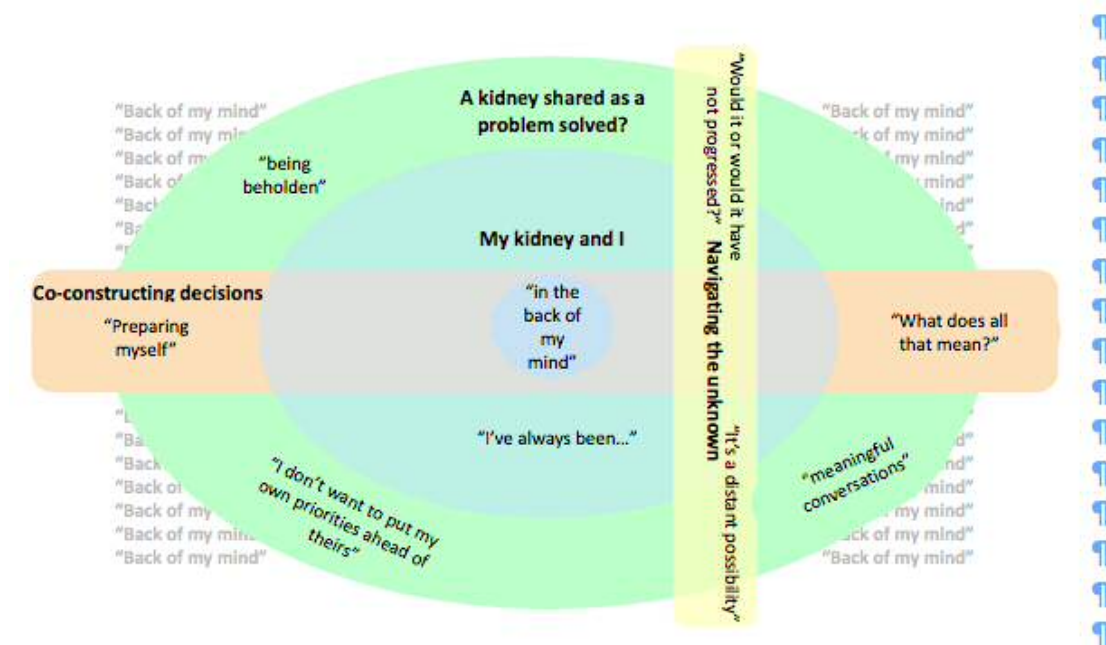


Figure 2
Relationships between themes

Theme 1: My Kidney and I

All participants reflected on their relationship with their illness. The subordinate themes capture these relationships and this theme is presented first because of its focus on the individual and their health condition. Theme One (“the back of my mind”) highlights the psychological consequences and awareness of an uncertain future. Some of these experiences led people to reflect on their values and a desire to protect their identity (Theme Two: “I’ve always been…”).

“The back of my mind”

All interviewees described being preoccupied with their illness progression. Owen and Carys, who had discussed RRT options with their consultants, illustrate this preoccupation:

“I’m worried; it’s on my mind all the time really. It’s constantly on your mind” (Owen, p.29)

“It’s the worry of it all. The thought of dialysis makes me feel sick. The thought of a transplant makes me feel sick. And then to think that one of my family will probably have to donate” (Carys, p.38)

Respondents who indicated minimal consideration towards renal replacement options were alert that their condition could progress:

“It’s always in the back of your mind, but I don’t think you can delve into it too much” (Aled, p.74)

This enduring awareness was experienced as “isolating” (Owen, p.35) and the cause of distress:

“I do break down sometimes” (Mina, p.6)

“I’ve always been...”

All participants perceived CKD progression as posing a threat to their identity and values, and a desire to maintain their sense of self, questioning how this might change following RRT. Perceived threats to privacy, dignity and positions of social status were barriers to donor sourcing:

“I’m a little embarrassed...I’ve always been a fit person. I find I don’t like discussing it with the wider circle” (Owen, p.28-29)

Benefits of PELDKT were evaluated according to criteria of remaining independent; while PELDKT avoided the dependence of dialysis, concerns were held over the dependence created by immunosuppressant medication. Many participants described dissonance in

wanting the benefits of PELDKT to maintain quality of life, but also wanting to maintain values of not disadvantaging others and retaining relationship structures.

“I would like a kidney. I do not want my family to suffer because of me” (Mina, p.6)

Offers from adult children were largely viewed unfavourably to preserve the relationship and the idea of parent as a protector. However, postponing PELKDT offers could be in conflict with a desire to maintain the Self:

“Let’s go for the transplant and let’s get it over and done with and let me get back...Just take me and give me a new kidney! I want it over and done with. I just want to get on with my life and get back to me” (Carys, p.43)

For some, a non-directed living donor was more acceptable when considering PELDKT, due to perceptions of being absolved of responsibility. Four interviewees referenced the age 70 as being the indicator for having lived a full life, with ideas that transplantation should benefit younger people:

“If I was a lot younger, your thoughts would be different...you would want to extend your life, I imagine. But at 70, I really think I’ve had a good life” (Julia, p.15)

Theme 2: Co-constructing decisions

All participants reflected on the resources necessary for decision-making. This was largely centred on the quality and timing of information from clinicians (Theme One: “What does all that mean?”), and reflections regarding their internal resources (Theme Two: “Preparing myself mentally”).

“What does all that mean?”

All participants discussed the importance of having accurate and personalised medical advice to support them in their choices, and to instil trust and confidence in any donor sourcing activity. Some respondents outlined stages before entering into conversations, with information being the first step:

“Before you get into any of the other stuff you’ve got to have [information] first and what does all that mean...what are the risks involved?” (Ian, p.89)

“[information] about the risks to myself of surgery and trying to balance that with the risk of deteriorating in the future...and risks to the donor if they were living” (Vanessa, p.103)

“...it doesn’t feel very...like I’m an individual human being. It’s like I’m another patient, in/out...I do find it a bit difficult” (Vanessa, p.111)

The timing of receiving information was important for all interviewees. Some people felt uninformed and alone in their search for information regarding RRT, but especially regarding managing and delaying CKD progression.

“Preparing myself mentally”

A common experience for the majority of interviewees was the desire for mental preparation and the avoidance of surprise conversations:

“If they [the nephrologist] started saying ‘we are thinking about putting you on a list for pre-emptive transplants’, or whatever, I’d start thinking about it and start preparing myself mentally. I prefer things to not be a surprise” (Vanessa, p.104)

“He [the doctor] said ‘I’ve got two things to say to you - dialysis and transplant’ ...it’s a bit of a shock...it is very different when it happens to you and I don’t think some people realise that, and it’s the implications of it all” (Carys, p.41)

Interviewees shared the experience of reflecting on their own inner resources in considering RRT. For some people, this was a sense of self-efficacy in decision-making, and reflecting on the demands of medical intervention of any kind:

“I just can’t take anymore. I’m spending my life around hospital appointments...all I’m doing is thinking about medical appointments” (Thomas, p.126)

Ian reflected on his ability to psychologically assimilate the ownership of another person’s kidney and the emotional implications of graft rejection risks:

“If you’re taking something that’s not yours physically, then you know there’s – how do you manage that? How do you manage rejection and all that aspect of it?” (Ian, p.82)

This quote illustrates concerns of managing overwhelming emotions, a theme shared across cases. A sense of low control emerged throughout the narratives, especially when people had a preference for PELDKT, but either lacked opportunities within their networks, found the implications to be too risky, or were unsure of their suitability for transplantation. This sense of not knowing links with the theme “the back of my mind”.

Theme 3: A kidney shared as a problem solved?

This theme encompasses what it meant to involve family/friends in treatment decisions.

Theme One (“being beholden to somebody”) describes what an offer of a kidney from a living person meant to participants. Offers presented a dilemma (Theme Two: “I don’t want to put my own priorities ahead of theirs”), beyond which was recognising the importance of “Meaningful conversations” (Theme Three) to fully consider PELDKT.

“Being beholden to somebody”

Four of the interviewees had been offered a kidney from at least one relative, all of which had declined the offer. While two of these people preferred a PELDKT, implications such as a sense of indebtedness, were barriers:

“It’s a case of being beholden to somebody as well...it will be ‘oh well, I gave you my kidney’, and so sometimes I think it would be best for it to be from someone I didn’t know”
(Carys, p.40)

For others, there was the concern of taking something that another person may need, and a sense of rightful ownership.

“I would feel terrible if somebody I knew had given me a kidney and I was living the life of Riley and they were suddenly taken ill and something happened in their kidney and they’d only got one kidney left...I would feel awful then” (Aled, p.69)

For the majority, the offer of a kidney held more meaning than the kidney itself. While Mina had firmly refused her children’s offers, it symbolised family unity over the problem:

“[the offer from children] that is really valuable to me. So precious, something coming out of my own child and being fitted into me.” (Mina, p.11)

“I don’t want to put my own priorities ahead of theirs”

All interviewees described the dilemma of weighing-up the needs of other people when considering PELDKT, rather than lack of knowledge. Concerns included disrupting children’s careers or family planning, and of short-term gain for themselves against long term consequences for the donor:

“I know you can manage with one [kidney], it’s fine...but I’m not sure I want to commit my children long term to living with one kidney for the short-term option. I’m 70 years of age, I get the feeling I would be selfish...I’m committing somebody. I don’t want to commit them to something they might regret in future years... I don’t want to put my own priorities ahead of theirs” (Thomas, p.115-116)

Use of the word ‘commit’ has connotations of morality, power, and highlights the concern of holding influence over another. Wanting to avoid emotions such as guilt was a common theme across narratives, and the potential implications of harm for donors was a concern for all interviewees:

“say they were in a car accident and their kidney got damaged – I would feel – I would feel absolutely – not disgusted, but I think the first thing would be ‘well, why did I go for that?’”
(Aled, p.69)

While many interviewees commented on the benefits of non-directed donation as reducing worries of harm to their own family, some preferred certainty over knowing the organ’s origins:

“Although I know it comes with a lot of problems... I’d feel much happier having the kidney from my own than from a stranger, and especially from a dead person” (Carys, p.43)

The potential psychosocial benefits and likely outcome of donation for living donors were less commonly acknowledged:

“giving something to help somebody else I think is a fantastic thing...people can offer a kidney and still have a healthy life themselves” (Owen, p.35)

“Meaningful conversations”

The ability to have conversations were mired by the lack of opportunities, such as having a “*limited pool of options*” (Vanessa, p.105), and knowing medical reasons that would exclude relatives from donating. While it seemed important for preferences and options to be explored, it was also apparent from the narratives that pressing medical needs would guide the likelihood of a conversation:

“I’d have to be in a really desperate situation before I would do that” (Julia, p.18)

While some could see the value of holding conversations about treatment choices, there was also a pattern from respondents that donor sourcing conversations should be led by the relative:

“It could put the family in a very awkward position I think. They may feel obliged to think of it rather than really want to do it” (Julia, p.16)

Potential conversations may not be regarding donor sourcing but alerting relatives to plans to reject RRT. This was described by one interviewee as being a particularly difficult experience, causing some family conflict:

“I spoke to my wife about it, she went ballistic, ‘you’re not leaving me’, as you can understand...It’s very hard...I don’t want to talk about it and they don’t want to talk about it either. We need a more meaningful conversation than what we’ve had...where a decision has got to be made” (Aled, p.57-71)

Theme 4: Navigating the unknown

Interviewees reflected on the overall uncertainty of being someone with stage 3b-5 CKD. Theme One (“It’s a distant possibility”) acknowledges that RRT remains hypothetical for many of the people interviewed. Theme Two (“Would it or would it have not progressed?”) describes the doubt people experience and anticipate about their options.

“Distant possibilities”

The majority of respondents acknowledged that preferences change over time, on the advice that is provided, and experiences of illness. For some, considering PELDKT at this stage seemed too hypothetical:

“...unless I was faced with it...I don’t know. It’s your life isn’t it, and you may say ‘I don’t want to have a donor because of the issues for them’, but if push comes to shove, you might be persuaded to do it” (Julia, p.13)

In contrast, Ian described PELDKT and as something he would consider, but as the interview continued, he reflected:

“I don’t want dialysis and I’d consider options [PELDKT] to avoid dialysis...if they [family] did offer ...then I’d really have to think then about whether I would really want to do it because of the – up until that point it’s hypothetical” (Ian, p.88)

There remained hope among interviewees that RRT, especially dialysis, may be avoided or not required, and a current absence of a potential donor did not guarantee dialysis as an outcome:

“I could go on for two years...maybe something [a deceased kidney] might come in by then. You know, two years is a long time – people are dying every day and there’s loads of people who donate their stuff as well. So, I got to hope.” (Mina, p.9)

“It’s a distant possibility. It’s not a certainty – it’s something that might happen but then I might also, as they say, get run over by a bus” (Vanessa, p.108)

“Would it or would it have not progressed?”

This theme captured the doubt that was anticipated regarding PELDKT. Despite perceiving benefits, many interviewees were concerned about having a transplant before experiencing a noticeable decline in health, as indicated by reduced quality of life, increase in symptoms, or the need for dialysis:

“You might be putting somebody through the operation of donating a kidney when it may not be necessary in the long run... ‘would it or would it have not progressed?’” (Julia, p.14)

Those who has discussed PELKT with relatives or healthcare professionals, and who understood the clinical benefits, commented on becoming aware of what was being asked of their relatives and the subsequent doubt they experienced regarding the option:

“they make it all sound so easy...the reality can be different. Bloody awful” (Thomas, p.123)

Welsh Presumed Consent System

All of the interview participants welcomed the Welsh presumed consent system, with two respondents viewing the system as favourable to them in terms of potentially accessing a donor. One interviewee reported that the presumed consent system would deter them from discussing PELDKT due to a perceived sense of kidneys being more readily available.

Frustration was reported at kidneys from Welsh residents being used in other UK countries, as well as surprise that families of potential donors could prevent a donation.

Discussion

This study aimed to explore the perceptions held by a pre-RRT CKD population towards pre-emptive living donor kidney transplantation. Self-report questionnaires helped to situate the sample for semi-structured interviews through identifying illness perceptions, treatment knowledge, and treatment preferences. Qualitative analysis of respondents’ perspectives on PELDKT identified four themes: My Kidney and I; Co-constructing Decisions; A Kidney Shared is a Problem Solved?; Navigating the Unknown.

Phase One findings indicate the pre-RRT population perceived low personal control and high levels of concern regarding their illness. Transplantation modalities (deceased and pre-emptive living donors) were viewed equally as being helpful treatments, with dialysis perceived as offering less help. Opportunities to address misconceptions and concerns regarding living kidney transplantation knowledge were identified..

Consistent with Hanson et al. (2015), qualitative analysis found the PELDKT option was linked to consideration for maintaining quality of life, avoiding dialysis, knowing the origin of the kidney, and ascribing benefits to potential donors. PELDKT acceptability decreased from 52% to 26% should a transplant be advised while asymptomatic, and higher illness identity scores, representing symptoms participants associated to CKD, were found in those who would consider PELDKT. Martin (2014) found 85% of participants on deceased donor waiting lists would accept living kidney transplantation, with decisions to pursue the option coinciding with ESKD. Findings suggest that treatment decisions are framed through illness symptom awareness, rather than biomedical markers (eGFR), of which the person may not fully understand the significance. Pre-RRT populations have also been found to lack certainty regarding symptoms, such as attributing them to other illnesses and age (Pagels et al., 2015).

Similar to Clarke et al. (2016), Phase One participants perceived low personal control (median value: 7) and interviewees perceived insufficient illness management information to be provided by healthcare professionals. Poorer self-management practices and strategies such as avoidance and have been linked to low control representations (Hagger & Orbell, 2003). Enhancing pre-RRT support to discuss preferences and improve self-management in the absence of symptoms is recommended, and supported through systematic review (Morton et al., 2010).

The IPA enabled nuanced exploration of the impact of perceived illness severity, and participants acknowledged that their preferences and option appraisals could change with time and prognosis: 'Navigating the Unknown'. This finding may conform to the Transtheoretical Model's pre-contemplation stage (Prochaska & DiClemente, 1983), and

while such strategies allow for difficult decisions to be postponed (Janis & Mann, 1977), situations may arise whereby decisions are evaluated in desperate circumstances.

PELDKT elicited concerns similar to those found by Hanson et al. (2015), which were biomedical (e.g. graft failure); psychological (e.g. assimilating living with another person's kidney; causing harm to others); social (e.g. wanting to secure the wellbeing of others). To diminish such concerns, it appeared necessary for participants to envisage increasing illness severity and voluntary donation offers from relatives. This finding aligned with how concerns about coercion and inflicting harm were reported by Boulware et al. (2011) and Siegal et al. (2011). Similar to Barnieh et al. (2011), participants indicated confusion regarding PELDKT, particularly regarding non-relative and non-directed donors, and disclosed low confidence pursuing donation. While some interviewees judged absent offers from relatives as refusals to donate, Kranenburg et al. (2007) found 60% of potential donors would consider a request.

Qualitative analysis revealed that, rather than clinical outcomes, central to people's narratives were preferences for non-invasive interventions, where 'invasive' was perceived as incursions on the body, quality of life, dependence on immunosuppressant medication, social identity, and on the lives of others. This concurs with Tong et al. (2009), who also recruited from a pre-RRT population, and McGregor et al. (2010) who found potential liver recipients to rejected living donation due to perceived risks to the donor.

While the 'value' of a kidney offer was cherished by interviewees, the experience of gratitude was set alongside concerns of emotional indebtedness, often referred to as 'the tyranny of the gift' (Fox & Swazey, 2001). Gift Exchange Theory (Mauss, 1954) may be relevant to understanding this element of the living donation dilemma both when a living donor has self-

identified and when PELDKT is being contemplated. Healthcare professionals need to be mindful of using “gift of life” metaphor for donations (Buldukoglu et al., 2005; Siminoff & Chillag, 1999).

Conservative management was ranked by ten respondents as their first or second RRT preference, with interview data indicating a desire to maintain autonomy and to protect others from perceived harm or burden. Johnston and Noble (2011) moreover found those who opted for conservative management were content with their decision. This compares with identified challenges for recipients of living donor transplantation, such as disappointment regarding health outcomes (Tong et al., 2009) and graft rejection risks (Boaz & Morgan, 2014).

Developing clinical practice to respond to all options being considered by pre-RRT populations would seem necessary.

Interviews clarified that identifying a potential donor was not sufficient for pursuing PELDKT. Consistent with Wu et al. (2017) and Hanson et al., (2015), IPA themes ‘My kidney and I’ and ‘A kidney shared...’ showed the interviewees least likely to pursue PELDKT perceived themselves as older and cited unwillingness to put younger donors, particularly their children, at risk. Younger people’s deservedness on transplant waiting lists was also contemplated when thinking about deceased donor transplantation. These findings may be indicators of the respondents’ views of ‘successful ageing’ (Baltes & Carstensen, 1996) and warrants further study. The median age of UK kidney recipients is 53.8 years (Sharples, Casula & Byrne, 2017), and transplantation beyond age 70 offers increased mortality compared to dialysis (Heldal et al., 2010). While only one respondent was from a BME background, her concerns about risk for directed-living donors were consistent with those found among minority ethnic groups (Wu et al., 2017) and also not dissimilar to those

of the majority. This suggests the option appraisal process, in increasingly diverse healthcare systems, requires professionals to give attention to service-user concerns and be mindful of opportunities to challenge internalised ageism or misconceptions of risk.

Consideration of PELDKT involves negotiating with complex treatment and family systems where differing attitudes are held regarding risks, costs and benefits (Kaufman, Russ & Shim, 2006). The attitudes of nephrology and transplant teams towards PELDKT have been examined, with 87% of staff (Rios et al., 2008) and 71% of nephrologists (Pradel et al., 2008) supporting pre-emptive donation, due to the associated prognostic outcomes. This suggests a potential difference in what teams support and what people with CKD find acceptable. LDKT rates in Northern Ireland have become among the highest in the world (Wu et al., 2017) following a strategy to promote access within transplant teams. While such strategies have obvious altruistic and utilitarian intent, they may neglect to consider the perspectives and experiences of the potential recipient-donor dyad in pursuing such options.

Interviews identified the presence of visceral reactions, such as disgust, when considering transplantation, especially from unknown or deceased donors. Such reactions have been found to be more influential in donation decision-making than knowledge (Morgan, Stephenson, Harrison et al., 2008). While LDKT treatment knowledge may be important when considering PELDKT, qualitative analysis suggests the ethical, social and interpersonal dilemmas presented by PELDKT as dominant concerns. This could help explain why strategies to increase knowledge and access to LDKT have not always increased transplant rates (Hunt et al., 2018). The Welsh presumed consent system did not appear to influence preference appraisal, but assumptions were evident that deceased donor-waiting lists were shorter, contrary to current indices (Hawkes, 2017).

Strengths

This study, conducted in a context in which presumed consent has recently been adopted, used a clinical pre-RRT CKD sample to gain insights into their perceptions and concerns of PELDKT, with potential to inform related healthcare practice. Previous studies concerning PELDKT (Coorey et al., 2009, Barnieh et al., 2011) have not applied theory (SRM, Leventhal et al., 2016) to inform their method or quantitative findings to situate their samples. This approach addressed the topic's complexities, provided further credibility to the findings and limited some of the disadvantages of self-report questionnaires by showcasing the voices of participants. Findings largely corroborated those of previous research (Bailey et al., 2016; Hanson et al., 2015) but also differed, for instance, financial concerns were not cited when considering treatment options (Coorey et al., 2009). Focusing on a pre-RRT population, who may be less invested in their illness and hold more malleable views, may be important clinically for informing health care professionals as they negotiate treatment choices with patients and their families.

Limitations & Further Research

Although demographic data was representative, the Phase One sample was small. However, the response rate (10%) matched that of Coorey et al.'s (2009) study into attitudes to pre-emptive kidney transplantation, perhaps indicating the discomfort elicited by the topic, and requires further exploration. Non-respondents may be different to those who volunteered, resulting in non-response bias (Sedgwick, 2014). Further studies could identify the duration of illness, a potential mediating factor overlooked in this current study, and use the 'Treatment Acceptability and Preferences' measure (Sidani et al., 2009), as validated generic measure. The SRM has limitations when exploring behavioural intentions, as unlike

attitudinal models (e.g. Ajzen, 1991), the model does not acknowledge social norms.

However, utilising mixed-methods somewhat compensated for this. While the Brief-IPQ was selected for ease of completion, its psychometric properties compare less favourably to those of the multi-scale IPQ-R (van Oort, Schroder & French, 2011).

The IPA methodology limits generalisability to clinical populations, however, the study aimed to provide rich thematic results and generate hypotheses for future research rather than provide conclusive answers. The sub-sample was possibly more heterogeneous than intended, with two participants being placed on deceased donor waiting lists between Phase One and Two. However, both participants remained pre-RRT and their stories added richness to the analysis. Qualitative analysis validity could have been compromised by researcher subjectivity, although reflexivity was attended to throughout the process (Yardley, 2000).

Consistent with the extant literature, this study was cross-sectional. Illness perceptions are dynamic and longitudinal research might be necessary to optimise understanding of the impact of illness representations on treatment preferences throughout the CKD experience. Further qualitative research is required to explore the psychological impact of non-donorship, and how this impacts on relationships.

Clinical Implications

Families face stressful and life changing decisions when confronted with the possibility of PELDKT and disclosing intentions related to RRT. Participants who would consider PELDKT scored higher representations of emotion and concern, and at least three participants expressed an interest in the nephrology psychology service. Emotional distress in CKD pre-RRT (Palmer et al., 2013) and pre-emptively transplanted groups (Bzoma et al.,

2016) are becoming recognised, and pathways to psychological support are encouraged. Meaningful and timely healthcare interactions were important to participants, with interview comments indicating uncertainty regarding illness self-management to delay requiring RRT, reflecting findings that insufficient information and psychosocial support is received across the CKD journey (Morton et al., 2010; Tong et al., 2009). This is relevant as risk of premature death in CKD is up to ten times higher than the risk of progressing to ESKD (Webster et al., 2017).

Interview comments identified some representations (e.g. timeline or treatment control) were developed at an abstract level (“*things will be better for me* [following transplantation]”) (Owen), rather than an experiential level. As experiences of illness may form after pre-emptive transplantation, potentially conflicting with pre-transplantation beliefs (Bzoma et al., 2016), it is important for healthcare professionals to explore how illness perceptions operate over time from hypothetical abstract to concrete experiential levels (Leventhal, et al., 2003). Early elicitation of illness and treatment perceptions offers the potential for modification (Jansen et al., 2013); reduced CKD progression risk factors (Gould et al., 2014); improved psychological and health-related quality of life outcomes (Clarke et al., 2016; Meuleman et al., 2017), through establishing person-centred care. Research is encouraged that develops psychological interventions for illness perception modification in pre-RRT CKD populations.

The current study has implications for negotiating informed consent and assisting people to navigate complex decisions. This process and the health professionals involved need to be psychologically informed.

Conclusions

This study has provided insight into the illness experiences of a stage 3b-5 CKD pre-RRT population, and the potential psychosocial challenges related to pre-emptive living donor kidney transplantation. Medical advancement has created the possibility for intergenerational organ transplantation, contextualised within societal values of extending longevity. Kaufman, Russ & Shim (2006) have discussed challenges regarding societal and familial obligations to donate and postpone death. Optimal healthcare practice needs to be psychologically informed to assist people in navigating these complex decisions and informed consent, as well as ensure person-centred care and empowerment in treatment decisions.

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Critical Appraisal

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Introduction

This paper aims to discuss and evaluate the process and experience of conducting the Large Scale Research Project (LSRP). The context for the LSRP will be outlined, followed by a description and appraisal of the research process for both the systematic review and empirical papers. The implications for future research, clinical practice and methods for dissemination will be considered. The paper will conclude with the author's reflections regarding personal and professional development from undertaking the project.

LSRP Context

Organ donation is a current issue in the UK, especially in Wales following recent legislative changes to consent. The Human Transplantation (Wales) Act 2013 came into force in December 2015, whereby legal consent for organ and tissues for transplantation is either presumed or expressed for those over 18 who live and die in Wales, and who have the capacity to make a decision. Presumed consent in Wales means families, friends or caregivers will be approached to ascertain the deceased's decision on donation before donation can proceed. The Welsh Government (WG) anticipate the system to increase the donation rate by approximately 15 donors per year (WG, 2015), however, donation in Wales has dropped compared to the rest of the UK since implementation (Albertsen, 2018). The remaining devolved nations of the UK are debating the system.

There are also UK wide initiatives to increase organ donation from living donors, through emphasising the role of families in the process (NHS Blood and Transplant, 2013; WG, 2018). While the benefits of donation for transplantation appear obvious, donation remains an evolving area for study. Since the first successful kidney transplant in 1954, medical

advances have reduced the risks of graft rejection and identified alternative methods of transplantation (e.g. xenotransplantation), and legislative advances have made transplantation increasingly accessible. This includes UK legislative change in 2007 allowing the donation of a kidney and partial liver, from a living person to a stranger. The option of donation therefore presents legal, ethical and moral challenges at individual, service and national levels.

Choice of Research Project

The author was interested in developing a research project in this area due to the challenges raised by donation relating to informed consent, and an awareness of potential bias in public campaigns (Rady, McGregor & Verheijde, 2012). Medical advances have led to societal expectations that treatment should be routinely accepted (Kaufman, Russ & Shim, 2006), and the author was interested in the psychosocial implications of chronic health conditions and treatment decisions that people may face. The LSRP aimed to consider organ donation from multiple perspectives; through understanding the familial experiences of deceased donation in Paper One, and the perceptions and experiences of individuals related to living donor transplantation in Paper Two. Both papers have implications for informed consent, and consider the implications for presumed consent systems. The value of qualitative research in clinical healthcare has been well-established (Dierckx de Casterle et al., 2011), and was selected in both parts of the LSRP.

Paper 1: Systematic Literature Review

Identifying the Question

The systematic review originally aimed to complement the empirical paper through continued exploration of living kidney donation, specifically the post-transplantation impact on recipient-donor dyads, however recently published reviews were found (Thys et al., 2015; Ralph et al., 2017). Through becoming familiar with the research and literature related to organ transplantation, the author developed an awareness of the lack of summarised knowledge related to the impact of deceased donor transplantation for families. PROSPERO, the international prospective register of systematic reviews was searched in October 2017, which did not identify upcoming reviews in this area.

A scoping search helped to refine the question, and the identification of existing reviews developed the inclusion criteria. Chandler, Connors, Holland and Shemie (2017) conducted a scoping review examining 'effective' donation requests with the objective to improve donation request outcomes. Dicks, Ranse, Northam, Boer and van Haren (2017), focused on the post-donation request research in its entirety, with minimal inclusion/exclusion criteria, citing 120 studies in their narrative review. Reviewing Dicks et al's (2017) paper provided a foundation for the current review, and emphasised the value of exclusively identifying, summarising and appraising the qualitative literature. Ralph et al. (2014) conducted a qualitative review in 2012 which focused on the attitudes and reasons for donation decisions, in all families who had experienced a request at any timepoint after the request. A scoping search identified a number of studies were found to have been published since Ralph et al's search in 2012, and the research team agreed the research question was appropriate for review. The current review was unique in its focus on the longer-term impact of donation

decisions for those who experienced requests in unexpected circumstances, with the increased potential for complicated grief.

A review of qualitative research was selected due to its importance for identifying emerging areas of research and practice, and to explore specific phenomenon, which may not appear in controlled designs (Dixon-Woods & Fitzpatrick, 2001). It was intended for the review to inform the development of person-focused healthcare practice and research, and help ensure bereaved families are as satisfied as possible with their decisions.

Search Terms

Five databases were searched (CINAHL, Embase, Medline, PsycINFO and Web of Science), due to their comprehensiveness and appropriateness for including journals which relate to psychology, the social sciences, and chronic health conditions. Email alerts from each database ensured the author was notified of any additional relevant papers, of which, none were identified. A study published in June 2018 (Sque et al., 2018), was not able to be included in the synthesis, however the findings indicate support for the outcomes of the review, and would not have changed the overall outcome.

To develop a thorough and focused search strategy, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke, Smith & Booth, 2012) for qualitative and mixed-methods studies was considered. It is an alternative to the PICO (Population, Intervention, Comparison, Outcome) tool used for quantitative research. Initial search terms included qualitative methodology designs (e.g. “interview”; “qualitative”), however this had the potential for relevant studies to be missed (Methley, Campbell, Chew-Graham, McNally & Cheraghi-Sohi, 2014). Focus was purposefully withdrawn from the

Design and Research elements of SPIDER, which reduced the sensitivity of the search, but the decision enabled the author to gain confidence in the search results. Search terms were considered through reviewing the literature, and consultation with a Cardiff University health librarian (Table 1).

Table 1
Search terms and Boolean operators used for electronic databases

Post-bereavement		Relationship		Donation		End of life
Bereave*		Families		(organ adj3 donat*)		“end of life” Deceased
Grief		Family		(organ adj3 transplant*)		Cadaveric
Griev*	AND	Relative*	AND	Donor*	AND	“life support”
(psycholog* adj3 consequences)		Kin		Donation		Brain dea*
				Transplant*		Circulatory dea*

Campbell et al. (2011) recommend additional searches, such as reviewing reference lists to maximise the inclusion of relevant studies, while also acknowledging a missing study from a meta-ethnographic synthesis is unlikely to alter the outcome. An author from two seemingly relevant studies in the grey literature was emailed for more information, who responded that their research utilised quantitative methodology (Kentish-Barnes et al., 2018).

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were devised and applied for selecting studies. The criteria were modified during the selection process, to only include studies with a main focus on families’ experiences of grief, rather than recalling experiences of the donation request. The inclusion/exclusion criteria were:

- Studies exploring the experiences of families/ next-of-kin who were approached to donate a relative's organs or tissue, at least six months after the request.

The review was interested in the longer-term implications of donation requests, and so only studies of families from at least six-months post-bereavement were considered. While six-twelve months is still a time for uncomplicated grief to be processed (Boelen, 2016), it was felt this was an appropriate starting point in understanding how families evaluate and experience their decision related to donation.

- Studies involving the unexpected death of a relative (brain, circulatory, or instant death)

The review was interested in circumstances that may increase risk factors for complicated, or prolonged, grief, such as those following a sudden head injury, stroke, cardiac arrest, vehicle accident, or suicide. While bereavement can be challenging whatever the circumstances, studies involving bereaved families following a terminal illness, whereby donation decisions may have been understood prior to death, were not included.

- Studies using qualitative methodology

Studies that primarily adopted qualitative methodology as part of the data collection and data analysis process were included. Studies using a mixed-method design were considered, providing the qualitative component was relevant to the systematic review and was distinct from the quantitative component. A qualitative review was selected due to the increased

emphasis on qualitative research in informing clinical practice and policy in relation to transplantation (Tong, Morton & Webster, 2016).

- Studies where the primary or secondary aim focused on the aftermath of the request and the consequences for the family, rather than the decision-making process

The searches identified several studies that met the inclusion criteria but predominately focused on families' experiences of decision-making, and the hospital experience. The criteria were modified to exclude papers that did not primarily study post-donation experiences. Studies were also excluded if the family or next-of-kin were not the primary focus of the study, such as perspectives of clinicians.

- Studies published in English, in peer-reviewed journals

The author did not have capacity to translate non-English studies. Peer reviewed journals were selected to better ensure quality control of the selected studies. A decision was made among the research team to keep time-parameters unlimited to be able to review the full literature and to consider the impact of healthcare practices on families.

Quality Appraisal

Assessing the quality of qualitative studies is a debated topic, with a lack of consensus regarding the assessment of qualitative research (Leung, 2015) and what constitutes a 'better' study (Toye et al., 2014). The author chose to utilise an appraisal tool to demonstrate a commitment to provide credibility and rigour to findings (National Institute for Health and Clinical Excellence (NICE), 2012).

Several quality assessment frameworks for qualitative research were considered, including the Quality Framework (Spencer, Ritchie, Lewis and Dillon, 2003); the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury & Craig, 2007); and a protocol developed by Walsh & Downe (2006). The online versions of the Critical Appraisal Skills Programme (CASP) qualitative quality assessment tool (CASP, 2018) was selected for a few reasons:

- It is a specific qualitative assessment tool that is well-established in the literature (e.g. Dixon-Woods et al., 2007).
- The CASP includes two screening questions related to statements of aims and the appropriateness of qualitative methodology.
- Its structured approach and prompts were considered as beneficial for the author and to reduce ambiguity for peer inter-rating.
- It offers thoroughness in its evaluation of rigour, credibility and relevance.
- The ten-items on the CASP potentially make it more efficient than the 32-item COREQ, providing practical advantages for the author.

However, the CASP qualitative checklist has been criticised for its emphasis on methodological criteria (Leung, 2015) and absence of assessment of theory, which may be disadvantageous depending on the epistemological position of the study (Leung, 2015). This criticism applies to other qualitative research quality appraisal tools through their focus on methods rather than the concepts developed (Toye et al., 2014).

A rating scale of 0-2 was created for each item on the CASP, to provide a summary score of the quality. Although this is not suggested by the CASP authors who designed the checklist as a discussion tool, Chenail (2011) supporting the scoring approach if it facilitated the reviewer's ability to compare and contrast the material. All studies met the criteria from the first two questions to be reviewed in full. Maloney (1998) provided a weak description of aims (score of 1/2), however, the appropriateness of omitting a study based on lack of research aims has been questioned (Newton, Rothlingova, Gutteridge, LeMarchand & Rapheal, 2011). The decision was made to appraise papers after data extraction to ensure an unbiased approach and to emphasise a decision to not exclude papers based on rating (Boland, Cherry & Dickon, 2017). The quality assessment would have taken place before data extraction if studies were going to be excluded below a specified rating threshold. A peer independently rated four (25%) studies (NICE, 2012). Minor disagreements related to research design and data analysis were resolved through discussion.

In utilising the meta-ethnographic approach (Noblit & Hare, 1988), exploration of the data was prioritised, followed by the author's interpretations being qualified with the outcomes of the quality appraisal throughout the synthesis (Thomas & Harden, 2008). The included articles ranged in quality from author generated scores of 7/20-19/20. Eleven papers scored higher than 15/20, suggesting studies were of overall high quality according to the CASP criteria. Low scoring papers were used to support a theme if there were also papers of moderate to high quality. However, the low scoring (7/20) Maloney (1998) paper contained some powerful quotations, two of which were used to support the theme titles to acknowledge the value of people's accounts, even in a methodologically poor study.

The main issues identified from the quality appraisal were those of reflexivity and ethical considerations. The absence of reflexivity in six studies and limited commentary on the researcher's role in five studies have implications regarding credibility. The potential for bias remains unresolved without reflexivity statements, especially when some studies aimed to improve donation rates. Sque and Payne (1996) provided a particularly explicit description and reflection of their role as nurses in their research.

There were also poor examples related to ethical issues with 20% of studies making no reference to ethical considerations. While the author does not question that issues such as informed consent were undertaken, discussion of these issues may be helpful to other researchers when working with vulnerable populations and emotive topics. Limited studies referred to data saturation (Manzari et al., 2012; Sque, Long & Payne, 2005; Taylor et al., 2018; Walker & Sque. 2016), although for two cases saturation was intentionally not applied due to time-constraints (Sque et al., 2005; Walker & Sque. 2016). However, sample sizes seemed appropriate based on the aims of the selected studies. Low quality scores on the CASP may also be a reflection of focusing on published studies in peer-reviewed journals, which were possibly constrained by word counts and publication bias (Garside, 2014).

Meta-Ethnography

While there are a range of qualitative approaches to consider for a systematic review, a meta-ethnography (Noblit & Hare, 1988), was selected as a well-developed and widely used method of qualitative synthesis (Hannes & Macaitis, 2012). Meta-ethnography takes an interpretative approach to condense findings into themes, which provide an interpretation of the whole body of research to understand a phenomenon (Noblit & Hare, 1988). It is therefore aligned to that of Interpretative Phenomenological Analysis, and its selection

further emphasises the author's emerging epistemological stance. The seven step methodology enabled a systematic and detailed understanding of how the included studies were related, through the comparison of findings within and across studies.

A thematic synthesis approach (Thomas & Harden, 2008), could have been applied as an alternative synthesis, however this approach does not develop a new interpretation from the data and is less structured than the methodologically rigorous meta-ethnographic approach. The author was also guided by the qualitative literature, which regards meta-ethnography as an alternative to a quantitative meta-analysis (Campbell et al., 2011), whereby the analysis provides innovation to the research area rather than summarising findings.

Data Extraction and Analysis

The product of a meta-ethnography is the translation of studies into one another. Data sets of quotes (first order constructs) and themes (second-order constructs) were created for analysis through multiple reading of the included papers. The author developed 'third-order' constructs (Britten et al., 2002) through interpreting and synthesising the first and second order data sets. While the author approached the meta-ethnography with an open mind, a limitation to this synthesis is the potential for bias in a single researcher undertaking the data analysis and synthesis. While emerging constructs and themes were discussed in supervision, it is common for meta-ethnography to include multiple people involved in the synthesis. Meta-ethnography is also interpretative, which may mean the results are difficult to replicate. However, Noblit and Hare (1988) encourage different interpretations provided the constructs are found within the data and the method for meta-ethnography has been followed, which is an advantage of its highly structured and replicable method.

Implications and Future Research

The meta-ethnographic synthesis of 15 studies offers a new insight into the post-bereavement experiences for families approached with a donation request. While the samples used in the included studies varied in terms of age, religion and culture and healthcare system experiences, similar themes occurred, which were evident in the narratives of study participants. This may suggest the identified themes reflect the post-bereavement processes and experiences of families well. Synthesising the literature has provided a collection of the voices of 411 relatives, and the themes generated have added strength and opportunities for healthcare staff to support people related to organ donation requests. The review contributes to the evidence-base of understanding the impact of rapid medical advancements on family experiences (Dicks et al., 2018).

While the ethical challenges of conducting bereavement research are acknowledged (Sque, Walker and Long-Sutehall, 2014), the findings of the review indicate a paucity of studies which include families who reject donation; families who do not experience donation requests during end of life care; and families in presumed consent systems. Further research is required with such populations, as donation has implications for a person's concept of the assumptive world (Parkes, 1988), continuing bonds with the deceased (Field, Gao & Paderna, 2006), and posttraumatic growth (Calhoun, Tedeschi, Cann & Hanks, 2010).

Further engagement and understanding of the implications for Black, Asian and Minority Ethnic (BAME) populations are also required. The majority of studies reviewed were cross sectional, with only two longitudinal studies. Of these, Hogan et al. (2013) used the qualitative approach at six-months post-bereavement, followed by quantitative analysis for the remainder of the study (Hogan et al, 2014), and Sque et al. (2005) explored the first

twelve-months post-bereavement. Theoretical implications related to grief processes are dependent on longitudinal qualitative research which extend beyond the twelve-month post-bereavement period to richly understand the impact on donation requests.

In considering clinical implications, the synthesis highlights the potential implications of an organ donation request in grief. While the majority of people did not regret their decision, donation may raise unexpected challenges for families in grief. The review identified the significance in grief of knowing a relative's preference related to donation, confusion about brain-death, and post-bereavement follow-up. Clinical psychologists may be well positioned to provide both support to teams regarding matters of informed consent, and supporting families with issues related to grief and posttraumatic growth.

While campaigns to promote donation have altruistic and utilitarian purposes (Dalal, 2015), they must also be mindful of constructing societal expectations that non-donation is unacceptable, which may create guilt and shame for families who select this option.

Promoting informed choice should be at the heart of campaigns, which provide information for people to consider and discuss their intentions, as partially reflected in the current campaign in Wales (Organ Donation Wales, 2018; Noyes et al., 2018). Findings may support the argument that presumed consent is not the answer to improve donation (Fabre, 2014), and national organisational and infrastructure changes, such as improved facilities for families to stay with their relative are suggested (Fabre, Murphy & Matesanz, 2010; Noyes et al., 2018).

Reflections

The process of undertaking the systematic literature review developed the author's confidence in critiquing qualitative research, and the importance of studies describing

reflexivity and assessment of rigour to reduce the risk of bias (Yardley, 2000). It also illustrated the value and power of qualitative research, especially when quotations are used to illustrate themes, in bringing emotive and complex issues to life.

Paper 2: Empirical study

Research Objectives

The empirical paper initially aimed to develop an understanding of the post-donation experiences of non-directed ‘altruistic’ Welsh kidney donors, however, anticipated obstacles such as sampling constraints led to the development of an alternative research idea. The author engaged with a nephrology and transplant service, reviewed the existing literature, and attended a British Transplant Society forum on living donor organ transplantation. This activity established the research opportunities surrounding pre-emptive living donor kidney transplantation (PELDKT). Existing research predominately aimed to increase living kidney donation, and the author felt that a study without such aims and which utilised a psychological theory would be a valued contributing to the evidence-base.

The author became familiar with clinical health psychology models, such as stage theories (Transtheoretical Model, Prochaska & DiClemente, 1983), attitudinal models (Theory of Planned Behaviour, Ajzen, 1991) and expectancy value models (Health Beliefs Model, Becker, 1974), all of which can be useful to understand treatment decisions and behaviour in chronic illness. However, they do not fully describe individual representations of a chronic health condition (Dempster, Howell & McCorry, 2015). The Self-Regulatory Model (SRM) of illness (Leventhal, Phillips & Burns, 2016) was discussed and agreed with the research team to provide a psychological theoretical framework. The SRM was deemed particularly

appropriate for a pre-renal replacement therapy population as lay representations of illness are central to the conceptualisation of the model.

The SRM has been widely used to predict behavioural outcomes, explain psychological outcomes, and to help modify illness perceptions and coping strategies (Dempster et al., 2015). The constructs and processes proposed in the SRM have been tested, and illness perceptions have been found to correlate to behaviour and outcomes (Hagger & Orbell, 2003; Hagger, Koch, Chatzisarantis & Orbell, 2017).

The Decision for Mixed-Methodology

As found by Kranenberg et al. (2009), people can hold unspoken preferences regarding renal replacement therapy (RRT), and adopt wishful thinking about potential donors. A rationale for a mixed-methods design was developed, as a qualitative approach was regarded as more likely to elicit such disclosures than self-report questionnaires. Mixed-methods involves the collection, analysis and integration of both quantitative and qualitative data in a single study (Creswell & Plano-Clark, 2007), with the assumption that such methods can more comprehensively answer some research questions than single methods (Tariq & Woodman, 2013).

Quantitative research traditionally takes a deductive approach and a positivist stance, with the potential for generalisable findings. However, it does not explain complex social or cultural phenomenon. Qualitative research takes an inductive approach, with emphasis on the researcher's role in interpreting the multiple realities, contexts and meanings experienced by people, and to allow hypotheses and theory to be generated. However, the method is less generalisable. Through selecting mixed-methods, the ontological and epistemological

strengths of both approaches were combined, potentially offsetting the limitations of each paradigm. The approach has become increasingly applied to address the complexities associated with understanding chronic health conditions (Tariq & Woodman, 2013), rather than just focusing on specific variables at a fixed point in time. Mixed-methods were selected because:

- 1) Pre-treatment chronic kidney disease (CKD) populations are under-researched (Clarke, Yates, Smith & Chilcot, 2016).
- 2) Such methodology allows for in-depth exploration of people's experiences of illness and the issues they consider important, ensuring the responses are of sufficient detail to make recommendations (Tariq & Woodman, 2013).
- 3) While the Self-Regulation Model is a robust theory (Hagger & Orbell, 2003), it does not explore the role of relationships, and quantitative methods alone may not capture people's experiences and attitudes in the context of their relationships.

Consideration was given to the selection, order and priority of the methods. As the nephrology database only provided demographic and bio-medical information, a sequential explanatory design (Ivankova, Creswell & Stick, 2006) was selected, whereby the quantitative methodology precedes the qualitative method. The design can follow two routes (Creswell & Plano-Clark, 2007):

- '*Follow-up explanations*' - the qualitative component is used to specifically address a finding in the quantitative component.
- '*Participant selection*' - the larger population in the quantitative phase helps to situate the sample and purposefully select participants for in-depth interviews.

The *participant selection* approach was utilised, which places priority on the qualitative methodology in developing understanding of individual lived experiences of chronic illness. The original work of Leventhal also used qualitative inquiry (Meyer, Leventhal & Gutmann, 1985), which emphasised its value when exploring illness.

The mixed-methods design would ensure the voice of participants was heard, a somewhat political decision in response to the author's value for person-centred care, and one which has been identified as a valid reason for selected mixed-methods (Tariq & Woodman, 2013). Yardley (2000) has commented that such reasoning reflects traditional clinical practice, where importance is placed on the interaction between the researcher and the participant similar to the clinician-client relationship.

The Decision for Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) was selected as the qualitative methodology after evaluating the theoretical underpinnings and suitability of alternative qualitative approaches. The author considered the objectives of the study, the practicalities of an approach, and reflections in supervision about the author's epistemological stance.

Grounded Theory (GT) (Charmaz, 2014), was considered, but was rejected for several reasons. While GT can be applied to mixed-method designs (Guetterman, Babchuk, Howell-Smith & Stevens, 2017), the author was aware of the added complexity of selecting the most appropriate version for the research question (Willig, 2013). Engagement with the GT literature led the author to view GT as better suited for an exploratory design study, and as

unsuitable for the LSRP due to the application of the SRM in Phase One. Further, the LSRP aimed to elucidate personalised experiences rather than develop a new model. The GT approach requires concurrent data collection and analysis (Charmaz, 2014), and for data collection decisions to change as the potential theory emerges. There were therefore also practical reasons for not using Grounded Theory, through anticipating difficulties regarding sample size and theoretical sampling until saturation is reached, and the additional demands for the author in an already time-demanding mixed-methods study.

Thematic Analysis (TA) (Braun & Clarke, 2006), is a widely used method, however, there remains lack of clarity regarding how it should be conducted, and it is not connected to a pre-existing framework (Howlitt, 2016). While TA makes fewer demands on the researcher for data collection and analysis (Howlitt, 2016), it lacks focus on the process of sense-making and does not emphasise the researcher's role in the process. Although TA does not aim to provide a detailed interpretation of findings, this may limit the opportunity explore nuances within the data. In contrast, IPA has pragmatic systematic guidelines (Smith et al., 2009), to assist with data collection, theme identification and integration, which was viewed as beneficial by the author to provide an accessible and structured approach to the research. Whereas TA integrates data across the entire data-set, the IPA process enables researchers to remain close to the data through intensive engagement with each individual case and integrating cases in the latter stages of research (Willig, 2013; Howlitt, 2016).

The idiographic approach of IPA was deemed as suitable for the aims of the research due to its use of the phenomenological method of understanding and prioritising an individual's experiences and perceptions of the phenomenon of interest (Smith et al., 2009). IPA was also selected due to its well-established utility within the chronic illness literature (Smith &

Osborn, 2015), and its acceptance of existing psychological models or theoretical frameworks, provided the data collection and analysis are flexible and allow themes to emerge (Pietkiewicz & Smith, 2014). IPA has been applied in previous mixed-methods studies to explore illness perceptions and treatment choices (Brown, Dean & Hay-Smith et al., 2010).

Bracketing and Reflexivity

Quality control was carefully considered to best ensure rigour during data collection and analysis and improve the prospects for practical use of the findings (Yardley, 2000). The author engaged in 'bracketing' (Ahern, 1999; Chan, Fung & Chein, 2013) and reflexivity to ensure the research process and the researcher's role was scrutinised (Appendix M). This demonstrated a commitment to safeguard the double hermeneutic of IPA, where the researcher is required to make sense of an individual's sense-making of their own experiences. Reflexivity aimed to keep the participants' voices at the centre of the research, as opposed to using the voices of the participants to support the preconceptions of the researcher (Tufford & Newman, 2012). The bracketing off of assumptions was of central importance given the mixed-methods design, but also the professional and personal experience of the researcher. During IPA analysis, the author aimed as much as possible to understand the phenomenon through recurrent listening and reading of each participants' descriptions of their experiences, while holding to one side what the event presented to the author. However, the author acknowledges their view of the world is implicated in the analysis and the IPA produced for the LSRP is only the author's interpretation of the participants' experiences.

Ethical Considerations

Due to the confronting nature of the study, ethical issues were considered throughout the process to show duty of care (British Psychological Society, 2014). The author was concerned for potential participants, who may never require renal replacement therapy (RRT), receiving an unexpected invitation letter to a study about transplantation. To avoid causing unintentional emotional distress, a focus session was arranged with two recipients of deceased kidney transplants to ensure for clarity and suitability of wording in all correspondence to the target population. The feedback highlighted the confronting nature of the letter, especially the reference to ‘transplantation’. The focus group assisted in rewording the letter, and a recommendation was actioned to underline a statement about the study not implying anything about a person’s clinical care (Appendix E). While it was agreed the word ‘transplantation’ may be alarming, ethically it had a place in the initial letter for reasons of transparency regarding the study aims.

To ensure informed consent, the author answered any questions from potential participants over the phone or email. Pressure was never applied for people to take part, and people who requested the questionnaire pack were always reminded they were free to withdraw from the study at any point. Details were provided in the information sheet (Appendix F) for support services should people become emotionally distressed by the study and the issues it raised. Participants who opted-in to be contacted for the interviews were telephoned by the author and thanked for their involvement at Phase One, however this was restrained to avoid creating a sense of obligation to participate in Phase Two.

Recruitment

Phase One

A power calculation of $n=98$ for the survey was obtained based on the available total CKD population on the nephrology database who met the study inclusion criteria. Due to the results of previous research (Coorey, Paykin, Singleton-Driscoll & Gaston, 2009) and the sensitivity of the questions being presented to a potentially vulnerable and chronically ill population, a low response rate was anticipated. The mixed-methods design of the study was also pragmatic given that it was anticipated that the response rate might result in insufficient power to use multi-variate analyses.

The inclusion criteria for Phase One were based on information available from a database, such as age, bio-medical markers and stage of treatment, and a stratified sample was created based on age, to reflect the database. To avoid creating unnecessary concern, people in stage 1-3a CKD were excluded from the study as such groups may not be fully aware of their kidney problem and were less likely to be connected to services. A decision was made through consultation with the nephrology team to have 70-years as the cut off based on health-comorbidities limiting RRT options, however, the author somewhat regrets this decision and remains curious regarding the answers of those over 70-years.

The research did not target potential participants via posters or pre-dialysis courses as illness perceptions and knowledge may have already been influenced. The study was interested in a sample of people who may or may not define themselves as having CKD and may not have had discussions regarding RRT. By understanding lay representations of illness, the research

has remained close to the central conceptualisation of the SRM, and understanding the importance of people's 'perceptions' of illness and the choices they make accordingly.

Based on age, the Phase One 18-39 year-old cohort were representative of the database. The 40-59 years-old cohort respondents were underrepresented by 18%. People aged 60-70 were over represented by 9%. While additional Phase One recruitment was discussed among the research team, the author made an ethical decision not to persist with recruitment, based on the limitations of the database which only provided bio-medical data. Phase One responses alerted the author to vulnerability and sensitivity of living with CKD and raised awareness of the opportunity for richer insights through Phase Two.

Phase Two

The *participant selection* approach helped situate the sample (Elliot, Fischer & Rennie, 1999) for the IPA to better create a homogenous sample of people who would consider or who were unsure of their position regarding PELDKT. In conducting qualitative research, Braun and Clarke (2013) encourage sample sizes that generate enough data to develop themes while not compromising the researcher's ability for in-depth analysis of data. The idiographic nature of IPA makes it suitable for analysis of small samples, and the sample of eight people for Phase Two was congruent with published guidance (Smith et al., 2009). The six additional Phase One participants who were unable to be interviewed did not differ from the eight who were included, consisting of four male, three females, aged 50-70 with an eGFR rating 3-5 and a preference or uncertainty towards PELDKT.

Questionnaires

The selection of the Brief-IPQ (Broadbent et al., 2006) was for pragmatic reasons, as the

IPQ-R (Moss-Morris et al., 2002) required additional time demands from participants. While the Brief-IPQ is validated for a range of health conditions and was still able to be adapted specifically for CKD, its critics argue it lacks robust psychometrics (van Oort, Schroder & French, 2011). Broadbent et al. (2011) disputed claims of poor concurrent, content and discriminant validity, with subsequent systematic review reporting good psychometric properties for concurrent and predictive validity (Broadbent et al., 2015). For CKD populations, the IPQ-R dimensions of timeline, coherence and treatment control have demonstrated less support for validity (Pagels et al., 2012), and validity of the Brief-IPQ for this population requires further investigation. A strength of the study was therefore its mixed-design.

The Treatment Acceptability and Preferences measure (Sidani et al., 2009), a generic and adaptable measure that assesses the acceptability of different treatments, would be beneficial for future research presenting RRT options. It could be suggested that participants may also have benefitted from being provided with information on RRT options, including the pros and cons.

Interview Schedule

The interview schedule of open-ended questions was devised through analysis of the Phase One questionnaires, which indicated a requirement to further understand people's experiences of considering renal replacement therapies and discussing options with others. The SRM, and consequently the Brief-IPQ, does not consider or assess relationship or subjective norms. Interviews began with broad questions to allow respondents the opportunity to speak of their experience in an unbiased manner, consistent with the phenomenological method. The

interview guide aimed to develop content related to the research aims that was not spontaneously covered.

It was during the analysis stage that the author considered the more visceral reactions and subconscious beliefs that may exist towards receiving a body part, and which may be unable to be articulated. The interview schedule may have benefitted from much broader questions, although this may have taken the emphasis away from the research objective. The development of the interview schedule helped the author to feel confident in the interview process, but through this experience, the author has developed confidence in conducting more unstructured interviews. The data produced and analysed was dependent on the questions and the author's interview technique, and data may have been missed from an over-reliance on the schedule.

Data Collection

Six people who requested but did not return their questionnaires were sent written reminders after three weeks and were not pursued further to avoid coercion. Missing data was not an issue with any questionnaire, other than responses to open-ended questions, which some people left blank. Overall, participants equally preferred the questionnaire to be sent via email (51%) and postal (49%), with a better response rate from the people emailed a link to the questionnaire (89%) compared to the postal responders (78%). This was of interest to the author, who will aim to utilise technology in future research endeavours, while also ensuring choice where possible. Conducting the interviews had a significant impact on the author, who welcomed the opportunity to meet, talk and share in the experiences of others. The author developed additional interview skills due to the process being different to a clinical interview, although clinical skills were utilised if a respondent became upset.

Analysis

Due to the sample size, analyses such as logistical regression were not an option for the study, however data analysis was sufficient to situate the sample for Phase Two. While this current study prioritised the IPA, future research with larger samples may consider conducting multivariate analyses to achieve statistically robust explanations of the contribution of illness representations and knowledge of LKD to transplant treatment choices.

Consistent with Smith et al. (2009), the inductive and idiographic IPA analysis took place in stages (Appendix K). Each case was analysed separately, with frequent reference to the transcripts to ensure emerging themes reflected the respondent's experience. Cases were then integrated to combine findings until a master list of themes was produced and subordinate themes had been integrated or dropped from the analyses. This approach aimed to preserve the integrity of the data while also maximising the potential for enhanced understanding from combining data sets (O'Cathain, Murphy, Nicholl, 2010). The analysis process required additional reflexivity from the author, and independent reviews from a peer and supervisor ensured themes were not being created inaccurately and closely reflected the data.

Inspired by the meta-ethnographic literature (Toye et al., 2014), which advocates freedom to express research findings creatively, the author created a visual representation of the IPA (page 68 in Paper 2). This aimed to capture the phenomenon of being someone pre-RRT and considering PELDKT, as experienced by those he met. The picture is reminiscent of the London Underground logo, symbolising the health trajectory journeys that people are navigating. The same logo is also reminiscent of a 'no entry' sign, symbolising the barriers, obstacles and choices which people may face with their health condition and treatment

decision-making. The line across the middle also represents decisional balance and how people may weigh up risks differently to others. A crossroads symbolises the multiple directions that may be available to people, and the information that people require to choose a path. Finally, the concentric circles are representative of Bronfenbrenner's (1979) systems theory, whereby people exist within family, healthcare and societal systems, which may impact on their experiences and choices. At the centre and in the background is the awareness of the journey and decisions that people may face.

Evaluation

While there is a lack of consensus on the criteria to quality appraise mixed-methods studies, the Mixed-Methods Appraisal Tool (Pluye et al., 2011) was used to help evaluate the strengths and limitations of the LSRP empirical study.

The qualitative method

A strength of the study is the use of a phenomenological approach and semi-structured interviews to address the research objective of understanding people's subjective experiences. Phase One was used to 'situate the sample' (Elliott et al., 1999), by which Phase Two participants could be selected and described beyond demographic database information. Toma (2000), recommends researchers to attempt to understand the participants' experience as closely as possible, and the author met with a small focus group and visited the nephrology and transplant team to gain knowledge and insight into the systems, processes and procedures that surrounded the potential participants. The author reflected on these experiences throughout the process to maintain an openminded approach and to demonstrate a

commitment to conducting research that considers the needs of potential participants and service-user involvement (Moore & Meudell, 2017).

The study largely maintained a homogenous sample, and although there may have been slightly more heterogeneity than intended, this also allowed the potential for counter perspectives to enter the interview data. The qualitative component may have benefitted from situating the sample further, such as by illness perception ratings indicated in Phase One. However, the criteria chosen maintained a homogeneity, while ensuring recruitment aims were realistic for a real-life clinical population.

As with all qualitative research, the influence of researcher subjectivity can weaken validity. However, qualitative research can never be, and doesn't aim to be, completely objective (Yardley, 2000). Although challenging, the author demonstrated a commitment to minimise bias through the use of bracketing statements, a diary, and use of supervision. The author also engaged with the nephrology and transplant team to dispel any misconceptions.

While IPA was identified appropriate for the LSRP, it does have limitations. Exploration and interpretation of people's experiences can be restricted to a person's ability to convey or describe their experiences or emotions through language (Tuffour, 2017). Consequently, subtleties and nuance may not be captured, which creates the potential for the interpretation to relate to how people talk about their experiences, rather than the experience itself (Willig, 2013). The IPA findings are not generalisable to clinical populations of pre-treatment CKD cohorts, however, the study aimed to generate hypotheses for future research rather than provide conclusive answers.

The quantitative method

While the sample size of 31 was too low for multivariate statistics, the sample were generally representative of the population of the database based on age through use of stratified random sampling. The low 10% response rate matched that of Coorey et al. (2009), and the research may have benefitted from following up non-respondents to assist future studies in accessing this seemingly hard to engage group.

A strength of the study is the use of psychological theory through utilising the illness representations component of the SRM, a highly regarding model with meta-analytic review demonstrating theoretical robustness (Hagger & Orbell, 2003; Hagger et al., 2017). The Brief-IPQ and a pre-existing living kidney transplantation questionnaire were strengths of the study to understand the research objective and to contribute to the wider research through replicability and systematic review. The author acknowledges the potential psychometric limitations of the Brief-IPQ compared to the IPQ-R, but felt the pragmatic decision to use the Brief-IPQ was justified. As with any self-report questionnaires using rating scales, response bias may have been present.

As a cognitive model, the SRM may not capture responses to illness such as the “ick factor” (O’Carroll, Foster, McGeechan, Sandford & Ferguson, 2011), whereby factors such as body integrity may have had more impact than knowledge, attitude and social norms. Unlike the Theory of Planned Behaviour (Ajzen, 1991), the SRM does not consider social context and subjective norms, an area which appeared to greatly shape participants’ perceptions.

Mixed methods

The mixed-methodology was considered a strength of the study due to the few studies conducted on this population, especially in Wales and NHS healthcare systems. The use of sequential explanatory design provided structure, although the author acknowledges conducting mixed-methods was time-consuming, and the integration of the qualitative and quantitative data was challenging. While sequential explanatory design is considered suitable for single researchers, mixed-designs often benefit from additional researchers (Creswell & Plano-Clark, 2007), which was beyond the remit of this LSRP.

Participants were under a presumed consent system in Wales, and although this seemed to have minimal impact on the interview participants' choice-making, the context remains unique to the rest of the UK. However, the findings only describe the experiences of those who chose to participate in the study and differences may be found with non-respondents who may hold different perceptions of their illness and treatment choices. The LSRP placed the voices of participants at the centre of the study and provided an opportunity for voices to be known. The author welcomes the opportunity to disseminate the research findings to the relevant audiences.

Implications and Further Research

The study has developed an enhanced understanding of the illness perceptions, treatment beliefs and psychosocial issues involved for people with CKD, who may be less engaged with services due to their level of illness severity. This understanding may develop strategies to maximise patient-centred care, and enhance informed, shared decision-making within services. The study highlights the importance of personal meaning and context in decision-making, and the value of medical systems being psychologically informed.

The study presents an opportunity for healthcare professionals to hold early conversations with patients which are centred around illness and treatment perceptions. Through understanding the social, cognitive and emotional perceptions of illness and treatment, the conversations and interventions provided by healthcare professionals can be optimised. This may include responding to misconceptions or concerns patients may hold about their care and future; how best to deliver education programmes; enhanced communication; and improved shared decision-making.

Participants indicated a desire to manage the CKD to postpone RRT for as long as possible, but examples of uncertainty were evident regarding how this would be achieved. The study found participants perceived low personal control and were concerned about their illness. Illness perception modification (Jansen et al, 2013) may be beneficial for supporting pre-RRT cohorts with illness management. For example, people who perceived their condition as controllable were more likely to engage with interventions and experienced improved clinical and psychological outcomes (Keogh et al., 2011).

NICE Guidance for initiating renal replacement therapy are currently in development (NICE, 2018). Current recommendations suggest transplantation be discussed six months before the anticipated start date for dialysis (NICE, 2015). However, this may reduce the ability for families to have meaningful conversations due to the short timeframe for effective shared decision-making. Early exploration of patients' circumstances, beliefs and preferences regarding treatment may assist in the decision-making process and reduce concerns of coercion when discussing living transplantation with relatives or friends. Clinical

psychologists are well placed to support teams and service-users through this process through consultation or assessment (NICE, 2014).

Strategies (NHSBT, 2013) and recommendations Wu et al. (2017) to increase donation rates are clearly important and have enormous value. The study has emphasised the importance of ensuring people and their families are appropriately informed and supported in the choices presented to them in order to make meaningful and timely decisions for themselves. The role of a Nephrology and Transplant team may be considered in supporting the initiation of conversations with relatives regarding donation, or in instances where potential recipients decline offers from potential donors. This may include providing supportive and transparent environments where honest conversations could be held to foster effective decision-making, without the professional indicating their view of the decision. Healthcare teams in countries newly operating or considering presumed consent may be alert to patient expectations regarding organ availability which may also impact on their treatment choices.

As suggested by the title of Paper 2, there may be disparities in attitudes towards the risks and benefits of transplantation between those with medical knowledge, and patients, who may see the challenges the option presents to their family. The perceived risks and benefits of available treatment options will have different outcomes to different people. An implication, potentially supported by clinical psychology, may be for teams to have the space to question their own motivators, shared beliefs and biases in decision-making, alongside the beliefs held by the people they support.

Future research is recommended into the impact of non-donation for potential living donor-recipient dyads (whereby an offer or request was rejected), and the systematic review of studies exploring unsuccessful transplantation on the recipient-donor-recipient relationship.

Dissemination

Dissemination of findings is an important but often overlooked part of the research process (Kerner, Rimer & Emmons, 2005), and the author has considered dissemination at a range of levels. At a local level, the study will be presented to the Nephrology and Transplant team, and a poster will be offered for display in an area visible to service-users. Failure to include participants and the communities associated with the research in the dissemination activity has the potential to undermine the findings and community relationships (Ondenge et al., 2015). Participants in the study were therefore asked to indicate on their consent forms if they would like to be informed of the study outcomes, and an information sheet summarising the findings will be prepared and shared with those who requested it.

Professional and academic dissemination activity includes the empirical paper being presented on 21st September 2018 at the Welsh Renal Clinical Network conference in Llandrindod Wells. The empirical paper abstract will be submitted for podium presentation at the British Transplant Society Annual Congress in Harrogate (March 2019), with the systematic review abstract being submitted as a poster presentation. Both papers will also be submitted for journal consideration. The empirical paper will be submitted to *Psychology and Health* due to the relevant subject matter and the welcoming of qualitative and mixed-methods studies, which may necessitate larger word counts. The systematic literature review will be submitted to the *Journal of Death and Dying* (Appendix A).

Professional and Personal Development

The research process, from conception to completion, has developed the author's competence and confidence as a researcher and clinician. The experience of navigating NHS Ethics, and Research and Development systems developed an enhanced appreciation of the duties and obligations of a researcher when working with clinical populations (BPS, 2014; Health and Care Professions Council, 2012). Clinical psychologists are well trained and well placed to support teams and families by contributing to meaningful research (Dicks et al., 2018), although such skills and opportunities are underused in clinical practice (Smith & Thew, 2017). The author feels more confident in suggesting or leading on research post-qualification through having an experience which included ethical approval processes, and the opportunity to utilise mixed-methodologies. The study design was valued by the author, through broadening knowledge, experience and skills that can be applied to clinical settings.

The processes of bracketing and reflexivity have further developed the author's self-awareness of the assumptions they bring to both research and clinical settings, and he intends to continue a reflective journal. Through keeping the journal, the author will continue to reflect on what is challenging, interesting, assumed, and the role of power and responsibility. The author aimed to hold his assumptions and experiences to one side as best as possible in the interpretative analyses; it is up to the reader to assess the findings in the context of the author's bracketing statement.

Throughout the process, the author questioned, and continues to question, his epistemological stance. The subject matter evoked many emotional reactions in the author, and many of the quotations expressed in this LSRP are incredibly powerful, leading to the development of a strong connection to the phenomenological approach to producing knowledge, which

provides insight into subjective perspectives and experiences. The author's epistemology currently lies somewhere between phenomenology and empiricism, with an openness to vary his approach according to the research or clinical context.

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Appendices

Appendix A: OMEGA - Journal of Death and Dying Author Submission Guidelines

Description:

Drawing significant contributions from the fields of psychology, sociology, medicine, anthropology, law, education, history and literature, *OMEGA* has emerged as the most advanced and internationally recognized forum on the subject of death and dying. It serves as a reliable guide for clinicians, social workers, and health professionals who must deal with problems in crisis management, e.g., terminal illness, fatal accidents, catastrophe, suicide and bereavement. The journal brings insight into terminal illness; the process of dying, bereavement, mourning, funeral customs, suicide. Fresh, lucid, responsible contributions from knowledgeable professionals in universities, hospitals, clinics, old age homes, suicide prevention centers, funeral directors and others, concerned with thanatology and the impact of death on individuals and the human community. **Impact Factor:** 0.676

Instructions for Authors

Prepare manuscripts according to the latest Publication Manual of the American Psychological Association. Manuscripts can be submitted in APA style to <https://mc.manuscriptcentral.com/omega>. A synopsis of this manual is available from the American Psychological Association. <http://apa.org/>

Originality Authors should note that only original articles are accepted for publication. Submission of a manuscript represents certification on the part of the author(s) that neither the article submitted, nor a version of it has been published, or is being considered for publication elsewhere.

Manuscripts Manuscript must be word processed, double-spaced, with wide margins. Paginate consecutively starting with the title page, which should be uploaded as a separate file. The organization of the paper should be indicated by appropriate headings and subheadings. Author information should only be included on the title page.

Style Technical terms specific to a particular discipline should be defined. Write for clear comprehension by readers from a broad spectrum of scholarly and professional backgrounds.

Manuscript Submission Guidelines:

Manuscript must be word processed using Word or Open Office Writer, double-spaced, with wide margins. Paginate consecutively, starting with the title page. Title Pages should include the follow as applicable:

- Full article title;
- Acknowledgements/credits;
- Each author's complete name and institutional affiliation(s);
- Up to five keywords as it should appear if it were to be published.

Abstracts of 100 to 150 words are required to introduce each article.

Most articles are between 5000-7500 words and while we accept long pieces that mandates additional evaluation because of space limitations.

The organization of the paper should be indicated by appropriate headings and subheadings.

When possible, all illustrations, figures, and tables are placed within the text at the appropriate points, rather than at the end. Clearly identify all figures. Tables must be cited in text in numerical sequence starting with Table 1. Each table must have a descriptive title. Any footnotes to tables are indicated by superior lower case letters. Large tables should be typed on separate pages and their approximate placement indicated within text.

Appendix A (continued): Psychology & Health Author Submission Guidelines

Aims and scope: *Psychology & Health* promotes the study and application of psychological approaches to health and illness. The contents include work on psychological aspects of physical illness, treatment processes and recovery; psychosocial factors in the aetiology of physical illnesses; health attitudes and behaviour, including prevention; the individual-health care system interface particularly communication and psychologically-based interventions. The journal publishes original research, and accepts not only papers describing rigorous empirical work, including meta-analyses, but also those outlining new psychological approaches and interventions in health-related fields.

Peer Review Integrity: All research articles in this journal, including those in special issues, special sections or supplements, have undergone rigorous peer review, based on initial editor screening and anonymized refereeing by at least two independent referees.

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper. **There is no word limit for this journal.**

A typical paper for this journal should be inclusive of the abstract, tables, references, figure captions, endnotes.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper:

Font: Times New Roman, 12 point, double-line spaced. Use margins of at least 2.5 cm (or 1 inch).

Title: Use bold for your article title, with an initial capital letter for any proper nouns.

Abstract: Indicate the abstract paragraph with a heading or by reducing the font size.

Keywords: Please provide keywords to help readers find your article. If the Instructions for Authors do not give a number of keywords to provide, please give five or six.

Headings: Please indicate the level of the section headings in your article:

1. First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.
2. Second-level headings: bold italics, with an initial capital letter for any proper nouns.
3. Third-level headings: italics, with an initial capital letter for any proper nouns.
4. Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.
5. Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Tables and figures: Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables should be supplied either at the end of the text or in a separate file. The actual figures should be supplied as separate files.

Spelling and punctuation: Each journal will have a preference for spelling and punctuation, which is detailed in the Instructions for Authors. Please use British (-ise) spelling style consistently throughout your manuscript. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Please note that long quotations should be indented without quotation marks.

Appendix A (continued): Psychology & Health Author Submission Guidelines

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal.

References

Please use this [reference guide](#) when preparing your paper.

Checklist: What to Include

1. **Author details.** Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted.
2. Should contain a structured abstract of 200 words. Objective, Design, Main Outcome Measures, Results, Conclusion.
3. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants:* This work was supported by the [Funding Agency] under Grant [number xxxx]. *For multiple agency grants:* This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
4. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. [Further guidance on what is a conflict of interest and how to disclose it.](#)
5. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). [Templates](#) are also available to support authors.
6. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a [recognized data repository](#) prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
7. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our [Submission of electronic artwork](#) document.
8. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text.
9. **Units.** Please use [SI units](#) (non-italicized).

Appendix B: Reasons for the exclusion of articles read in full:

Studies focusing on decision-making and the donation experience
de Groot, J., van Hoek, M., Hoedemaekers, C., Hoitsma, A., Smeets, W., Vernooij-Dassen, M., & van Leeuwen, E. (2015). Decision making on organ donation: the dilemmas of relatives of potential brain dead donors. <i>BMC medical ethics</i> , 16(1), 64.
Dodd-McCue, D., Tartaglia, A., & Cowherd, R. (2007). The role of women in the donation consent decision: Building on previous research. <i>Progress in Transplantation</i> , 17(3), 209-214.
Fernandes, M. E. N., Bittencourt, Z. Z. L. D. C., & Boin, I. D. F. S. F. (2015). Experiencing organ donation: feelings of relatives after consent. <i>Revista latino-americana de enfermagem</i> , 23(5), 895-901.
Gironés, P., Crespo, M. L., & Santamaria, J. D. (2015). Impact of Organ Donation in Spanish Families: Phenomenological Approach Through Relatives' Lived Experiences. <i>Transplantation Proceedings</i> 47 (1) 4-6.
Haddow, G. (2004). Donor and nondonor families' accounts of communication and relations with healthcare professionals. <i>Progress in transplantation</i> , 14(1), 41-48.
Jensen, A. (2016). "Make Sure Somebody Will Survive from This": Transformative Practices of Hope among Danish Organ Donor Families. <i>Medical anthropology quarterly</i> , 30(3), 378-394.
Long, T., Sque, M., & Payne, S. (2006). Information sharing: its impact on donor and nondonor families' experiences in the hospital. <i>Progress in Transplantation</i> , 16(2), 144-149.
Pelletier, M. (1992). The organ donor family members' perception of stressful situations during the organ donation experience. <i>Journal of advanced nursing</i> , 17(1), 90-97.
Sque, M., & Galasinski, D. (2013). "Keeping Her Whole": Bereaved Families' Accounts of Declining a Request for Organ Donation. <i>Cambridge Quarterly of Healthcare Ethics</i> , 22(1), 55-63.
Thomas, S. L., Milnes, S., & Komesaroff, P. A. (2009). Understanding organ donation in the collaborative era: a qualitative study of staff and family experiences. <i>Internal medicine journal</i> , 39(9), 588-594.
Quantitative study
Ashkenazi, T. & Cohen, J. (2015). Interactions between healthcare personnel and parents approached for organ and/or tissue donation: influences on parents' adjustment to loss. <i>Progress in Transplantation</i> , 25 (2) doi: 10.7182/pit2015145.
Ashkenazi, T., & Guttman, N. (2016). Organ and tissue donor parents' positive psychological adjustment to grief and bereavement: Practical & ethical implications. <i>Bereavement Care</i> , 35(2),58-66.
Azuri, P., Tabak, N., & Kreitler, S. (2013). Contact between deceased donors' families and organ recipients. <i>Progress in Transplantation</i> , 23(4), 342-349.
Nakahara, N. (1998). Reflections by the families of organ donors in Japan. <i>EDTNA/ERCA journal (English ed.)</i> , 24(4), 23-26.
Tavakoli, S. A. H., Shabanzadeh, A. P., Arjmand, B., Aghayan, S. H. R., Heshmati, B. N., Razavi, S. E., & Nasab, H. B. (2008). Comparative study of depression and consent among brain death families in donor and nondonor groups from 2001-2002 in Tehran. In <i>Transplantation Proceedings</i> , 40 (10), 3299-3302
Mixed-methods with emphasis on quantitative data or the donation request
Berntzen, H., & Bjørk, I. T. (2014). Experiences of donor families after consenting to organ donation: A qualitative study. <i>Intensive and Critical Care Nursing</i> , 30 (5), 266-274.
Hogan, N., Schmidt, L., & Coolican, M. (2014). The bereavement process of tissue donors' family members: responses of grief, posttraumatic stress, personal growth, and ongoing attachment. <i>Progress in Transplantation</i> , 24(3), 288-293.
Morton, J. B., & Leonard, D. R. (1979). Cadaver nephrectomy: an operation on the donor's family. <i>British Medical Journal</i> , 1(6158), 239-241.
Ormrod, J. A., Ryder, T., Chadwick, R. J., & Bonner, S. M. (2005). Experiences of families when a relative is diagnosed brain stem dead: understanding of death, observation of brain stem death testing and attitudes to organ donation. <i>Anaesthesia</i> , 60(10), 1002-1008.
Focus on recommendations for services
Bellali, T., Papazoglou, I., & Papadatou, D. (2007). Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. <i>Intensive and critical care nursing</i> , 23(4), 216-225. (Same sample as the Bellali & Papadatou (2007) paper included in the review)
Focus on experiences of hospital death, not specific to donation requests
Warren, N. A. (2002). Critical care family members' satisfaction with bereavement experiences. <i>Critical care nursing quarterly</i> , 25(2), 54-60.
Literature review
Riley, L. P., & Coolican, M. B. (1999). Needs of families of organ donors: facing death & life. <i>Critical Care Nurse</i> , 19, 53.
Unrelated to brain or circulatory death
Carey, I., & Forbes, K. (2003). The experiences of donor families in the hospice. <i>Palliative medicine</i> , 17(3), 241-247
Themes not presented or discussed
Soriano-Pacheco, J. A., Lopez-Navidad, A., Caballero, F., Leal, J., García-Sousa, S., & Linares, J. L. (1999). Psychopathology of bereavement in the families of cadaveric organ donors. <i>Transplantation Proceedings</i> , 31 (6), 2604-2605

Appendix C: List of key concepts for the synthesis

Bellai & Papadatou (2007)	Haddow (2005)	Hogan, Coolican & Schmidt (2013)	Hoover, Bratton, Roach & Olson (2014)	Kesselring, Kainz & Kiss (2007)	Maloney (1998)	Manuel, Solberg & MacDonald (2010)
<p>Ongoing confusion about brain damage: Worry of decision to donate causing the death.</p> <p>Donation not sufficient to ease suffering. Loss saturated any benefits of donation. Intense and unchanged grief: anger, rage, guilt (donor and non-donor).</p> <p>Donation outcomes: experience of unsettled grief/ A need to know outcome to evaluate 'worthiness' of donation</p> <p>Donation as easing grief: Ongoing bond with the deceased;</p> <p>Keep donor alive via recipient: Helping another live.</p> <p>Seeking the deceased child within the recipient.</p> <p>Satisfaction with refusal; but upset at thinking 'everything' is gone. Regret at non-consent;</p> <p>Reflections on the wishes of the donor</p> <p>Personal growth. Donation evoked relief, tranquillity, sense of purpose.</p>	<p>Respecting the deceased's body: Destruction of social identity.</p> <p>Detachment from the body.</p> <p>The dissolution of the embodiment dichotomy: the relative lives on.</p> <p>The continuing relationship.</p>	<p>Feeling empty/despair following the loss.</p> <p>The Ongoing attachment with the donor.</p> <p>Finding meaning and solace in the loss.</p> <p>Honouring the wishes/attributes of the donor.</p> <p>Gratitude for the unexpected opportunity.</p> <p>Something good coming from the death.</p> <p>Living on through others.</p>	<p>Making something good out of the death.</p> <p>Honouring the child's preferences (known or imagined).</p> <p>Distress at being unable to donate.</p> <p>Protecting the body/prevent further trauma.</p> <p>Death of a child not eased by donation.</p> <p>Donation as a meaningful contribution: saving other lives.</p> <p>Connection with other families affected by donation.</p> <p>Value of letters or donation outcome/ Despair at learning about recipient (older).</p> <p>Uncertainty about donation choices.</p>	<p>Flashbacks/nightmares of the ICU experience.</p> <p>Religious blessing.</p> <p>Peace in preserving certain organs (heart).</p> <p>Value of time to make a decision, information and offered psychological support.</p> <p>The impact of person focused vs organ focused teams.</p> <p>Worry of causing death by consenting.</p> <p>Putting valuable organs to use.</p>	<p>Relief at knowing intentions/family discussion.</p> <p>Consolation in something positive coming from a tragedy: providing another family with hope.</p> <p>Keeping the memory alive: Publicly honouring the life of the donor.</p> <p>Donor lives on: Making sense out of something senseless.</p> <p>Extending time with loved one (in ICU): prepare for grief.</p> <p>A shift from death to life.</p> <p>Isolation in a unique grief: The paradox of joy and pain.</p> <p>Extended kinships</p> <p>Bittersweet Miracles.</p>	<p>Creating a sense of peace.</p> <p>Giving meaning to the life of the deceased > helped rationalise the death.</p> <p>Comfort from the decision to donate.</p> <p>Knowledge of outcome of donation as helpful in grief.</p> <p>Honouring the attributes, wishes and values of the donor.</p> <p>Creating a living memory.</p> <p>Buying time: Consent meant able to see recovery was unlikely /more time to come to terms with the death.</p> <p>Child donor: disruption to inner peace, powerlessness and guilt.</p>

Appendix C: List of key concepts for the synthesis

Manzari, Mohammadi & Heydari et al (2012)	Shih, Lai & Lin et al (2001)	Sque & Payne (1996)	Taylor, Buffington & Scalea (2018)	Tong, Holroyd & Cheng (2006)	Tymstra Heyink, Pruijm & Slooff (1992)	Walker & Sque (2016)
<p>‘Serenity in eternal freedom’.</p> <ul style="list-style-type: none"> -Donating perceived to reduce psychological distress and retained normalcy. -Support from others emphasised the value of the donation. -Advocates for donation. -Closeness to God; protection from harm; Spiritual connection with the deceased. -Knowledge of donation outcome . - ‘Resentful Grief’: Declining to donate: regret, sorrow and dissonance. A wasted opportunity to save a life/ No regret and contentment with decision. -Consenting families: regret and worry the decision had disturbed the deceased; body integrity. -Family responses/disagreement: demoralisation, guilt, shame. -Doubt of decision – did consent deny change for recovery > guilt. -Accurate information on brain death/coma manages dissonance in grief. -Psychological distress of potential hasty decision – what if they recovered? -Distress at going against the decision of the donor. 	<p>An extra burden.</p> <p>The impact of the decision on the afterlife; body integrity</p> <p>Acknowledging the virtues and attributes of the donor.</p> <p>The negative psychological consequences of the loss.</p> <p>Value of spiritual support , family, friends, health professionals or self-help to manage the loss.</p> <p>Personal growth.</p> <p>Promotion of organ donation in social systems.</p> <p>The desire for outcome.</p> <p>Religious affiliation in framing the impact of the decisions (souls are immortal; fulfilling destiny)</p>	<p>Parting – What do I do now? Little support or advice on grief. Isolation.</p> <p>Coping –the emphasis from death to a focus on achievement.</p> <p>Donor attributes living on.</p> <p>The gift of life: a less harsh road, a less final death.</p> <p>Meaning in death and grief.</p> <p>Comfort in information about organ distribution.</p> <p>A desire to know/not know about outcomes.</p> <p>Intentions.</p> <p>Relatives contribution to be acknowledged.</p> <p>Theory of Dissonant Loss.</p>	<p>Waste of something, precious; wasted opportunity.</p> <ul style="list-style-type: none"> - Letting others (recipients) down. <p>Younger donor, important for donation vs body integrity.</p> <p>Inability to honour the donor; validate/display virtues; counteract adversities; Lack of redemption.</p> <p>Struggling to find meaning in the death</p> <ul style="list-style-type: none"> -Hopes that donation would lessen the pain and grief. Grief interrupted. <p>Importance of loved one living on spiritually and physically.</p> <p>Worry: Consent denied a final chance to survive. Comfort in knowing had good intentions</p>	<p>During donation: confusion, stress and uncertainty – dreamlike.</p> <ul style="list-style-type: none"> -Reassurance about donors appearance after donation. -Making sense of decisions Family responses. <p>Satisfaction with decision to donate.</p> <ul style="list-style-type: none"> -Thank you cards provided comfort/solace and showed the value of donation <p>Concerns for the recipient.</p> <ul style="list-style-type: none"> Making use of the organs -The donors destiny. <p>Promotion of donation .</p> <p>Stress, guilt and regret about decision.</p> <p>Denial/confusion about brain death;</p> <p>Cultural beliefs: harm in afterlife.</p> <p>Left alone to cope.</p>	<p>Positive influence on mourning however dramatic the grief.</p> <p>Certainty of outcome of the organs.</p> <p>Regret for saying yes – body integrity and not knowing donor wishes.</p> <p>Mithered about outcome – were they used? Successful?.</p> <p>Family secret/taboo.</p> <p>Being satisfied with decision (to say yes or no) based on knowing donor preferences.</p> <p>Regret for saying no – request badly delivered or timed – guilt; negative impact on mourning.</p> <p>Hope and confusion (brain death terminology).</p>	<p>Relative living on through others.</p> <p>A ‘gift of life’ or sacrifice.</p> <p>Dissonant loss – A legacy, but rather have the relative.</p> <p>Donation and grief are separate processes.</p> <p>Donation can balancing hope and despair (providing the wishes of the deceased and bereaved are fulfilled).</p> <p>No psychological impact on grief.</p> <p>Donation reduced emotional pain and helped accept the death and the bereavement.</p> <p>Pride at the act (for donor and themselves).</p> <p>Follow-up: Comforting/Bittersweet.</p>

Appendix D: CASP Quality Appraisal Results

	Aims clearly stated	Qualitative methodology appropriate	Research design addresses the aims	Appropriate recruitment strategy	Data collection	Consideration of reflexivity	Ethical issues	Rigour of data analysis	Clear statement of findings	Value of the research
<p>Bellali & Papadatou (2007)</p> <p>17/20</p>	<p>Clear aims identified in relation to the literature: To explore the grieving process of donor and non-donor parents and the impact of their decision on their grief</p> <p>2/2</p>	<p>Yes. Qualitative approach used due to the limited knowledge of the phenomenon a under study.</p> <p>2/2</p>	<p>Grounded Theory methodology selected to develop a theoretical model. Rationale provided.</p> <p>2/2</p>	<p>Selection of the theoretical sampling method and the recruitment process outlined. Inclusion criteria stated.</p> <p>2/2</p>	<p>Interview method described and justified. Interviews were audio-recorded and transcribed. Flexible interview schedule described, which was modified to incorporate emerging concepts. Saturation not discussed.</p> <p>1/2</p>	<p>The relationship between the researchers and the participants was not considered or discussed.</p> <p>0/2</p>	<p>Details were provided regarding obtaining ethical approval from a hospital ethics committee. Informed consent processes were described.</p> <p>2/2</p>	<p>In-depth description of the analysis process provided. Quotes were used to illustrate findings. For each aim. Three external researchers contributed to data triangulation.</p> <p>2/2</p>	<p>Findings were explicit and a model was presented for parental grief. The research question and aims were discussed and findings were related to the literature. Credibility was discussed.</p> <p>2/2</p>	<p>Implications for clinicians, researchers and theorists were identified.</p> <p>Areas for future research were discussed.</p> <p>2/2</p>
<p>Hogan, Coolican & Schmidt (2013)</p> <p>17/20</p>	<p>Aims clearly outlined in response to a literature review: To describe the grief experienced by family members 6 months after donation.</p>	<p>Yes. Qualitative methodology justified as part of a longitudinal study.</p>	<p>A mixed methods longitudinal design was justified for studying family members 6, 13 and 25 months after donation.</p>	<p>Recruitment methods were described. Inclusion and exclusion criteria were not stated.</p>	<p>Formulation of two open ended questions requiring written responses described and justified. Use of memos to maintain an account of the</p>	<p>Although the researchers did not meet the participants due responses being obtained via questionnaire, the ‘virtual’ relationship was not</p>	<p>Ethical approval was received and issues of informed consent and confidentiality outlined.</p>	<p>Content analysis and theme development procedures were outlined. Validity checks were conducted by the authors. Quotes were used to</p>	<p>Findings were clearly stated in relation to the research question. Credibility was discussed.</p>	<p>Implications for professionals were discussed. Limitations in terms of the sample and timing of the study were described, and ideas future</p>

Appendix D: CASP Quality Appraisal Results

	2/2	2/2	2/2	1/2	researcher's reflections. 2/2	considered or discussed. 0/2	2/2	support the findings. 2/2	2/2	research presented. 2/2
Hoover, Bratton, Roach & Olson (2014) 18/20	Aims are clearly outlined in relation to the literature: To explore the experiences of parents who were approached for a donor request.	Yes. The methodology addresses the aim of understanding subjective experiences.	Qualitative Exploratory Analysis was stated but not discussed further.	Purposeful selection criteria stated and inclusion/exclusion criteria described. Recruitment process described.	Audio-recorded interviews were described. The interview guide was developed via literature review, consultation and modified based on a pilot study.	The intent to develop participant-centred data described. Pilot study conducted to understand participant experiences of the interview. No further reference to reflexivity.	Ethical approval was granted and informed consent mentioned.	AtlasTI. Analysis process was described. Reference to the literature and peer review throughout analysis/triangulation process reduced investigator subjectivity.	Several findings were clearly stated. Credibility was discussed.	Implications, limitations and ideas for future research was presented.
Kesselring, Kainz & Kiss (2007) 13/20	Aims clearly states and relevant to the clinical settings described: To explore relatives' experiences following a donation request.	Yes. The study is a qualitative component of a multi-centre study.	The design was Grounded Theory, however there was not a rationale provided for this.	Inclusion and exclusion criteria are not specified or described. A description of expanding the original sample from the multi-centre study is provided.	Audio-recorded interviews. A flexible schedule was described & modified to incorporate emerging concepts. Saturation was not discussed. A rationale for the methods used.	The relationship between the researchers and the participants was not considered or discussed.	Ethical approval was received by a local committee and issues of informed consent outlined.	An outline of the analysis was provided. winMAX software was used, with 5 participants reviewing the results and hypotheses. Themes were stated with quotes to illustrate the findings.	Findings were clearly stated in relation to the research question. Credibility of the research was not discussed.	Implications for the model developed discussed. A training workshop developed following the research. Limitations and areas for future research were not considered.
	2/2	2/2	1/2	1/2	1/2	0/2	2/2	2/2	1/2	1/2

Appendix D: CASP Quality Appraisal Results

<p>Manuel, Solberg & MacDonald (2010) 12/20</p>	<p>Aims and objectives stated and presented: To improve our understanding of the experiences of donor families.</p> <p>2/2</p>	<p>Yes. A phenomenological is appropriate to capture people's experiences.</p> <p>2/2</p>	<p>A phenomenological approach is described but a rationale for this methodology is not provided.</p> <p>1/2</p>	<p>Inclusions and exclusion criteria were specified. It was not described how the sample were recruited.</p> <p>1/2</p>	<p>Data was collected via unstructured taped interviews. No further details are provided.</p> <p>1/2</p>	<p>The relationship between the researchers and the participants was not considered or discussed.</p> <p>0/2</p>	<p>Ethical approval was obtained. Further considerations were not provided.</p> <p>1/2</p>	<p>Thematic analysis process not described. Themes were outlined with quotes. Participants reviewed transcripts to validate it reflected their experience.</p> <p>1/2</p>	<p>Findings are explicit and discussed in relation to the research objective.</p> <p>1/2</p>	<p>Implications for clinical teams were outlined. Future areas of research with alternative qualitative methodologies were considered.</p> <p>2/2</p>
<p>Manzari, Mohammadi & Heydari et al (2012) 18/20</p>	<p>The aim is clearly stated as examining organ donation requests within Iran and its cultural framework</p> <p>2/2</p>	<p>Yes. The study aimed to explore human experiences and emotions.</p> <p>2/2</p>	<p>There is not a justification for the use of content analysis as the chosen qualitative method.</p> <p>1/2</p>	<p>The use of purposive sampling is described. However, inclusion and exclusion criteria and recruitment strategy was not discussed.</p> <p>1/2</p>	<p>Data was collected via unstructured interviews. Field notes were discussed. Data collection up to the point of saturation was described.</p> <p>2/2</p>	<p>The researchers described their commitment to a stance of 'openness' to avoid presuppositions and presumptions. Field notes were used during analysis.</p> <p>2/2</p>	<p>Ethical consideration clearly detailed, including approval; informed consent; confidentiality; and signposting participants to a counsellor if necessary.</p> <p>2/2</p>	<p>The thematic analysis process was outlined and data credibility strategies were discussed. Quotes were used to illustrate themes.</p> <p>2/2</p>	<p>Findings were explicitly stated and discussed in relation to the research question. Credibility was discussed in detail.</p> <p>2/2</p>	<p>Implications for teams and families were clearly described. Limitations and areas for future research were considered.</p> <p>2/2</p>

Appendix D: CASP Quality Appraisal Results

<p>Shih, Lai & Lin et al (2001) 17/20</p>	<p>Four aims were clearly presented to explore the impact of deceased organ donation for families.</p> <p>2/2</p>	<p>Yes. Qualitative approach used due to the limited knowledge of the phenomenon a under study.</p> <p>2/2</p>	<p>Justification was provided for selecting Grounded Theory and related to the aims.</p> <p>2/2</p>	<p>Sampling justified with reference to the qualitative methodology literature. Incl./excl. criteria not described. Explanation provided for non-responders.</p> <p>1/2</p>	<p>Semi-structured tape-recorded interviews described and justified. Described interviewing techniques and the development of interview guide.</p> <p>2/2</p>	<p>The researchers describe using reflexive journals which were used throughout the process.</p> <p>2/2</p>	<p>Ethical considerations are not described.</p> <p>0/2</p>	<p>Nine levels of qualitative analysis are described. Several strategies are outlined to enhance the rigor of the findings. Quotes are used to illustrate the findings.</p> <p>2/2</p>	<p>Findings were explicitly reported in relation to the four research aims. Credibility was discussed.</p> <p>2/2</p>	<p>Implications are outlined for healthcare providers, families and support groups. Theoretical and empirical opportunities are outlined.</p> <p>2/2</p>
<p>Sque & Payne (1996) 19/20</p>	<p>Aims outlined and justified in relation to the literature: To describe the experiences and emotional reactions of donor relatives.</p> <p>2/2</p>	<p>Yes. Qualitative approach justified by the aims.</p> <p>2/2</p>	<p>The use of Grounded Theory was justified (to suggest inductive theory to explain people's experiences)</p> <p>2/2</p>	<p>Purposive sampling described and rationale provided. Reasons for non-participation were detailed.</p> <p>2/2</p>	<p>Audio-recorded interviews were described. Pilot interviews were conducted to develop the interview guide. Methods were modified throughout the study, with an explanation.</p> <p>2/2</p>	<p>Sensitivity of the topic considered during data collection. Pilot studies were carried out to best prepare the interviewers. Thank you letters sent out following the study. Professional backgrounds discussed and reflected.</p> <p>2/2</p>	<p>Ethical approval was not described. The sensitivity of the topic and issues of confidentiality were considered and described.</p> <p>1/2</p>	<p>Themes and generation of the theory of 'dissonant loss' were detailed. Quotes were used to support the themes. A discussion of the analysis is provided. Participants reviewed and validated the interpretation of their interviews.</p> <p>2/2</p>	<p>Findings were explicitly reported in relation to the aims and the literature. Issues of credibility discussed.</p> <p>2/2</p>	<p>The study generated the first theory to explain the experience of donor families and the implications for services. Use of the theory as a framework for further investigation discussed.</p> <p>2/2</p>
<p>Taylor, Buffington & Scalea et al (2018)</p>	<p>Aims clearly stated and justified: To</p>	<p>Yes. The study was</p>	<p>Qualitative content analysis was</p>	<p>Inclusion and exclusion criteria was</p>	<p>Audio recorded interviews</p>	<p>An independent anthropologist</p>	<p>Ethical approval was obtained.</p>	<p>Analysis process described.</p>	<p>Findings were explicitly reported in</p>	<p>Implications for practice and future</p>

Appendix D: CASP Quality Appraisal Results

18/20	characterize the harms of unsuccessful donation experienced by family members of the deceased non-donor.	exploratory in nature.	described but without justification for its selection.	outlined. The use of purposefully selected sampling and the recruitment process was described.	were described and justified. Development of interview guide was explicitly described. Modification as described and justified. Saturation was discussed.	without previous organ donation experience was hired to conduct the interviews.	Issues of consent and considering the sensitive nature of the topic for participants were described.	NVIVO software was used alongside 4 coders from a range of backgrounds and three adjudicators. Triangulation outlined. Quotes used to illustrate findings.	relation to the research aim. Credibility was discussed.	areas of research were discussed.
	2/2	2/2	1/2	2/2	2/2	1/2	2/2	2/2	2/2	2/2
Tong, Holroyd & Cheng (2006) 18/20	Aims were clearly outlined: To explore the perceptions of families who had experienced the deceased organ donation of a family member.	Yes. Little was known about the experiences of deceased donor families in a Chinese context.	The selection of an exploratory qualitative design was not discussed in detail.	The use of convenience sampling was discussed. Inclusion and exclusion criteria were stated. Response rates and reasons for non-participation were stated.	Audio-taped interviews were described. The interview guide was developed via literature review and consultation. Questions rearranged following pilot study. Field notes discussed	Interview schedule was modified (wording & question order) due to emotional responses pilot study. Field notes used. Explicit consideration of the relationship not presented.	Ethical approval was granted. Informed consent, right to withdraw and confidentiality discussed. Debrief and signposting to bereavement support were described.	The content analysis process was described, including the involvement of an independent expert to evaluate themes.	The findings are clearly stated with reference to the literature. Credibility discussed.	Implications of the study are discussed in detail and linked to healthcare professionals. Recommendations are made. Further areas for research are briefly discussed.
	2/2	2/2	1/2	2/2	2/2	1/2	2/2	2/2	2/2	2/2
Tymstra, Heyink, Pruijm & Slooff (1992) 11/20	Aims were stated in relation to the literature: To explore the	Yes. An exploratory qualitative methodolo	The selection of the research design was not discussed or justified.	The process for the random selection of families was described.	Tape-recorded interviews were described. An interview checklist was	The relationship between researchers and participants	Ethical approval and informed consent processes not described.	The data analysis process was not described. Quotes are used to	The findings were clearly stated. Credibility was not	Implications for services are considered in detail. New areas of research are

Appendix D: CASP Quality Appraisal Results

	experience of the bereaved relatives of deceased organ donors	gy is justified.			described. Modifications were made for participants who refused to be recorded.	were not described in detail.	Examples of responding ethically: accommodating 2 requests to be involved and not audio recorded (written /tel. call).	illustrate themes but without explaining how the themes were generated.	considered or discussed.	not discussed. Limitations not discussed.
	2/2	2/2	0/2	2/2	2/2	0/2	1/2	0/2	1/2	1/2
Walker & Sque (2016) 19/20	Aims clearly stated in context of literature: To understand the perceived benefits of organ and tissue donation for grieving donor families.	Yes. The aim sought to generate data about the experiences of the bereaved.	Qualitative content analysis justified with literature review. Time and financial constraints discussed justified decision to not apply saturation.	Purposive sampling was described and justified. Inclusion criteria were stated and the response rate was discussed.	Data collection described. Issues of saturation were discussed. Modifications discussed and justified (1 family x written response).	Reflexivity is not explicitly addressed. Experience and considerations for working with bereaved participants was described.	Ethical approval was granted. Ethical considerations for working with bereaved families is discussed.	Qualitative Consent Analysis described referring to the literature. Intercase analysis and independent coding from a 2 nd analyst and team discussion.	The findings are clearly stated. Credibility and methodological limitations were discussed.	Implications for the research was discussed, along with areas for future exploration.
	2/2	2/2	2/2	2/2	2/2	1/2	2/2	2/2	2/2	2/2

Appendix E: Invitation letter to the study



Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board



NHS
WALES
GIG
CYMRU

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glingol



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CAV_psychology.training@wales.nhs.uk

dd/mm/year

Request to take part in a research study

I am writing to let you know about an opportunity to take part in a research study being conducted by Jonathan Harrold, a Trainee Clinical Psychologist studying at Cardiff University. The study aims to improve our understanding of the views people with a diagnosis of chronic kidney disease have about their condition and about pre-emptive (before dialysis) kidney transplantation. It is not being suggested that you require dialysis or transplantation now or in the future. This letter is part of a research project and is in no way connected to your clinical care.

You have been invited to participate because you are a service user of Cardiff and Vale University Health Board, with a diagnosis of chronic kidney disease and who has not had a kidney transplant and who is not receiving dialysis. We are interested in hearing about your views of your condition and treatment options.

You do not have to take part, but if you do decide to participate, a questionnaire pack will be sent out to you via post or email (your preference) for you to complete at home. The survey should take between 20-30 minutes to complete and **all answers will be anonymous**. If you do take part, you will be asked to give your consent on a form that will be included with the questionnaire. Even if you consent to take part, you are free to withdraw up until 2 weeks after your questionnaire has been returned to the researcher. Your decision to participate or withdraw from the study will not have any implications for the care you receive and the answers you provide through participating in the study will not imply anything about your access to treatment now or in the future.

Should you wish to take part, please contact Jonathan by either telephone or email and he will send a more detailed information letter, the survey, and consent form to you by post or email (your preference).

Jonathan's contact details are:

Jonathan Harrold (Lead Researcher & Trainee Clinical Psychologist)

Email address: [REDACTED]@cardiff.ac.uk

Mobile: [REDACTED]

Please feel free to contact me or Jonathan and ask any questions if there is anything that is not clear or if you would like more information before deciding if you wish to take part.

With kind regards,

Dr Catherine O'Leary
Project Supervisor & Consultant Clinical Psychologist
Nephrology & Transplant Psychology & Counselling Dept.
Pentwyn Dialysis Unit, Cardiff, CF23 8HE
Telephone: [REDACTED]

Jonathan Harrold
Lead Researcher & Trainee Clinical Psychologist
School of Psychology, Cardiff University, 11th Floor
Tower Building, Park Place, Cardiff, CF10 3AT
Email: [REDACTED]@cardiff.ac.uk Tel: [REDACTED]

Appendix F: Participant Information Sheet (Phase One)



Participant Information Sheet

My name is Jonathan Harrold and I am a second-year Trainee Clinical Psychologist studying at Cardiff University. Thank you very much for contacting me and for showing an interest in this research study. Before you decide to take part, it is important that you know what the study will involve. Please take the time to read the following information carefully and feel free to contact me and ask any questions if anything is unclear or if you would like more information before deciding if you wish to take part.

Title of study: The influence of illness perceptions and illness knowledge on pre-emptive (pre-dialysis) live donor kidney transplantation.

What is the purpose of the study?

The aim of this study is to improve our understanding of the beliefs held by people with chronic kidney disease towards their condition and living donor kidney transplantation. Improved understanding of the psychological challenges, expectations and priorities that people have regarding pre-emptive transplantation could help improve nephrology and transplant services.

The study is being completed as part of the South Wales Doctorate Programme in Clinical Psychology, at Cardiff University, and is being funded by NHS Wales.

What is living kidney donation? Living kidney donation is a surgical procedure in which a healthy kidney is transplanted from a living person (a blood relative; a non-blood relative; or a stranger) into a person with chronic kidney disease. Living kidney donation is an alternative treatment to dialysis.

Why have I been asked to take part?

You have been invited to participate in this study because you are a service user of Cardiff & Vale University Health Board with a diagnosis of chronic kidney disease and who has not had a kidney transplant and who is not receiving dialysis. We are interested in hearing about your views and experiences of your diagnosis and treatment options. **It is not being suggested that you require either dialysis or a transplant now or in the future. This letter is part of a research study and participation in it will not influence your treatment or clinical care.**

Do I have to take part?

No, participation is entirely voluntary. It is up to you to decide whether to participate. If you do decide to take part, you will be asked to give your consent by completing the enclosed consent form and returning this with the completed questionnaire. Even if you consent to take part you are still free to withdraw at any time up until your data has been anonymised, approximately 2 weeks after your questionnaire has been returned to the researcher. You do not need to provide a reason for not taking part or for withdrawing. The decision to withdraw from the study will not have any implications for the standard care you receive.

Appendix F: Participant Information Sheet (Phase One)

What will I have to do?

Phase One – Questionnaire

- The questionnaire pack included with this information sheet should take approximately 20 to 30 minutes to complete.
- There are a range of questions, such as Yes/No questions, multiple choice questions and opportunities to provide a written answer.
- You will also be asked to provide demographic information about yourself such as gender, age, your estimated Glomerular Filtration Rate (eGFR) and marital status.
- If you do wish to take part, please read, sign and return the enclosed Consent Form along with the completed questionnaire in the stamped addressed envelope provided.
- Although questionnaires are requested to be returned within 3 weeks of you receiving them, late returns will be gratefully received.
- One reminder letter/email may be sent out to you if the questionnaire has not been returned after three weeks of your receiving it.
- **All answers are anonymous**
- Your answers will not imply anything about your access to treatment now or in the future.

Phase Two - Interview

- **Taking part in Phase One does not mean you are obliged to take part in Phase Two.**
- Phase Two will be an audio-recorded follow-up interview with me.
- The interview will last up to 60 minutes and will take place at Cardiff University or a location convenient to you (such as your home).
- The aim of the interviews will be to gather more detailed information and expand on the questions from the questionnaire. I aim to interview 6-9 individuals.
- Audio-recorded information will be transcribed and anonymised.
- If you are happy to be contacted about participating in Phase Two, you can consent to this by completing the option at the end of the consent form. If you are contacted to take part in Phase Two, you will be provided with a separate information sheet and Consent Form.

Will taking part be confidential?

Yes, all information will be handled in confidence and your answers will be anonymised. Any information about you (e.g. your consent form) will only be known to me and will be securely stored at Cardiff University. Identifiable information will not be used in the research report. Your participation will not impact upon the care you receive from the Nephrology & Transplant Service.

The research team for this study have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. Although your responses are confidential, should you disclose anything which is felt to put you or others at risk of harm, it may be necessary to report this to the appropriate persons. All data will be kept in accordance with the Data Protection Act 1998 and Cardiff University policies.

Participants are reminded of the need to uphold confidentiality and as such do not provide any identifiable information about themselves (such as names) within their answers.

Are there any benefits in taking part?

You may not notice any direct benefit by taking part, but some people may find the opportunity to think and reflect on their beliefs about their diagnosis and potential future treatment options to be

Appendix F: Participant Information Sheet (Phase One)

beneficial. Your contribution to this study may help improve our understanding of the psychological experiences of people with chronic kidney disease regarding living kidney transplantation, which could help improve NHS services. This could also have future implications for considering whether current guidance and/or training could be amended.

Are there any disadvantages or risks in taking part?

Thinking about your beliefs about diagnosis and potential future treatment options may be a difficult and possibly upsetting experience for you, as you may not have thought about these things in detail before. **If at any point you wish to withdraw from the study, you are free to do so without giving a reason.** You are welcome to contact me should you need to discuss or feedback on your experience. Included with this information sheet are the contact details for the Psychology & Counselling Service within the Nephrology & Transplant team. You may also wish to speak to your GP or nephrology nurse should you feel you would benefit from discussing matters further.

Taking part in the research will not result in payment. Reasonable travel costs can be reimbursed should you opt in to Phase Two of the study and prefer not to be interviewed in your home.

What will happen to the results of the study?

The study will be written up as part of the South Wales Doctorate in Clinical Psychology Programme requirements. It may also be submitted for publication in a journal and presented at relevant events. Data collected from the questionnaires will be used in the report, including anonymised quotes from any written answers you provide. You will not be identifiable in any way. If you would like feedback about the results of the study, I will send you a letter summarising these once the research is completed. All data will be stored and retained on a Cardiff University approved system for 15 years following completion of the study. The answers you provide through participating in the study will not imply anything about your access to treatment now or in the future.

Who has approved this study?

This study has been approved by the South Wales Doctorate in Clinical Psychology Programme, as well as an independent NHS Research Ethics Committee on 27/06/2017. The Cardiff and Vale NHS Research and Development committee approved the study on 10/08/2017. This approval ensures your rights and dignity are protected.

Who is monitoring this study?

This study will be monitored throughout by Dr Jenny Moses and Dr Catherine O'Leary to ensure high quality standards and safety are being maintained.

What if there is a problem?

If you have a concern about any aspect of this study, please contact me and I will respond to any concerns. If you remain unhappy and wish to raise a complaint, you can do this by contacting: Dr Jenny Moses (Academic Supervisor) or Dr Catherine O'Leary (Clinical Supervisor). Alternatively, you can contact Dr Dougal Hare, Research Director for the South Wales Doctorate in Clinical Psychology Programme. All contact details are given at the end of this information sheet.

Thank you for taking the time to read this information

Appendix F: Participant Information Sheet (Phase One)

Contact details

If you have any other questions or queries about the study then please feel free to contact Jonathan Harrold, the lead researcher. Alternatively, please contact Dr Jenny Moses or Dr Catherine O’Leary who are supervising the study (details below). The contact details for Dr Dougal Hare are provided should you wish to contact someone independent of the research team.

Jonathan Harrold (Lead Researcher)

Trainee Clinical Psychologist

South Wales Clinical Psychology Doctoral Programme, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Email address: harroldj@cardiff.ac.uk

Telephone: [REDACTED]/02920870582

Dr Jenny Moses (Academic supervisor for the study)

Consultant Clinical Psychologist

South Wales Clinical Psychology Doctoral Programme, 11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Email address: jenny.moses@wales.nhs.uk

Telephone: 02920870582

Dr Catherine O’Leary (Clinical supervisor & Principal Investigator for the study)

Consultant Clinical Psychologist

Nephrology & Transplant Psychology & Counselling Department, Pentwyn Dialysis Unit, Cardiff, CF23 8HE

Email address: Catherine.oleary@wales.nhs.uk

Telephone: 02920748455

Dr Dougal Hare

Research Director for the South Wales Clinical Psychology Doctoral Programme

11th Floor, Tower Building, 70 Park Place, Cardiff, CF10 3AT

Email address: harred@cardiff.ac.uk

Telephone: 02920870582

Additional support

If you feel that you would benefit from accessing emotional support regarding chronic kidney disease, kidney transplantation, dialysis or any other issue related to your condition raised by this study, you can contact:

The Nephrology & Transplant Psychology & Counselling Department: 02920748455

You can also speak to your local Nephrology Nurse.

Appendix F: Participant Information Sheet (Phase Two)

Participant Information Sheet: Version 2: 8th May 2017. IRAS Project ID: 223178



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University Health Board



School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



Cardiff University
School of Psychology
Tower Building
70 Park Place
Cardiff CF10 3AT

tel: 0117 441020 235 23862
GIV_psychology@nrcp@wales.nhs.uk

Participant Information Sheet: Phase Two

Thank you very much for recently taking part in Phase One of this research study (the questionnaire), and for consenting to be contacted regarding Phase Two, which is an interview with Jonathan Harrold, Trainee Clinical Psychologist at Cardiff University.

Before you decide to take part in the interview, it is important that you know what will be involved. Please take the time to read the following information carefully and feel free to contact me to ask any questions if anything is unclear or if you would like more information before deciding if you wish to take part.

Title of study: The influence of illness perceptions and illness knowledge on pre-emptive (pre-dialysis) living donor kidney transplantation.

What is the purpose of the study?

The aim of this study is to improve our understanding of the beliefs held by people with chronic kidney disease towards their condition and living donor kidney transplantation. Improved understanding of the psychological challenges, expectations and priorities that people have regarding pre-emptive transplantation could help improve nephrology and transplant services.

The project is being completed as part of the South Wales Doctorate Programme in Clinical Psychology at Cardiff University, and is being funded by NHS Wales.

Why have I been asked to take part?

You have been invited to participate in this study because you are a service user of Cardiff & Vale University Health Board with a diagnosis of chronic kidney disease, and who has not had a kidney transplant and who is not receiving dialysis. We are interested in hearing about your views and experiences of your diagnosis and treatment options. **It is not being suggested that you require either dialysis or a transplant now or in the future. This letter is part of a research project and participation in it will not influence your treatment or clinical care.**

Do I have to take part?

No, participation is entirely voluntary. It is up to you to decide whether to participate. If you do decide to take part, you will be asked to sign a consent form and will be offered another opportunity to ask questions about the study before the interview begins. Even if you consent to take part you are free to have a break or end the interview, and you will not be forced to answer any questions that make you feel distressed or uncomfortable. You are also free to withdraw from the study at any time up until your data has been transcribed and anonymised, approximately 2 weeks after your interview. You do not need to provide a reason for not taking part or for withdrawing. The decision to withdraw from the study will not have any implications for the standard care you receive.

What will the interview involve?

The interview will involve meeting Jonathan Harrold in either your home, the Cardiff University Psychology Building in Cardiff (directions will be provided), or another suitable location that is convenient to you. The interview will be audio-recorded, last up to 60 minutes, and will be about your thoughts, experiences and

Appendix F: Participant Information Sheet (Phase Two)

results of the study, I will send you a letter summarising these once the research is completed.

All data will be stored and retained on a Cardiff University approved system for 15 years following completion of the study. The answers you provide through participating in the study will not imply anything about your access to treatment now or in the future.

Who has approved this study?

This study has been approved by the South Wales Doctorate in Clinical Psychology Programme, as well as an independent NHS Research Ethics Committee on 27/06/2017. The Cardiff and Vale NHS Research and Development committee approved the study on 10/08/2017. This approval ensures your rights and dignity are protected.

Who is monitoring this study?

This study will be monitored throughout by Dr Jenny Moses and Dr Catherine O'Leary to ensure high quality standards and safety are being maintained.

What if there is a problem?

If you have a concern about any aspect of this study, please contact me and I will respond to any concerns. If you remain unhappy and wish to raise a complaint, you can do this by contacting: Dr Jenny Moses (Academic Supervisor) or Dr Catherine O'Leary (Clinical Supervisor). Alternatively, you can contact Dr Dougal Hare, Research Director for the South Wales Doctorate in Clinical Psychology Programme. All contact details are given at the end of this information sheet.

Thank you for taking the time to read this information

Contact details

If you have any other questions or queries about the study then please feel free to contact Jonathan Harrold, the lead researcher. Alternatively, please contact Dr Jenny Moses or Dr Catherine O'Leary who are supervising the study (details below). The contact details for Dr Dougal Hare are provided should you wish to contact someone independent of the research team.

Jonathan Harrold (Lead Researcher): Trainee Clinical Psychologist

South Wales Clinical Psychology Doctoral Programme, 11th Floor, Tower Building, Park Place, Cardiff, CF10 3AT
Email address: harroldj@cardiff.ac.uk Telephone: [REDACTED]/02920870582

Dr Jenny Moses (Academic supervisor for the study): Consultant Clinical Psychologist

South Wales Clinical Psychology Doctoral Programme, 11th Floor, Tower Building, Park Place, Cardiff, CF10 3AT
Email address: jenny.moses@wales.nhs.uk Telephone: 02920870582

Dr Catherine O'Leary (Clinical supervisor & Principal Investigator for the study): Consultant Clinical Psychologist

Nephrology & Transplant Psychology & Counselling Department, Pentwyn Dialysis Unit, Cardiff, CF23 8HE
Email address: Catherine.oleary@wales.nhs.uk Telephone: 02920748455

Dr Dougal Hare: Research Director for the South Wales Clinical Psychology Doctoral Programme

11th Floor, Tower Building, Park Place, Cardiff, CF10 3AT
Email address: hared@cardiff.ac.uk Telephone: 02920870582

Additional support

If you feel that you would benefit from accessing emotional support regarding chronic kidney disease, kidney transplantation, dialysis or any other issue related to your condition raised by this study, you can contact The Nephrology & Transplant Psychology & Counselling Department: 02920748455. You can also speak to your Nephrology Nurse.

Appendix G: Consent Form (Phase One)

Consent form: Version 2.1 23/6/17. IRAS Project ID: 223178



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South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol



Cardiff University
School of Psychology
Tower Building
70 Park Place
Cardiff CF10 3AT

Tel Ffôn +44(0)29 208 70562
CAV_psychology_training@wales.nhs.uk

Consent Form

Title of Study: The influence of illness perceptions and illness knowledge on pre-emptive (pre-dialysis) live donor kidney transplantation: A Mixed Methods Study.

Objectives of the study:

The aim of the research study is to improve our understanding of the beliefs people with a diagnosis of chronic kidney disease have about their diagnosis and about kidney transplantation. The project is being completed as part of a Doctorate in Clinical Psychology qualification at Cardiff University.

Researcher: Jonathan Harrold (Trainee Clinical Psychologist)

Please **initial** the relevant boxes on the right and **sign and date at the bottom of the page**:

i.	I confirm that I have read and understood the information sheet dated (23/06/17, version 2.1) for the above study and have had the opportunity to consider the information and ask questions that have been answered satisfactorily.	
ii.	I understand that my participation in Phase One of this study will involve completing a questionnaire, which will require approximately 20-30 minutes of my time.	
iii.	I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason and without my healthcare or legal rights being affected.	
iv.	I understand that the information provided by me will be held confidentially and in accordance with the Data Protection Act 1998.	
v.	I understand that only the lead researcher (Jonathan Harrold) will have access to any personal data that I provide (such as my consent form) and that the questionnaire will be fully anonymised within two weeks of returning the questionnaire.	
vi.	I understand that I can ask for the information I provide to be destroyed at any time, up until the data has been anonymised.	
vii.	I understand that the anonymised questionnaire will be kept securely for a minimum of 15 years, in accordance with Cardiff University Guidelines, and may be looked at by members of the research team, for the purpose of the study.	
viii.	I understand that verbatim extracts from my anonymised questionnaire responses may be used within the research report but that I will not be identifiable. I give permission for Cardiff University to use my anonymised questionnaire responses.	
Viii.	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Cardiff University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
X.	I agree to take part in Phase One of the study.	

I, _____ (NAME) consent to participate in the study conducted by Jonathan Harrold, School of Psychology, Cardiff University with the supervision of Dr Jenny Moses.

SIGNED: _____ DATE: _____ Please see reverse page

Appendix G: Consent Form (Phase One)

Consent form: Version 2. 28/4/17. IRAS Project ID: 223178

Please tick here if you would like to receive a summary of the results once the research has been completed:

Phase Two (INTERVIEW – OPTIONAL)

Please only complete this section if you would like to be contacted about taking part in Phase Two of the study (a follow-up interview later in 2017).

i.	I agree to be contacted by the lead researcher (Jonathan Harrold) to take part in Phase Two of the study (an interview).	
ii.	I understand that if I agree to be contacted to take part in Phase Two of the study, I will receive an additional Participant Information Sheet explaining the interview process, and the lead researcher will obtain my consent to participate.	
iii.	I understand that if I do choose to take part in an interview, it will be audio-recorded and my anonymised responses may be published verbatim in the research report.	
iv.	My preferred contact details are: Name Telephone number/email address: Signed:	

Appendix G: Consent Form (Phase Two)

Consent form Phase Two: Version 1.2. 23/6/17. IRAS Project ID: 223178



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Cardiff University
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Tower Building
70 Park Place
Cardiff CF10 3AT

Tel Ffôn +44(0)29 208 70562
CAV_psychology.training@wales.nhs.uk

Consent Form – Phase Two (Interview)

Title of Study: The influence of illness perceptions and illness knowledge on pre-emptive (pre-dialysis) live donor kidney transplantation: A Mixed Methods Study.

Researcher: Jonathan Harrold (Trainee Clinical Psychologist)

Objectives of the study: The aim of the research study is to improve our understanding of the beliefs people with a diagnosis of chronic kidney disease have about their diagnosis and about kidney transplantation. The project is being completed as part of a Doctorate in Clinical Psychology qualification at Cardiff University.

Please **initial** the relevant boxes on the right and **sign and date at the bottom of the page**:

i.	I confirm that I have read and understood the information sheet dated (8/5/17, version 2) for the above study and have had the opportunity to consider the information and ask questions that have been answered satisfactorily.	
ii.	I understand that my participation in Phase Two of this study will involve an audio-recorded interview with Jonathan Harrold, which will require up to 60 minutes of my time.	
iii.	I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason and without my healthcare or legal rights being affected.	
iv.	I understand that the information provided by me will be held confidentially and in accordance with the Data Protection Act 1998.	
v.	I understand that only the lead researcher (Jonathan Harrold) will have access to any personal data that I provide (such as my consent form) and that the audio-recording will be transcribed and then deleted to ensure anonymity within two weeks of the interview	
vi.	I understand that I can ask for the information I provide to be destroyed at any time, up until the data has been anonymised.	
vii.	I understand that the anonymised transcript will be kept securely for a minimum of 15 years, in accordance with Cardiff University Guidelines, and may be looked at by members of the research team, for the purpose of the study.	
viii.	I understand that verbatim extracts of my responses may be used within the research report but that I will not be identifiable. I give permission for Cardiff University to use my anonymised responses.	
Viii.	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Cardiff University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
Viii.	I agree to take part in Phase Two of the study.	

I, _____ (NAME) consent to participate in the study conducted by Jonathan Harrold, School of Psychology, Cardiff University with the supervision of Dr Jenny Moses.

SIGNED: _____ DATE: _____

Please tick the box if you would you like to receive a summary of the results once the research has been completed:

Appendix H: Questionnaire Pack

Version 2: 4/5/2017



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Cardiff CF10 3AT

Tel Ffôn +44(0)29 206 70562
CAV_psychology_training@wales.nhs.uk

Instructions for completing the questionnaire

Please read the Participant Information Sheet, and sign the consent form if you are happy to continue with the study.

To answer some of the questions in the questionnaire, please indicate your answer by **circling** the number corresponding to your choice.

For questions that require a written answer, please respond with as much detail as you feel comfortable sharing.

It is important to realise that there is no "right" or "wrong" answer as we are asking for your own opinion, which is valid and important. Your responses will be looked at anonymously and only once all questionnaires have been completed.

Please return the completed questionnaire, **along with your completed consent form**, in the stamped addressed envelope enclosed. If you need any help in completing the questionnaire, please contact me on the number below. I am very grateful for your time and effort in participating in this study.

Best regards,

Jonathan Harrold
Trainee Clinical Psychologist
South Wales Clinical Psychology Doctoral Programme
11th Floor, Tower Building, Park Place, Cardiff, CF10 3AT
Email: [REDACTED]
Telephone: [REDACTED]

Appendix H: Questionnaire Pack - Brief Illness Perceptions Questionnaire (Broadbent et al., 2006)

Version 2: 4/5/2017

For the following questions, please circle the number that best corresponds to your views regarding chronic kidney disease (CKD):

How much does chronic kidney disease affect your life?	0	1	2	3	4	5	6	7	8	9	10
no affect at all											severely affects my life
How long do you think your illness (CKD) will continue?	0	1	2	3	4	5	6	7	8	9	10
a very short time											forever
How much control do you feel you have over your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
absolutely no control											extreme amount of control
How much do you think living donor kidney transplantation (a kidney donated from a living person) can help your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
not at all											extremely helpful
How much do you think deceased donor kidney transplantation (a kidney donated from a deceased person) can help your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
not at all											extremely helpful
How much do you think pre-emptive (pre-dialysis) living donor kidney transplantation (a kidney donated from a living person) can help your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
not at all											extremely helpful
How much do you think dialysis can help your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
not at all											extremely helpful
How much do you experience symptoms of chronic kidney disease?	0	1	2	3	4	5	6	7	8	9	10
no symptoms at all											many severe symptoms
How concerned are you about your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
not at all concerned											extremely concerned
How well do you feel you understand your illness (CKD)?	0	1	2	3	4	5	6	7	8	9	10
don't understand at all											understand very clearly
How much does your illness (CKD) affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally											extremely affected emotionally

Appendix H: Questionnaire Pack – Living kidney donation knowledge questionnaire (Barnieh et al, 2009).

Version 2: 4/5/2017

Please list in rank-order the three most important factors that you believe caused the chronic kidney disease.

1. _____

2. _____

3. _____

Based on your knowledge, please indicate your level of agreement or disagreement for each statement:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
In Wales a family member can donate a kidney for a person with kidney disease	1	2	3	4	5
In Wales a friend can donate to a person with kidney disease	1	2	3	4	5
Kidneys from living donors last longer than kidneys from deceased donors	1	2	3	4	5
The sooner I get a kidney transplant, the better off I will be	1	2	3	4	5
People who have a living donor will wait less time for a kidney than those without	1	2	3	4	5
I understand that living donation means a kidney is donated by a living person	1	2	3	4	5
Individuals who donate a kidney are more likely to end up with kidney failure themselves	1	2	3	4	5
Individuals who donate a kidney are more likely to end up with high blood pressure	1	2	3	4	5
I could tell someone who is interested in donating a kidney how to contact the living donor programme	1	2	3	4	5
I know how I would ask someone to donate their kidney	1	2	3	4	5
I would rather not discuss kidney transplantation until I know I will need renal replacement therapy	1	2	3	4	5

Appendix H: Questionnaire Pack

Version 2: 4/5/2017

1. Would you ever consider receiving a living donor kidney transplantation? (please circle)

YES

NO
(please answer question 2
and go to question 5)

UNSURE

2. Please can you provide reasons for your answer

3. Would you consider having a pre-emptive kidney transplant (a transplant before starting dialysis) from a LIVING donor?

YES

NO
(please answer 3a,
then go to question 5)

UNSURE

3a. Please can you provide reasons for your answer

4. Would you consider having a pre-emptive (pre-dialysis) kidney transplant from a LIVING donor, before experiencing a deterioration in symptoms?

YES

NO

UNSURE

4a. Please can you provide reasons for your answer (if different from question 3a)

5. Would you consider having a pre-emptive kidney transplant (a transplant before starting dialysis) from a DECEASED donor? (please circle)

YES

NO
(please go to question 7)

UNSURE

6. Would you consider having a pre-emptive (pre-dialysis) kidney transplant from a DECEASED donor, before experiencing a deterioration in symptoms? (please circle)

YES

NO

UNSURE

Appendix H: Questionnaire Pack

Version 2: 4/5/2017

7. Should you require renal replacement therapy in the future, what would be your preferred first form of treatment? Please rank each of the following treatment options in order of preference, #1 being the most preferred option to #6 being the least preferred option:

Dialysis	
Living donor kidney transplantation from a blood relative	
Living donor kidney transplantation from someone I know but who is not a blood relative	
Living donor kidney transplantation from a stranger	
Deceased kidney transplantation	
Conservative management (care without renal replacement therapy such as dialysis or transplantation)	

8. Thinking about the option you ranked as #1, how certain are you with your answer?

1	2	3	4
Very uncertain	Fairly uncertain	Fairly certain	Very certain

9. Please state your reasons for the item you have ranked as your first preference (#1)

10. Thinking about kidney transplantation from a living donor, would you have any family or friends who could donate, or who may offer to donate, a kidney to you? (please circle)

YES NO UNSURE

11. Please circle your response for each of the following questions that are relevant:

A) Have you DISCUSSED living kidney donation with family and/or friends?	YES go to B	NO go to C	
B) Have you IDENTIFIED a potential living kidney donor?	YES go to D	NO go to C	
C) Do you plan to discuss living kidney donation with family or friends in the future?	YES go to E	NO go to Q14	UNSURE go to E
D) If you have discussed living kidney donation with a relative or friend, who started the conversation?	You go to Q14	Another person go to Q14	
E) Who would you prefer to start this discussion?	You	Another person	

Appendix H: Questionnaire Pack

Version 2: 4/5/2017

14. Do you feel pressurised by anyone to accept a kidney from a living donor? YES/NO

Additional information (e.g. who you feel pressurised by):

15. Do you feel pressurised by anyone not to accept a kidney from a living donor? YES/NO

Additional information (e.g. who you feel pressurised by):

Please use this space if you have any additional comments about any of the questions you have been asked:

Please circle which of the following best describes you. Leave blank any question you prefer not to answer:

I am...	Male	Female			
I am aged...	18 - 29	30 - 39	40 - 49	50-59	60-75
I am...	Single	Married/significant other	Separated/Divorced	Widowed	
I am...	Presently employed	Presently unemployed or unable to work	Retired	Student	
I have...	Children under 18	Children over 18	No children		
My current eGFR (estimated glomerular filtration rate) is...	10-15 (stage 5 chronic kidney disease)	16-29 (stage 4 chronic kidney disease)	30-44 (stage 3 chronic kidney disease)	Unsure	
My ethnicity is...	White	Black	Asian	Mixed	Other

And finally...

Version 2: 4/5/2017

Thank you very much for your time and your valuable contribution in completing this questionnaire.

Please return your completed questionnaire, along with the signed consent form, in the stamped addressed envelope provided.

This is the end of Phase One.

Phase Two (follow-up interview):

If you are happy and willing to be considered for Phase Two of the study (follow-up interview), please indicate this on the reverse page of the consent form provided. A separate information sheet will fully explain the interview process, to help you decide whether you would like to take part, if you are contacted about this in the future.

- The interview will be with Jonathan Harrold (lead researcher)
- The interview will last up to 60 minutes and will take place in your home, or another location that is convenient to you.
- The interview will be audio-recorded and will expand on the questions from the questionnaire.
- Audio-recorded information will be typed up by Jonathan, anonymised and only accessed by Jonathan. The audio-recording will be deleted.
- Participating in Phase One does not mean you have to participate in Phase Two.

You can contact Jonathan Harrold (Trainee Clinical Psychologist) on [REDACTED] or [REDACTED]@cardiff.ac.uk, should you have any questions about being interviewed before making a decision.



Health Research Authority

London - Fulham Research Ethics Committee

Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8021

23 June 2017

Dr Jenny Moses
South Wales Clinical Psychology Doctoral Programme
11th Floor, Tower Building, 70 Park Place
Cardiff
CF10 3AT

Dear Dr Moses

Study title:	The influence of illness perceptions and illness knowledge on pre-emptive live donor kidney transplantation: a mixed methods study.
REC reference:	17/LO/1033
Protocol number:	SPON1596-17
IRAS project ID:	223178

Thank you for your letter submission, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Appendix I: NHS ethical approval

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering letter]		01 June 2017
Covering letter on headed paper [Covering letter]		23 June 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]		18 July 2016
IRAS Checklist XML [Checklist_23062017]		23 June 2017
Letter from funder		
Letter from sponsor [Cardiff University sponsor acceptance letter]	1	08 May 2017

Appendix I: NHS ethical approval

Letter from statistician		03 May 2017
Letters of invitation to participant [Introduction/invitation letter to potential participants from Dr O Leary]	1	17 March 2017
Non-validated questionnaire [Barriers to living kidney donation questionnaire]	2	04 May 2017
Other [eGCP for Jonathan Harrold]		15 August 2016
Other [GCP for Principal Investigator]		24 March 2017
Participant consent form [AMENDED Consent Form Phase One]	2.1	23 June 2017
Participant consent form [AMENDED Consent Form Phase two]	1.2	23 June 2017
Participant information sheet (PIS) [Phase Two Participant Information sheet]	2	08 May 2017
Participant information sheet (PIS) [AMMENDED Phase One Participant Information Sheet]	2.1	23 June 2017
REC Application Form [REC_Form_02062017]		02 June 2017
Referee's report or other scientific critique report		
Research protocol or project proposal [Jonathan Harrold Project Proposal]	1.2	04 May 2017
Summary CV for Chief Investigator (CI) [Jenny Moses Chief Investigator CV]	1	22 May 2017
Summary CV for student [Jonathan Harrold CV]	1	20 June 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary of protocol]		
Validated questionnaire [Illness Perceptions Questionnaire (revised)]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/LO/1033	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



The Rev'd Nigel Griffin (Chair)
Chair

Email: nrescommittee.london-fulham@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Mrs Helen Falconer*
Professor Christopher Fegan, Cardiff and Vale UHB R&D Department

Appendix I: Cardiff & Vale Research and Development Approval



Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

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From: Professor C Fegan
R&D Director
R&D Office, 2nd Floor TB2
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Cardiff
CF14 4XW

10 August 2017

Dr Catherine O'Leary
Consultant Clinical Psychologist
Nephrology and Transplant Psychology and Counselling Department
Pentwyn Dialysis Unit
Cardiff
CF83 8HE

Dear Dr O'Leary

Study title	The influence of illness perceptions and illness knowledge on pre-emptive live donor kidney transplantation: a mixed methods study.
Cardiff and Vale UHB reference	17/JUN/6964
IRAS reference	223178

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the Health and Care Research Wales Permissions Service. A Governance Review has now been completed.

I am pleased to inform you that based on the review of the documents submitted to the Health and Care Research Wales Permissions Service, the UHB has no objection to your proposal

You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care. Please accept this letter as confirmation of permission for the project to begin within this UHB.

I note that Health and Care Research Wales has determined that this study is ineligible for adoption onto the Clinical Research Portfolio and your Directorate R&D Lead has determined that it does not meet the criteria for Pathway-to-Portfolio. The

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board is the operational name of Cardiff and Vale University Local Health Board



Appendix I: Cardiff & Vale Research and Development Approval

Directorate R&D Lead has confirmed that he is satisfied that arrangements are in place for meeting any costs from outside of the R&D Activity Based Funding allocation.

May I take this opportunity to wish you success with the project and remind you that as Chief / Principal Investigator you are required to:

- Inform the Health and Care Research Wales Permissions Service and the UHB R&D Office if any external or additional funding is awarded for this project in the future
- Ensure that all study amendments are submitted to the Health and Care Research Wales Permissions Service
- Ensure the Health and Care Research Wales Permissions Service is notified of the study's closure
- Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
- Provide information on the project to the UHB R&D Office as requested from time to time.

Yours sincerely,



Professor Christopher Fegan
R&D Director / Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC

R&D Lead
Chief Investigator
Sponsor Contact
Student
Clinical Board Assistant Head of Finance
Finance

Dr Sian Griffin
Dr Jenny Moses
Cardiff University
Mr Jonathan Harrold
Chris Bimson
Anthony Williams

Interview Schedule

I would like to speak with you to hear about your experiences of living with chronic kidney disease and the treatment choices related to transplantation which you may or may not be required to make. The interview will take no more than an hour, and we can stop at any point, including now. I have an information sheet for you at the end of the interview.

Setting Questions

Living with kidney disease or having kidney problems can affect people in different ways. The first question I'd like to ask is how does having kidney problems currently affect you?

- How does it affect your life?
- What changes, if any, have you noticed?

What have been your experiences of having to make decisions related to the chronic kidney disease?

Q1: If I mention living donor kidney transplantation, what thoughts and feelings does that raise for you?

Explanation if required: *Living kidney donation is a surgical procedure in which a healthy kidney is transplanted from a living person (a blood relative; a non-blood relative; or a stranger) into a person with chronic kidney disease. Living kidney donation is an alternative treatment to dialysis or a kidney from a deceased person.*

- What do you understand by the term 'living donor kidney transplantation'?
- What is your experiences of considering this option for yourself?
- What do you consider might be the pros and cons to have a transplant from a living kidney donor?

Appendix J: Semi-structured interview schedule

- In what ways is living donation better/less preferable than the alternatives?
- Can you think of any circumstances in which you might prefer the alternative options? (e.g family pressure/becoming more sick/length of wait)

Q2: Some people with kidney disease may consider having a transplant from a living donor before their condition progresses to needing dialysis, and while they may still feel relatively healthy. This is called ‘pre-emptive living donor kidney transplantation’? Have you considered the pros and cons of this option for yourself?

Further clarification if required: *Some people with kidney problems may be offered, or may be asked to consider a pre-emptive living kidney transplantation by their nephrologist. This means the transplant is completed before other treatments, such as dialysis, are started. In some cases, this may mean the person is still physically feeling relatively well/ the person is not experiencing severe symptoms of their illness.*

- What are your experiences of considering this option?
- What are the potential benefits as far as you are concerned?
- What are the potential disadvantages as far as you are concerned?
- In what ways is pre-emptive living donation better/less preferable than the alternatives?
- Can you think of any circumstances in which you might prefer the alternative options? (e.g family pressure/becoming more sick/length of wait)
- Has pre-emptive living kidney donor transplantation been discussed in clinic? What are your thoughts on this?

Relationships (Social norms)

Living kidney donation can come from friends, family members or from a stranger who wants to help by donating their kidney.

Q3: What are your experiences of exploring living kidney donation with donors who might want to help or who may be suitable e.g. friends, family or a person who wants to help by donating their kidney?

- What actions if any have you taken to follow up on this?

Appendix J: Semi-structured interview schedule

Prompts for those who have discussed:	Prompts for those who have not discussed:
<ul style="list-style-type: none">- How was the matter of live donation raised and by whom? Initial reactions?- How did you decide to ask a family member/friend for a kidney?- Could you describe the experience of please?- What does it mean to you to have family/friends involved in treatment decisions?- What impact has your conversation had on you and your family/friends; your relationship?	<ul style="list-style-type: none">- What impact do you imagine such a conversation would have on you, and your relationships?- What impact has not talking about living donation had on you and your family/friends?- How do you feel about discussing/not discussing this?- What does it/would it mean to involve family or friends in treatment decisions?

Sense of control

Some people are asked by their consultant to search for a living kidney donor, or some people may be offered and encouraged to accept a kidney from someone they know.

Q5: Can you tell me about how you make choices about your treatment?

- What are your experiences of making treatment choices?
- What control do you have regarding your treatment choices for CKD?
- How would such a request/offer affect you and those around you?
- What is your experience of being pressured to accept, or not to accept, a particular treatment option, should your condition deteriorate? (e.g from family/friends/medical teams/media etc)

Q6. How do you view your health condition in relation to donation or dialysis?

The Welsh organ donation system

Q7 Wales now has an ‘opt-out’ system for organ donation as opposed to ‘opting in’. What do you think of this system?

- What are the advantages or disadvantages you?
- How do you think of this system as a person with a kidney problem?

Q8 How has the legislation change in Wales affected your thinking regarding kidney donation?

- Has the legislation impacted on discussing organ donation preferences with family/friends?
- How has the legislation impacted on how you view potential treatment regimes?
- Have you thought about the issue any more/less?
- How do you view the system should you ever require a transplant in the future?

Q9. Can you suggest any ways in which your experience might be improved/made easier for you?

Q10. This is the last question I have for you. Is there anything that we haven’t discussed that you would like to add?

Thank you for your time and for sharing your experiences and thoughts today.

Debrief.

Appendix K: IPA analysis process (Smith, Flowers & Larkin, 2009, pp. 79-108)

Stage one
<ul style="list-style-type: none"> - Transcripts were repeatedly read. - Bracketing and reflexivity was used when moving between cases. - Wide-ranging and unfocused notes, reflecting initial thoughts and observations, were recorded in the left margin.
Stage two
<ul style="list-style-type: none"> - Initial/emerging themes were identified and labelled that characterised the essential quality of a section of the text. - The theme titles were conceptual and recorded in the right margin. - These emerging themes were derived from the left-margin notes rather than the transcript.
Stage three
<ul style="list-style-type: none"> - Structure was introduced into the analysis. - All initial themes identified in stage two were listed and considered in relation to one another to form ‘clusters’ or concepts that shared meanings, or hierarchical relationships. - Clusters of themes were given labels that capture their essence (e.g. brief quotes or descriptive). - The original data was reviewed to ensure that theme clusters still related to the original data. The themes were supported by quotations from the transcript.
Stage four
<ul style="list-style-type: none"> - A summary table of the structured themes was developed, with quotation that was felt to best to illustrate each theme. - The table only included themes that captured something about the quality of the participants experience of the phenomenon . - What the researcher includes or excludes is influenced by their interests or orientation and bracketing was used.
Stage five
<ul style="list-style-type: none"> - Stages one -four were repeated for each case. - The emergent themes from the previous case were held to one side to allow new ideas to emerge from subsequent cases.
Stage six
<ul style="list-style-type: none"> - Recurrent themes were searched across cases. - Themes included convergence and divergence between cases. - Transcripts were referred to when uncertainty arose. - Groups were identified as ‘sub-ordinate themes’ and were clustered into super-ordinate themes that the author felt described the phenomenon of interest.
Stage seven
<ul style="list-style-type: none"> - Themes were reviewed by a peer and supervisor and referred back to the transcripts to assess validity.

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

Audio Title: Interview 6
Audio Length: 46 minutes

Respondent They are not the sort of people I'm going to be sitting down having a conversation with. And the ones I see more often, certainly when I was in England, I don't see them now. There's my brother. He made an offer once. I mean. I think 30 years ago, yeah. So you know. I haven't discussed it with him recently, you know.

Trust / Pride?
Lack of opportunity

An idea of what a carer might be like

Safe env.

(Formal) Confidenced conversations

Opportunity and trust

indebtedness

Interviewer What does it, or would it mean to you to be involving family in making treatment decisions?

Respondent Oh - that's an interesting question. I don't think I can answer that question. What would it mean? Well I mean I'd - you know, decisions that affect my family I would involve them in anyway. So this would be no different, you know. I mean I would only discuss it if - you know, until I've had the discussion with the consultant. I don't think I have any problem with involving them at all. But maybe there's no point having that discussion until I know what the position is.

Shared decision

Family involvement important but difficult?

Family as a unit - they share & talk

Need to be medically led - protection of family?

Idea of doing it late better or what?

(rather than own) (state of health)

Shared + informed decision making

Avoidance + Protection

Family + Medics

Interviewer How do you think other people see such involvement?

because of the medical backing? (i.e. they want to help?)
Respect choice avoid coercion?
'not a problem' - could mean dialysis or long waiting lists

Respondent Well I don't know. I don't think they would have a problem. It would be up to them to be involved perhaps. I wouldn't have any expectation for people to, you know. And if - even - I mean if they didn't that's not a problem - end of subject. If they

no expectations - accept science as an answer

Keeping ones safe

end of subject if don't discuss/offer? what if they are waiting for him to offer?

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

Audio Title: Interview 6
Audio Length: 46 minutes

The offer creates the dilemma
 what wants feels appropriate but aware the reality/No Sirachin could be different when required to make a decision
 offer = dilemma
 son risks + benefits himself
 weighing up the needs of others.
 Time - urgency age of himself + donor.
 the underlying question?
 Self: Value of life vs value of others lives.
 Intergenerational ageing?
 help the young.
 Guilt? Concern

were the ones to bring it up. I don't know. I don't want dialysis and I'd consider options from family to avoid dialysis. But if they did offer then that's a different matter because then - then I'd have to - then I'd really have to think then about whether I would really want to do it because of the - up until that point it's hypothetical, so you know - do I want my - Say it was my son and he says, "Yes, Dad, you can have one of my kidneys." And I think, right, he's 34, I take one of his kidneys, he's got one that's perfectly healthy but what about - you know, he's got - he's probably got 50 years in front of him yet. Do I want to leave him with one kidney just to benefit me for a limited period of time? Because you know I'm already into whatever they call - whatever semester I'm in, you know, in my life. So that would - so that would require some discussion and some thought.

Charges over time.
 Hypothetical becomes real
 Weighing up the dilemma.
 Values: - 'successful ageing!'

Interviewer Could you tell me some more about the thought process?

a process
 Not clear cut
 An offer is not a solution, can the line ever be drawn?
 The dilemma? -> ongoing uncertainty?

Respondent Yes. And I think, you know, you don't just say, "Okay, off we go." You'd be - because they're - you know, nothing is - nothing is ever that simple is it. You can't just draw a line and say, "Oh, it's black and white and yes or no."

An ongoing dilemma / an unsolvable problem.

Interviewer What are the things that you would need to help through that process?

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

Interview 4 - Initial list of themes	
<ul style="list-style-type: none"> • Adapting to new processes/medical systems • Self-identity changed/lost due to worsening health • Loss/unfairness of CKD • Difficulty adjusting to the medical experience • Worry about future in relation to identity (employment) • Psychological impact of RRT decisions/options – for self; for others • Weighing up the options • Hope • Psychological impact of LKD • Changes to self image • Risks of harm to family and unknown outcomes • Making sense of the options • Anticipating feelings of guilt should graft failure occur • The tyranny of the gift • Experience of medical teams and an undesired reality/future made real • Medical teams language vs patient needs • Mental processing • Personal control and weighing up decisions 	<ul style="list-style-type: none"> • Preferences for a donor source • Relationships with medical teams and control • Lack of control • Time being wasted • Identity – coping • Psychological responses - criticism and blame • Fighting for a solution • Desperation and how preferences will change over time • Sooner rather than later/a return to normalcy • Powerlessness in the process • Faith Vs Fear • Family bonds • Assessing the offers • The family dance of weighing up competing needs and priorities • The meaning of an offer • Gratitude for the offer vs protection of others • Identity – role of a mother as a protector • Impact of an offer on relationships • Secret preferences and hopes • Weighing up risks as potential future problems (familial)

Clustering of Themes	Quotes	Page no.
Self-concept <ul style="list-style-type: none"> • Self identity changed/lost due to health decline. Values. • Changes to self image: protection of self concept • Identity – role of a mother as a protector; loss of role in society • Identify – a copier/inner resources 	“I’ve worked hard to attain what I’ve attained, late in life, and now I don’t think I’ll be going back...that’s a big thing for me. Work has been a big part of my life and then they’re now looking at dialysis and transplants”	2
	“My family say I’ve changed so much and I’m now much more irritable. I’m much more irritable and I’ve got no patience...I’m just a miserable old woman, really, and the kids say ‘you’ve changed Mum. You’ve really changed – you used to be so optimistic but now you’re pessimistic’ “	4
	“I just feel as though I haven’t had it easy and I’ve struggled”	8
	“let’s go for the transplant and let’s get it over and done with and let me get back”	11
	“I’m one that if it needs doing, let’s get it done, so in my head, and then, hopefully I’d have the transplant and start to feel better, and then I can get on with my life instead of dragging it all out until I’m older, and who knows what other health issues are going to pop up”	13
	“as long as my kids are alright, I’m okay. I hate them to be worried. I just hate it...so maybe going on the steroids to delay things would be the best thing for everybody”	19

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

	<p>“I’ve always been a copper, always. I just get on with it...sorting problems out”</p>	25
<p>Adapting and adjusting</p> <ul style="list-style-type: none"> • Adapting to new processes/medical systems • Isolation (link to self-concept?) • Loss/unfairness of CKD • Difficulty adjusting to the medical experience • Experience of medical teams and an undesired reality/future made real • Medical teams language vs patient needs • Relationships with medical teams and control 	<p>“it’s been a short space of time – not even - I’ve seen the nurse and we’ve looked at the different types of dialysis. They’ve talked about transplants and I’ll need one next year sometime”</p> <p>“they’re now looking at dialysis and transplants and I’ve had to talk to my relatives about transplants and that sort of thing”</p> <p>“[the] doctor said dialysis and transplant...it’s a bit of a shock”</p> <p>“things that are the norm to [medics] and not the norm to everyone else...[they] can be a little bit sort of blasé and it”</p> <p>“[the doctor] said ‘I’ve got two things to say to you: dialysis and transplant’...it’s a bit of a shock... it is very different when it happens to you and I don’t think some people realise that, and it’s the implications of it all”</p> <p>“I just think the way they give information isn’t very sensitive. They’re very factual, ‘this is it’.”</p> <p>“the professionals seem very factual, ‘this is this and when it gets to this, we’ll do this that and the other’. Yeah, okay, that’s fine but then you’ve got to interpret that and then you’ve got to live with all that”</p>	1 2 7 6 7 28 31
<p>Psychological impact</p> <ul style="list-style-type: none"> • Worry about future in relation to identity • Psychological (physiological/visceral?) impact of RRT options – for self; for others • Psychological impact of LKD • Mental processing 	<p>“I’m awake most of the night, so the decisions for me are about work and what do I do if I don’t work...there’s a financial implication”</p> <p>“it’s the worry of it all. The thought of dialysis makes me feel sick. The thought of a transplant makes me feel sick. And then to think that one of my family will probably have to donate one...it’s the implications for them”</p> <p>“you don’t think it’s going to happen, and then they mention it..it was ‘right, okay. Oh God””</p> <p>“it’s scary”</p>	2 3 6 4
<p>Weighing up the options/Hope and Guilt</p> <ul style="list-style-type: none"> • Risks of harm to family and unknown outcomes • Making sense of the options • Assessing the offers • Gratitude for the offer vs protection of others • Weighing up risks as potential future problems (familial) 	<p>(LKD) “it’s just the implications of it all, it’s ‘if’s why’s and but’s’, and I’m sure everything will be fine, but you don’t know do you?”</p> <p>“my children...have said they will donate...it’s the thought of them having to be compromised, their health compromised. They’re all busy, they’re all working and they’ve all got families. It’s the possible ramifications for them and the implications for them....it’s scary”</p> <p>“the thought of having a dead person’s kidney in me makes me feel sick. I just need to make sense of it all”</p> <p>[family donors] “hopefully everything will be fine because you can manage on one kidney anyway, but what happens if an anomaly comes our way and something happens that’s detrimental to their health? I’ll never forgive myself”</p>	3 4 5 5

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

	<p>“If I’m honest I’d rather not take steroids and be monitored, and let’s go for the transplant and let’s get it over and done with and let me get back”</p>	11
<p>The meaning of the gift</p> <ul style="list-style-type: none"> • Anticipating feelings of guilt should graft failure occur • The tyranny of the gift • Indebtedness 	<p>“plus, it’s a case of being beholden to somebody as well...it will be ‘oh well, I gave you my kidney’ and so sometimes I think it would be best for it to be someone I didn’t know”</p> <p>“I feel with him...he brings it up, when the chips are down ‘oh well, I helped you do this’..If I’m honest, (<i>whispers</i>) I hope its not him...the person I would want it to be would be [child’s name] because. there would be no sort of agenda or anything”</p>	5 21
<p>Personal control and power</p> <ul style="list-style-type: none"> • Personal control and weighing up decisions • Preferences for a donor source • Powerlessness in the process • Fighting for a solution • Lack of control • Time being wasted 	<p>“let’s go for the transplant and let’s get it over and done with and let me get back”</p> <p>“Although I know it comes with a lot of problems I’d feel much happier having the kidney from my own than from a stranger, and especially from a dead person”</p> <p>PEKD: “I’d much rather have it now...and get it over and done with...I don’t want to wait until I’m not feeling well. I think to take on a big operation you’ve got to be at the optimum”</p> <p>“I’m one that if it needs doing, let’s get it done, so in my head, and then, hopefully I’d have the transplant and start to feel better, and then I can get on with my life instead of dragging it all out until I’m older, and who knows what other health issues are going to pop up”</p> <p>“ultimately it’s my choice...I don’t feel pressured because I know I can say no at any time for anything, but it’s wanting to do the right thing for me, but it’s having the information”</p> <p>‘As the nurse said, ‘sometime next year you’ll need a transplant. You’ll be on dialysis and you’ll need a transplant’. When will that happen – who knows? So there’s that uncertainty”</p> <p>“come on let’s just do it, instead of messing about and putting me on...dialysis...it’s better to have it done where I’m relatively okay”</p>	11 11 12 13 23 24 25
<p>A desire to return to normalcy</p> <ul style="list-style-type: none"> • Desperation: preferences will change over time • Sooner rather than later/a return to normalcy 	<p>“I suppose if my health deteriorated quickly and it wasn’t feasible to have a live family, friend or relative, or even an unknown, because of the matches, I just needed the transplant, then I’d have to have that [deceased donor] and I would accept that”</p> <p>“hopefully for them [children donors], they’ll recover very quickly and get on with life. For me..I’ll recover and get some quality of life back and then see where the baseline is there”</p> <p>“I’m hoping that once I get a new kidney that we’ll all be fine..and re-evaluate life”</p> <p>“Just take me and give me a new kidney! I want it over and done with. I just want to get on with my life. I’m relatively young and I just want to stop feeling like this...irritable and pessimistic”</p>	12 20 20 31
<p>Doubt</p> <ul style="list-style-type: none"> • Faith Vs Fear 	<p>“you hear so many stories of people going in for routine things and dying or perforating something that’s caused mammoth problems, but then you can’t live your life like that and you’ve got to put your faith in people and get on with it”</p>	14

Appendix L: IPA case examples of developing the initial list of themes from the left-right process, the first stage of clustering the themes.

<p>The family dance</p> <ul style="list-style-type: none"> • Family bonds • The family dance of weighing up competing needs and priorities • The meaning of an offer • Impact of an offer on relationships • The needs of others 	<p>The advantages of not into PELD: “giving people more time, my relatives a bit more time to get their heads around it, to get their life in order, for them to come to terms with it”</p> <p>“with my son....he’s like ‘I can’t understand why we’ve got to wait’...’it’s the process and we have to wait’..he’s a bit ‘I want to get this sorted now and I want my mum to be alright’”</p> <p>“it was lovely. It was warming...really kind. Yeah, it was nice”.</p> <p>“I just want to get it over and done with, but he’s [potential relative donor] just started up a new business...so he’s extremely busy...it’s the practicalities of it...[another potential relative donor] has got kids and she wants a job”</p> <p>“as long as my kids are alright, I’m okay. I hate them to be worried. I just hate it”</p> <p>“I think for them [children donor offerers] to go through a major operation would put a spanner in the works for them’</p> <p>“I don’t want them to feel they have to at all. I never asked them to. They came forward...if they’re going to give something, it’s got to be given with good heart”</p>	<p>14</p> <p>16</p> <p>18</p> <p>18</p> <p>19</p> <p>20</p> <p>30</p>
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Appendix M: The author's bracketing statement and selected diary excerpts

The researcher:

I conducted this LSRP as a trainee clinical psychologist who is white, British, male, in my thirties, married, identifies as gay, and has no children. I do not have any kidney problems and have never been affected by donation. None of my relatives have chronic kidney problems or have been affected by organ donation. Through my training and experience, I have become familiar with psychological theories and principles which have shaped my understanding of clinical health psychology. My interest in clinical health psychology is attached to a desire to promote psychological thinking in medically dominant cultures. I have experience of delivering psychological therapy to those with chronic health conditions and who might have to make complex decisions related to their care. Based on these experiences, I agree with the idea that people's treatment choices, provided they have capacity, are their own to make with the support of who they feel appropriate, and that timely and personalised information from medical systems is essential for people to make informed decisions. I also understand medical teams may weigh up risks and benefits differently to how the people they support may weigh them up. I recognise that as a clinician. I feel it is important for people to be able to make informed choices. As a researcher I recognise my role is not to intervene but to generate an account of the participants lived experiences.

The researcher's original position regarding donation:

I have never registered my decision related to donation (either to opt-in or opt-out), partly due to an ambivalence about my decision. I have previously given blood, but have been restricted from doing so for many years due to donation rules related to my sexuality. I have wondered if this means I view donation as something that does not apply to me, nor requires my consideration. I have never personally experienced a medical emergency. However, I have relatives who have been saved through emergency blood transfusions. While I am ambivalent about my own intentions to donate in death, I have no intentions to be a living donor to a stranger. I would like to think I would genuinely offer to become a living donor for a relative, should their life be at risk. I would willingly and gratefully accept a deceased donor or non-directed donor's organ/tissue if I were ever in a position to require a transplant. I do not know what my stance is regarding living donation from a relative or a friend and I would be concerned of the risks to them. At the start of this research project, I don't know what other people think about donation based on my lack of experience and thought to the area. I know that there is a shortage and there are national campaigns to change this.

Family and treatment decisions:

A relative underwent unexpected emergency bowel surgery four years ago, which almost resulted in their death. My relative survived, following days in intensive care, with the addition of a colostomy bag. It struck me how much of an inconvenience we relatives in the family room were to some of the senior healthcare staff. Afterwards, my relative was told it may be possible to reverse the surgery. I was interested in the split family reaction to this information. While some advocated a return to surgery, the majority were firm that the shortcomings of a colostomy bag outweighed the risks of surgery. My relatives preference was clear, and it was interesting to see the influence of others on treatment choices. This personal experience, along with clinical experience in physical health settings, shaped my interest in clinical health psychology, choice, and person-centred approaches, and how people in families may weigh up risks differently to people in medical contexts.

Bracketing diary summary examples:

In conducting IPA I have questioned my ability to 'bracket' off what I know, what I believe, and what I am unsure about. I feel I have the attitude and ability to put aside my knowledge and beliefs for this project. My training and experience have allowed me to develop skills in holding non-judgemental and open stances, and I am willing to learn of the experiences of others. I intend to remain curious about people's experiences, even after the questionnaire phase. After phase one, I will remain open to people's experiences. I regularly ask myself 'do I feel curious?' and if the answer is always 'yes', it implies I am managing preconceptions.

Appendix M: The author's bracketing statement and selected diary excerpts

Diary examples during the interview and analysis phases:

I think I relied on the schedule too much. I need to use the questions as a guide and give the person time to think and speak. Ask more 'anything else' 'can you expand on that please?', and clarification questions.

I feel upset for them. I wonder why their family are not donating? I wonder if I should register to become a deceased donor? It's so difficult for people being at the mercy of other people or a machine.

I think I was more like a clinician at times today. I can see why it takes a long time to become an experienced and skilled IPA researcher. I was too focused on the schedule at times – I could see time running out and it was hard to keep the person on the topic. I am glad I was able to lead them gently back to the topic and kept the questions open. I don't think I led them – I think I rushed them.

I am surprised by people favouring conservative management. I wouldn't have thought people felt so strong towards it. It made me feel sad (angry?) that at 70 people feel their life may be complete, but I really admire them for (potentially) making a choice that they feel is right for them. It makes me think of the book 'Never let me go' – just because we can do something through medical advancement doesn't mean people are obligated to comply. It has made me think on what I would want and how difficult it may be when family members make choices that are right for them which may not be supported by other relatives. Do medical teams listen to this? Turning down medical advances must be a David and Goliath situation? He felt liberated by his decision!

I hadn't fully appreciated before just how divisive, confusing, and difficult these decisions are for people. I keep on thinking about my own views towards donation and how they change from not wanting to donate anything, to donate everything, back to an ambivalence. I need to find out from my family what they want regarding donation. Today's interview was powerful. They obviously don't want to suffer themselves but put the needs of others ahead of their own. There are acts of altruism at every turn – those who offer and those who reject. Against a backdrop of desperation? Does a decision for conservative management free someone from the desperation?

Am I answering my research question? Has my agenda changed? No – keep the schedule as a guide, the answers are very useful to understanding how much and how little people are thinking about pre-emptive transplantation.

I am struck by some people's experiences of medical teams. Do I report this in my LSRP? I don't want to seem like I am attacking them or have an anti-medic agenda as this is not true. Is it true? The quotes are not my words, but I have the choice to present those words or not in the report. It angers me how some people are spoken to and not treated as an individual – it reminds me of when we were all at the hospital. I also have to appreciate the demands of working in busy and stretched services.

Appendix N: Themed questionnaire responses to considering PELDKT

Potential benefits of PELDKT	Potential limitations of PELDKT	Lack of opportunities/
<p>Benefits identified for self</p> <ul style="list-style-type: none"> • Enable me to live longer • To improve quality of life • Why wait? • Make me live longer • I would prefer someone who is unknown. • My children have said they would donate if a match. I would feel better knowing where it came from • Comfort in knowing who gave me the kidney • Want a kidney from someone I don't know. • Others can manage fine on one kidney <p>Benefits identified for others</p> <ul style="list-style-type: none"> • I would consider to have kidney as soon as possible because I still have small children • I do not want my family to suffer <p>Benefits identified over other RRT</p> <ul style="list-style-type: none"> • Avoid dialysis • I do not want to be in pain or go on dialysis • More healthy kidney that my body wont reject • Family a better match 	<p>Knowledge limitations</p> <ul style="list-style-type: none"> • Don't have enough knowledge on it • I need more information to make a decision. • I would need professional guidance and advice before making a decision • How do you ask? Wouldn't want to force folk into doing something they don't want to do. <p>Perceived harm to others</p> <ul style="list-style-type: none"> • Someone else will be worse off than me • Long waits so need to get used to dialysis and don't want to put family at risk • My daughter has offered and would like a child and I would not take one of hers • I'm getting too old and have other illness so don't want to put my family through it • I would rather not put someone's health at risk for the sake of mine <p>Age as an obstacle</p> <ul style="list-style-type: none"> • Don't want it at my age • Let someone younger than me have a chance <p>Avoidance</p> <ul style="list-style-type: none"> • I prefer not to think about it <p>Medical mistrust?</p> <ul style="list-style-type: none"> • Wish I knew damage of lithium on body <p>Perceived benefits of dialysis as an alternative</p> <ul style="list-style-type: none"> • I would rather have dialysis until a transplant was absolutely necessary • Dialysis is more accessible • Dialysis better before transplant • Prefer dialysis first as its least intrusive and a transplant only if life threatening <p>The need to feel ill</p> <ul style="list-style-type: none"> • I would like to wait until it is absolutely necessary • Would only want a kidney when absolutely necessary <p>Rejection of LKD</p> <ul style="list-style-type: none"> • It would be surviving and not living • I would not want that level of obligation placed upon me. If the kidney failed after transplantation the disappointment would be overwhelming for both parties. 	<ul style="list-style-type: none"> • Medically not a choice • Family cant donate for their own health reasons <p>Not in awareness</p> <ul style="list-style-type: none"> • Would not have thought about it • Unnecessary so not thought about it