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### Renal patients' lived experiences and perspectives on conservative kidney management and kidney transplantation

Chan, Rebecca

*Award date:*  
2021

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**Renal patients' lived experiences and perspectives on conservative kidney management and kidney transplantation**

Bangor University

2021

Rebecca Chan

Submitted as partial fulfilment of the doctorate in Clinical Psychology (DClinPsy).

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## **Thesis Abstract**

This thesis explores the perspectives and experiences of renal patients across three chapters.

Chapter one reports a meta-ethnography (Noblit & Hare, 1988) of renal patients' experiences of living with conservative kidney management (CKM). As the first known meta-synthesis to focus solely on patients who have opted for CKM, this study synthesised the findings of ten peer-reviewed journal articles and one unpublished doctoral thesis, reporting the cumulative experiences of 129 patients with advanced chronic kidney disease. Patients experienced CKM as congruent with their personal priorities and developmental life stage, an option which enabled them to maintain personal continuity and autonomy. However, they also experienced biases in clinical and social interactions, which guided them unwillingly towards dialysis during decision-making. Recommendations included communication training for clinicians and proactive sharing of information about CKM and disease progression.

Chapter two reports a cross-sectional, interpretative phenomenological analysis study (Smith et al., 2009), which explored the experiences of six adult kidney transplant recipients one year post-transplantation, including how expectations may have shaped their experiences. The first year post-transplantation was characterised by uncertainty, unpredictability, and continued restriction, with recipients retaining ongoing patient status and experiencing heightened vulnerability. While participants reported minimal expectations, their accounts indicated psychological and interpersonal challenges which were not necessarily anticipated by patients or their families. Implications included the need for clinicians to initiate honest and balanced discussions with patients and families to normalise conflicting emotions post-transplantation.

Chapter three considers theoretical and clinical implications indicated by key findings from both studies. The final section offers personal reflections on the research process and outcomes. Utilising researcher reflexivity, this section seeks to make explicit, as far as possible, the first author's motivations, biases, subjectivities and contexts, to enable the reader to situate and interpret the research findings in consideration of these subjectivities.

## Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

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Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

Signed:

Date: 4/6/2021



## **Acknowledgements**

I am hugely indebted to my research supervisors, Dr Beth Parry-Jones, Dr Mike Jackson, and Dr Paul Gardner, who provided valuable guidance and support throughout this project. Thank you for sharing your time and expertise, and for your enduring commitment and enthusiasm.

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## **Word Count**

### **Main content of thesis:**

#### **Thesis Title**

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#### **Thesis Abstract**

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#### **Chapter 1: Literature Review**

Word Count without tables, figures and references: 7920

#### **Chapter 2: Empirical Study**

Word Count without tables, figures and references: 7923

#### **Chapter 3: Contributions to Theory and Clinical Practice**

Word Count without tables, figures and references: 3139

**Total for the main substance of thesis: 19,292**

### **References, tables, figures and appendices:**

#### **Chapter 1: Literature Review**

References: 1384

Tables, figures and appendices: 2687

#### **Chapter 2: Empirical Study**

References: 866

Tables, figures and appendices: 940

#### **Chapter 3: Contributions to Theory and Clinical Practice**

References: 568

Tables, figures and appendices: 0

**General Appendices: 9431**

**Total for references, tables, figures and appendices: 15,876**

# **Chapter One**

## **Literature Review**

A meta-ethnography of the lived experiences and perspectives of renal patients who have  
opted for conservative kidney management

Submission Guidelines for 'Qualitative Health Research' Journal:

<https://s3-us-west-2.amazonaws.com/clarivate-scholarone-prod-us-west-2-s1m-public/wwwRoot/prod1/societyimages/qhr/QHR%20Author%20Submission%20Guidelines.pdf>

**A meta-ethnography of the lived experiences and perspectives of renal patients who have opted for conservative kidney management**

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## **Abstract**

The perspectives of renal patients who have opted for conservative kidney management (CKM) are under-represented in research. This meta-ethnography (Noblit & Hare, 1988) aimed to develop the first known meta-synthesis of patients' experiences of living with CKM. PsycInfo, Web of Science, CINAHL and PubMed were searched following a study protocol [PROSPERO CRD42020218645]. Ten studies (identified within ten journal articles and one doctoral thesis) explored the cumulative experiences of 129 patients with advanced chronic kidney disease who had opted for CKM. Five key themes were identified, highlighting: diversity in CKM decision-making experiences; patients' perception of choosing CKM as defying societal norms and expectations; perceiving CKM as aligned with life stage and personal priorities; experiencing chronic kidney disease as uncertain and ambiguous; and strategies used to maintain continuity, including acceptance and present-moment living. Findings support CKM as an acceptable and preferred option enabling patients to maintain quality of life and continuity.

## **Key words**

conservative kidney management; end-stage renal disease; chronic kidney disease; patient experience; decision-making; meta-synthesis; meta-ethnography; qualitative

## **Introduction**

Patients with end-stage renal disease (Stage 5 Chronic Kidney Disease) rely on renal replacement therapies such as dialysis or kidney transplantation to survive. Increasing numbers of older people (aged 65 and above) are starting dialysis (US Renal Data System, 2017); however, survival advantages on dialysis have been found to be minimal, particularly for those over 75 who have comorbidities and poorer functional status (Murtagh et al., 2007; Chandna et al., 2011). Dialysis patients experience high disease burden (Davison, 2006) and older people are more likely to have comorbidities and age-related problems including frailty. As this may translate into reduced benefits for dialysis, conservative kidney management is increasingly considered a viable and preferable alternative (Burns, 2003).

Dialysis may not necessarily improve older people's quality of life. In a prospective study conducted in the Netherlands, a functional decline within 6-months of starting dialysis was observed in patients aged 65 and over (Goto et al., 2019). A Canadian survey of end-of-life preferences of patients with advanced chronic kidney disease found that 61% regretted starting dialysis, and that the choice to start dialysis more often reflected their doctor or family's wishes than their own (Davison, 2010). Dialysis, therefore, may not align with older patients' goals and values. Indeed, older patients with advanced kidney disease may prioritise maintaining independence over staying alive (Ramer et al., 2018). About 15% of people with advanced kidney disease do not initiate dialysis; these patients are likely to be older and to have comorbidities and higher dependence (NHS Improving Quality, 2015). For these individuals, conservative kidney management may better facilitate quality of life.

There is variation in terminology and a lack of consensus over what constitutes conservative kidney management. Terms such as 'conservative care' and 'maximum conservative care' are

common, however, so are the misleading terms ‘supportive care’ and ‘palliative care’, both of which are components of conservative kidney management (Murtagh et al., 2016). For this article, we use the recommended term ‘conservative kidney management’ to describe the “full supportive treatment for those with advanced kidney failure who, in conjunction with carers and the clinical team, decide against starting dialysis” (NHS Improving Quality, 2015). Conservative kidney management (commonly shortened to CKM) is holistic and multi-disciplinary, usually led by a nephrologist or specialist nurse, and incorporates all aspects of kidney care including medical, psychological, spiritual, and social care, apart from dialysis. CKM shifts the focus from prolonging life to providing supportive care, maintaining quality of life, protecting remaining kidney function, and managing symptoms. Across countries and regions, CKM varies in how well-established it is as a pathway and which components are routinely available. While inconsistency in terms and provision has limited research, evidence supports the benefits of CKM for older patients with end-stage renal disease. In a prospective study comparing self-reported quality of life in patients choosing dialysis or CKM, patients who started dialysis experienced a subsequent reduction in life satisfaction, while those who chose CKM maintained satisfactory quality of life (da Silva-Gane et al., 2012). Patients with multiple comorbidities have also maintained satisfactory quality of life on CKM (de Biase et al., 2008). Despite its benefits, nephrologists have reported reluctance to discuss CKM with patients (Ladin et al., 2018). In this US interview-based thematic analysis study, nephrologists reported equating CKM with ‘giving up’ or ‘no care’, and omitted to discuss CKM due to prognostic uncertainty, desire to preserve hope, and fear of upsetting patients. Such findings may reflect unease associated with a wider lack of understanding about CKM.

Research into treatment decision-making and end-of-life preferences of patients with advanced kidney disease is beginning to highlight what matters most to patients. Morton et al.’s (2010)

thematic synthesis of eighteen studies on patient and carers' perspectives on treatment decision-making for chronic kidney disease found that patients were generally more concerned about a treatment's impact on their quality of life than its potential for longevity. Major reasons for choosing CKM included an aversion to the lifestyle changes and potential burden to family members associated with dialysis. More generally, the synthesis suggested that peer influence, problematic timing of information about treatment options, and a desire to maintain the status quo heavily influenced patients' decision-making. The authors highlighted that existing studies more often focus on renal replacement therapies than CKM, therefore under-representing perspectives on CKM. More recently, Tong et al.'s (2014) thematic synthesis of 26 studies on patient and caregiver perspectives on end-of-life care in chronic kidney disease reported that patients experienced invasive physical and psychosocial suffering and psychological vulnerability. In making end-of-life care decisions, patients considered the treatment burden of dialysis and negotiated existential tensions around the perceived value and sanctity of life. Hesitance to discuss treatment preferences with doctors and loved ones due to fear of being misunderstood and ambivalence about prolonging life were reported. While illuminating, the review combined the views of patients on different treatment pathways, including pre-dialysis, dialysis and CKM. No qualitative systematic reviews have focused purely on the perspectives of renal patients who have opted for CKM.

Given the under-representation of patients who have opted for CKM in research, understanding of these patients' perspectives and subjective experiences of CKM is limited. A meta-synthesis providing insight into their experiences would help to identify patients' priorities and support needs to improve the end-of-life experiences of patients with end-stage renal disease. Therefore, the aim of this meta-synthesis was to answer the following research question: What



are the experiences and perspectives of renal patients who have opted for conservative kidney management?

## **Methods**

### *Rationale for meta-ethnography*

Noblit and Hare's (1988) meta-ethnographic approach was chosen for its potential to offer new conceptual insights while preserving the central ideas of original studies. Meta-ethnography aims to further understanding by generating novel interpretations across a specified set of studies, systematically drawing together and synthesising a body of qualitative research to create a "whole" greater than the sum of its parts (Noblit & Hare, 1988; France, Cunningham, & Ring et al., 2019). It has been successfully applied to wide-ranging areas of health psychology research (Campbell et al., 2011), and was considered most appropriate for synthesising renal patients' experience and perspectives on living with conservative kidney management.

The method and search process were based on eMERGe reporting guidance for meta-ethnography (France et al., 2019) and PRISMA guidelines (Moher et al., 2009). To improve transparency, the study protocol was pre-registered with PROSPERO, the international prospective register of systematic reviews [CRD42020218645].

### *Data collection*

A systematic literature search was performed on four electronic databases from their date of inception up until the date of the searches (7<sup>th</sup> December 2020): PsycInfo (ProQuest), PubMed, CINAHL (EBSCOhost), and Web of Science. This applied Boolean operators to combine key

search terms. Subject alerts were set up in databases to retrieve newly published articles (up until 14<sup>th</sup> May 2021).

Search strategies (see Table 1) and eligibility criteria (see Table 2) were developed following STARLITE standards for reporting literature searches (Booth, 2006). Search terms (see Table 3) were developed in consultation with a university librarian with specialist subject knowledge, SPIDER criteria (Cooke et al., 2012), and identification of key terms in known published articles on the topics of interest. Search terms were adapted for each database. The terms “non dialysis care”, “non-dialysis care” and “supportive care” were omitted after preliminary searches in Web of Science and PubMed retrieved no additional relevant articles. For holism, electronic databases ProQuest and EThOS were searched for unpublished doctoral theses (Conn, 2008; Paez, 2017).

**Table 1.** Sampling and search strategies using STARLITE standards for reporting literature searches (Booth, 2006)

<b>Element</b>	<b>Approach</b>
Sampling strategy	Selective: sampled 4 databases from nursing and allied health, life sciences and biomedical, psychology, and interdisciplinary fields; attempted to identify all relevant studies within specified limits
Type of study	Qualitative studies reporting primary qualitative data collection and analysis (including ethnography, narrative, phenomenological, grounded theory, and case study); published peer-reviewed research studies, or unpublished doctoral theses
Approaches	Electronic database searches; backward and forward citation chaining
Range of years	No restrictions: from inception to date of search (7 <sup>th</sup> December 2020); subject alerts also set up in all electronic databases to retrieve newly published articles (up to 14 <sup>th</sup> May 2021)
Limits	English full-text available; no restrictions on origin of study or date of publication; peer-reviewed if journal article
Inclusions and exclusions	See Table 2 for eligibility criteria
Terms used	See Table 3 for search terms
Electronic sources	CINAHL (EBSCOhost), PubMed, Web of Science and PsycInfo (ProQuest) for journal articles; ProQuest and EthOS for doctoral theses

**Table 2.** Eligibility criteria

<b>Element</b>	<b>Include</b>	<b>Exclude</b>
Sample	<p>Patients with advanced chronic kidney disease (stages 4 or 5) or end-stage renal disease who have opted for conservative kidney management (CKM); mixed samples such as patients and caregivers will be considered only where data clearly refers to patient experiences</p> <p>Adults; older adults (aged 18 years and over)</p>	<p>Renal patients not currently living with CKM (e.g. have yet to engage with or are currently engaged in decision-making processes regarding CKM); family caregivers; healthcare providers; mixed samples where it is not possible to extract findings derived from patients</p> <p>Children; adolescents (aged 17 years and under)</p>
Phenomenon of interest	Experience of living with CKM	Studies that do not address patients' experience of living with CKM in the context of end-stage renal disease; palliative care only; acute kidney injury
Methodology and Research type	Qualitative methods including ethnography, narrative, phenomenological, grounded theory, and case study; data collection including interviews and focus groups; studies reporting primary qualitative data collection and analysis; mixed-methods studies will be considered only if findings derived from qualitative data can be extracted	Methods whereby quantitative analyses are applied to texts (i.e. qualitative interpretations are not provided; studies lack sufficient transcript excerpts or analytic interpretation of findings); secondary research (i.e. analysis of pre-existing data, systematic reviews)
Evaluation	Research question addresses experiences, perceptions, perspectives, views, attitudes, beliefs, coping strategies of renal patients who have opted for CKM	Research question does not address these aspects
Setting	All settings considered, e.g. hospital (inpatient, outpatient), community, care home	No exclusions
Type of publication	Published peer-reviewed journal articles; unpublished doctoral theses	Non peer-reviewed documents; unpublished undergraduate or masters-level dissertations

**Table 3.** Final search terms

Database	Search Terms
PubMed (advanced search)	<p>renal or kidney (title/abstract)  AND  “conservative” or “conservatively” or “nondialytic” or “non-dialytic” or “without dialysis” (all fields)  AND  “qualitative” or “qualitatively” or “narrative” or “narratives” or “phenomenology” or “phenomenological” or “grounded theory” or “discursive” or “discursively” or “discourse” or “discourses” or “thematic” or “thematically” or “interview” or “interviews” or “interviewed” or “interviewing” or “interviewer” or “interviewee” or “interviewers” or “interviewees” or “focus group” or “focus groups” or “interpretative” or “interpretation” or “interpretations” or “ethnography” or “ethnographies” or “ethnographic” (all fields)</p> <p>Limits: English only</p>
CINAHL (EBSCOhost) (advanced search)	<p>renal or kidney (abstract)  AND  conservativ* or nondialytic or "non-dialytic" or "without dialysis" (all fields)  AND  qualitativ* or narrativ* or phenomenolog* or "grounded theory" or discursiv* or discourse* or thematic* or interview* or "focus group*" or interpretat* or ethnograph* (all fields)</p> <p>Limits: Peer-reviewed and English only</p>
Web of Science (basic search)	<p>renal or kidney (topic)  AND  conservativ* or nondialytic or "non-dialytic" or "without dialysis" (all fields)  AND  qualitativ* or narrativ* or phenomenolog* or "grounded theory" or discursiv* or discourse* or thematic* or interview* or "focus group*" or interpretat* or ethnograph* (all fields)</p> <p>Limits: English only</p>
PsycInfo (ProQuest) (advanced search)	<p>renal or kidney (abstract)  AND  conservativ* or nondialytic or "non-dialytic" or "without dialysis" (all fields)  AND  qualitativ* or narrativ* or phenomenolog* or "grounded theory" or discursiv* or discourse* or thematic* or interview* or "focus group*" or interpretat* or ethnograph* (all fields)</p> <p>Limits: Peer-reviewed and English only</p>

### *Search procedure*

Database searches and screening were conducted by the first author. After removing duplicate records, retrieved articles were screened by title and abstract to determine eligibility. Full-texts of potentially relevant articles were then retrieved and assessed for eligibility. A subset of articles were independently screened by the second and third authors at each stage, with discrepancies resolved through discussion.

Relevant studies were sought through backward and forward citation chaining, that is, reviewing the references of included studies and citations via Google Scholar's 'cited by' feature. Primary studies referenced in identified systematic reviews were also reviewed.

### *Analytic procedure*

Noblit and Hare's (1988) meta-ethnographic approach was used. This dynamic and iterative analytic process involved seven phases: 1) identifying a research interest, 2) determining relevant studies via a systematic search strategy, 3) repeated readings of studies, 4) determining how studies are related, 5) study 'translation', 6) synthesising translations, and 7) reporting the final synthesis.

Phases 1 and 2 identified the topic of interest and comprised the literature search outlined above. Phase 3 involved repeatedly reading studies in chronological order (earliest publication first) to aid engagement with the data and extracting study characteristics.

To identify relationships between studies, phase 4 began by extracting key themes, concepts and metaphors from studies in chronological order, as originally expressed by participants through interview quotes (first-order constructs), and by original authors through their

identification of key themes, concepts and metaphors (second-order constructs). Data were extracted from the ‘Findings’ sections of studies. Additional authors’ interpretations and contextual details were sought from ‘Discussion’ sections. This applied Britten et al.’s (2002) definitions, whereby themes are (descriptive) central ideas, concepts are (analytical) exploratory ideas, and metaphors are explanatory ideas involving figures of speech. Second-order constructs were visually mapped-out for each study in mind-mapping programme ‘MindNode’, using original authors’ phrasing or close paraphrases plus consideration of quotes to preserve the central ideas. Where studies included participants other than patients living with CKM, only data relating to patients living with CKM were analysed.

The aim of meta-ethnography is to develop ‘third-order constructs’ from original authors’ second-order constructs. Table 4 shows the definitions of first, second and third-order constructs used, based on guidance by Noblit & Hare (1988), Britten et al. (2002) and Malpass et al. (2009).

**Table 4.** Definitions of first, second and third-order constructs

<b>Order</b>	<b>Definition</b>
First-order construct	Renal patients’ perspectives, experiences and interpretations of chronic kidney disease and CKM (as expressed in raw transcript excerpts)
Second-order construct	Original authors’ perspectives, interpretations and understanding of renal patients’ views of chronic kidney disease and CKM (as indicated by key themes, concepts and metaphors)
Third-order construct	Reviewers’ perspectives and interpretations (as indicated by key themes and concepts)

In phase 5, translation of studies employed a constant comparative approach, whereby second-order constructs within a study were compared in turn to one another, and interactions of these

between studies were identified, while maintaining original central ideas. ‘Reciprocal’ translation was used, where similar or complementary interpretations across studies were grouped together. ‘Refutational’ translation was considered where contradictions or disagreements in interpretations across studies were identified. Second-order constructs were again visually mapped-out and grouped in MindNode.

In phase 6, a ‘line of argument’ synthesis was employed to provide further analysis and interpretation, integrating similarities and differences across studies to form a novel conceptual framework. ‘Third-order constructs’ across studies were developed in MindNode. The final synthesis was reported in phase 7, as the ‘Meta-synthesis findings’ section.

### *Researcher reflexivity*

The lead researcher is a trainee clinical psychologist with experience working in clinical health settings, where biomedical approaches are commonly used. Clinical Psychology training often applies a biopsychosocial approach to illness, health and well-being, and in particular considers the interaction of psychological, social, developmental and contextual factors. It is recognised that this training, along with the researcher’s personal contexts and fluctuating subjectivities, will influence the research process throughout, particularly data analysis. Researcher reflections, biases and assumptions were recorded throughout the process to make explicit (as far as possible) the lenses through which interpretations were made.

## **Results**

### *Search outcome*

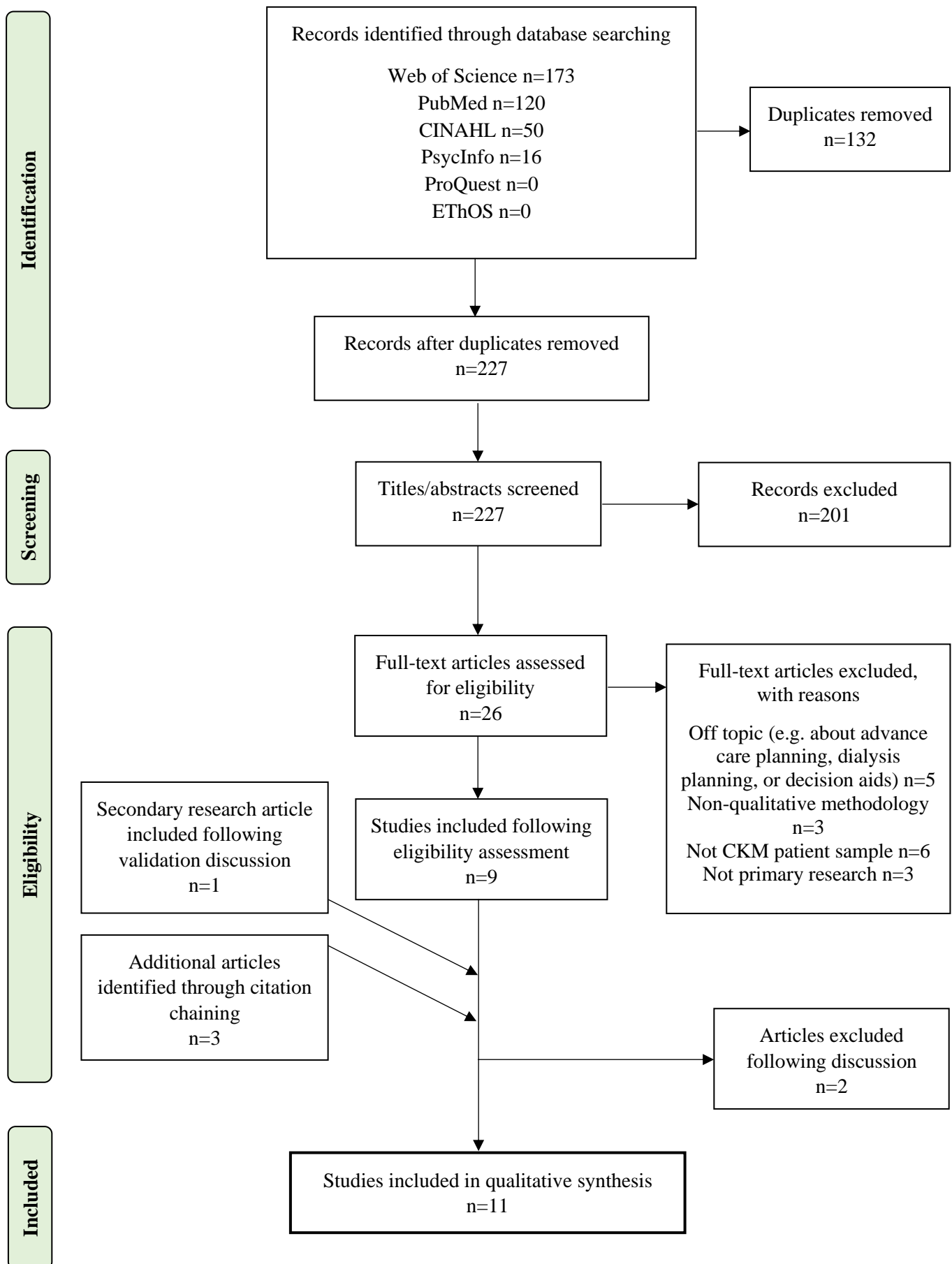
Eleven articles were included in the final meta-synthesis, comprising ten published peer-reviewed journal articles and one unpublished doctoral thesis (see Figure 1 for PRISMA flow



diagram). After removing duplicates, 227 retrieved articles were screened by title and abstract to determine eligibility. A subset of 22 abstracts independently screened by the second author resulted in full agreement. 26 full-text articles were then retrieved and assessed for eligibility, of which, nine articles met eligibility criteria. A subset of 25 full-text articles independently screened by the third author resulted in agreement with 24 articles. The contended article (Bristowe et al., 2019), initially excluded for reporting secondary analysis of pre-existing data, was discussed and subsequently included as it reported a thematic analysis of in-depth qualitative interviews directly related to patients' experience of CKM, not published elsewhere.

Citation chaining retrieved two additional journal articles and one unpublished doctoral thesis. As the thesis reported on two already-identified published articles in significantly more detail, it was agreed to exclude these two articles in favour of the thesis. No other doctoral theses were identified.

**Figure 1. PRISMA (2009) Flow Diagram**



### *Quality appraisal of included studies*

The first and third authors independently appraised the quality of studies using the ten-item Critical Appraisal Skills Programme (CASP, 2014) (see Table 5). Following discussion, there was a moderate level of agreement (102:8 ratio for agreements to disagreements, the unresolved incidences falling on items 6, 7, and 8). All studies were considered satisfactory in quality, however, most failed to explicitly consider the relationship between researcher and participants, while consideration of recruitment strategy and ethical issues were inconsistently reported. For example, reasons for non-participation were commonly omitted. Understanding non-participation is pertinent for this population who, due to factors such as limited prognosis and high symptom burden, may face greater barriers to research participation. No studies were excluded based on quality appraisal.

### *Demographic characteristics*

This meta-synthesis reports the cumulative experiences of 129 patients with advanced kidney disease who have opted for conservative kidney management. Study publication spans ten years (2009-2019). Two articles (Selman, 2019; Bristowe, 2019) report data from the same participants and interviews conducted in 2007, therefore demographic data are reported from Selman (2019) only, and the following demographics are based on ten studies (see Table 6).

Five studies were conducted in the UK, two each in Singapore and Australia, and one in the Netherlands. Nine studies recruited from hospital-based renal units, one from a university medical centre. Five studies recruited patients on CKM only, while five recruited combinations of patients on CKM, patients on pre-dialysis or dialysis pathways, and/or caregivers.

117 participants had end-stage renal disease, twelve had advanced kidney disease. Participants had a collective age range of 61–96 years old. Nine studies reported data on the sex of participants, of which 54 were female (47%) and 61 were male (53%). Four studies reported ethnicity data, of which one reported White majority, two reported Chinese majority, and one reported joint White and Afro Caribbean majority. Two studies reported length of time on CKM: mean=21 months [range 1–40 months] (Llewellyn, 2014), and median=11 months [inter-quartile range 9–31] (Tonkin-Crine, 2015).

### *Meta-synthesis findings*

Articles from this point on are referred to by their ‘study number’, as indicated in Table 6. Ten articles reported on patients’ experiences of CKM decision-making and/or reasons for opting for CKM. Seven articles reported on the experience of living with chronic kidney disease and/or CKM. Table 7 sets out the five themes (third-order constructs) generated by the synthesis.

**Table 5.** CASP qualitative checklist for the meta-synthesis

*Demonstrating how each study addresses the CASP qualitative checklist (2014) quality aspects*

Study	CASP Checklist Questions									
	1 Was there a clear statement of the aims of the research?	2 Is a qualitative methodology appropriate?	3 Was the research design appropriate to address the aims of the research?	4 Was the recruitment strategy appropriate to the aims of the research?	5 Was the data collected in a way that addressed the research issue?	6 Has the relationship between researcher and participants been adequately considered?	7 Have ethical issues been taken into consideration?	8 Was the data analysis sufficiently rigorous?	9 Is there a clear statement of findings?	10 How valuable is the research?
<b>Noble (2009)</b>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Visser (2009)</b>	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓
<b>Johnston &amp; Noble (2012)</b>	✓	✓	✓	✓	✓	?	✓	✓	✓	✓
<b>Llewellyn (2014)</b>	✓	✓	✓	?	✓	✗	✓	✓	✓	✓
<b>Moustakas (2015)</b>	✓	✓	✓	?	✓	✗	✓	✓	✓	✓
<b>Seah (2015)</b>	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
<b>Tonkin-Crine (2015)</b>	✓	✓	✓	?	✓	✗	✗	?	✓	✓
<b>Hoffman (2017)</b>	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
<b>Selman (2019)</b>	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
<b>Bristowe (2019)</b>	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
<b>Han (2019)</b>	✓	✓	✓	✓	✓	?	✓	✓	✓	✓

Key:

(✓) indicates that the study was assessed as possessing the specified quality aspect

(✗) indicates that the study was assessed as lacking the specified quality aspect

(?) indicates that it was not possible to sufficiently assess whether the study possesses the specified quality aspect

**Table 6.** Studies included in the meta-ethnography

Study Number	Authors, Year, Publication Type and Location	Study Population and Setting	Reported Method of Sampling	Sample Characteristics	Reported Method and Methodology	Reported Study Aim
1	Noble, 2009  Unpublished doctoral thesis  UK	30 renal patients with stage 5 chronic kidney disease who had opted not to undergo dialysis (i.e. had chosen supportive care), and 19 carers  'Renal Supportive Care Service' renal unit in London	All eligible patients and carers invited until theoretical saturation reached	Relevant sample n=30  18 females, 12 males  Majority of patients older and over age 70 years. Median age = 78 (range=65-91)  12 White (including 2 from Greece), 12 Afro Caribbean, 4 Bangladeshi, 1 Indian, 1 Pakistani  20 lived with carers, 4 lived with carers who were also sick, 5 lived alone with little input from friends and family, 1 in a nursing home  29 had one or more comorbidities	Semi-structured interviews during "naturally occurring clinical consultations" (some with carers present)  Prospective longitudinal practitioner research study based on "subtle realism" and interpretative paradigm. "Rigorous qualitative analysis" (de Wet & Erasmus, 2005), constant comparative method (Miles & Huberman, 1994), and grounded theory	To explore the experiences of patients with stage 5 chronic kidney disease who had opted not to undergo dialysis to treat their renal failure
2	Visser, Dijkstra & Kuiper et al, 2009  Journal article  The Netherlands	6 patients with end-stage renal disease who had declined dialysis (defaulting to conservative treatment), and 8 patients with end-stage renal disease who had opted for dialysis  Renal failure outpatient clinic or dialysis centre of a university medical centre	Purposive sampling	Relevant sample n=6  1 female, 5 males  Mean age=82.5 years $\pm$ 6.0  2 married/living together, 4 widowed  4 had children, 2 did not	"In-depth" interviews  Qualitative analysis, not otherwise specified – "themes were identified and discussed until agreement was reached"	To explore the considerations taken into account by patients aged 65 years and older with respect to the question of whether or not to start dialysis treatment

Study Number	Authors, Year, Publication Type and Location	Study Population and Setting	Reported Method of Sampling	Sample Characteristics	Reported Method and Methodology	Reported Study Aim
3	Johnston & Noble, 2012  Journal article  UK	9 patients with stage 5 chronic kidney disease who had opted for conservative management  chronic kidney disease clinics in a renal unit in an acute NHS Trust	All 10 eligible patients invited	Relevant sample n=9  5 females, 4 males  Mean age=86 years (range 74-96)	Semi-structured interviews during “naturally occurring clinical consultations”  Practitioner research study. Qualitative analysis based on constant comparison (Glaser & Strauss, 1967) and grounded theory	To explore patients’ decision-making when opting for conservative management including the patients’ experiences of their decision-making and the role they felt they adopted during that process
4	Llewellyn, Low & Smith et al., 2014  Journal article  UK	19 patients with stage 5 chronic kidney disease on CKM  4 specialist renal clinics in London	Purposive sampling	Relevant sample n=19  7 females, 12 males  Age range=73-94 years  All had several co-morbid chronic conditions	Semi-structured interviews (independent interpreters used for 3 interviews)  Qualitative analysis based on analytic perspectives of phenomenology (Desjarlais & Throop, 2011; Strauss & Corbin, 1998); themes and patterns identified, data analysed narratively, temporal sequencing of themes explored	To examine the lived experiences of older people with chronic kidney disease receiving CKM
5	Moustakas, Bennett & Tranter, 2015  Journal article  Australia	6 patients with advanced chronic kidney disease who had chosen supportive care  2 major metropolitan hospitals in Sydney	Purposive sampling	Relevant sample n=6  2 females. 4 males  Age range=73-87 years  All married  Range eGFR=12-15 ml/min/1.73 m <sup>2</sup>	Semi-structured interviews (with spouses or family members present) and medical case notes review  Mixed methods case study approach. Qualitative thematic analysis (Braun & Clarke, 2006)	To explore the education and information needs of people who have chosen supportive care

Study Number	Authors, Year, Publication Type and Location	Study Population and Setting	Reported Method of Sampling	Sample Characteristics	Reported Method and Methodology	Reported Study Aim
6	Seah, Tan & Srinivas et al., 2015  Journal article  Singapore	9 patients with end-stage renal disease who had opted to forgo dialysis (defaulting to conservative non-dialytic management)  Renal departments of 3 public hospitals	All eligible patients invited, targeting 7-9 participants	Relevant sample n=9  4 females, 5 males  Median age=82.6 years (range=61-84)  All from a Chinese background	Semi-structured interviews (translator used for one interview)  Cross-sectional qualitative study. Interpretative phenomenological analysis (IPA)	To examine patients' decision-making process and reasons for declining dialysis, their beliefs and feelings of the value and impact of conservative management in a local context
7	Tonkin-Crine, Okamoto & Leydon et al., 2015  Journal article  UK	14 patients with chronic kidney disease on conservative management, 14 patients with predialysis chronic kidney disease, and 14 patients with chronic kidney disease on dialysis  9 renal units	Purposive sampling until data saturation reached	Relevant sample n=14  Characteristics based on all 42 patients, reported not to differ substantially between groups  67% males  Mean age=82 years (range=74-92)  90% White British  57% had a partner with whom most lived (52%), 33% lived alone, 6% lived with children, 2% lived with friends, 4% lived in a care home	Semi-structured interviews (some with family members present)  Qualitative thematic analysis	To explore the experiences of older adults who had made a decision between different treatments for chronic kidney disease stage 5
8	Hoffman, Tranter & Josland et al., 2017  Journal article  Australia	12 patients with advanced chronic kidney disease who had chosen conservative management and were attending a renal supportive care clinic, and 11 of their family/carers  A major renal service in Sydney	Not stated; until data saturation reached	Relevant sample n=12  6 females, 6 males  Mean age=84 years (range=77-91)  2 lived alone, 8 lived with spouse/partner, 2 lived with daughters in family home	Semi-structured interviews; where possible, follow-up interview 6 months after based on same questions  Case study approach. Qualitative thematic analysis (Braun & Clarke, 2006)	To gain a greater understanding of the experiences of patients and their carers/families within a renal supportive care service



Study Number	Authors, Year, Publication Type and Location	Study Population and Setting	Reported Method of Sampling	Sample Characteristics	Reported Method and Methodology	Reported Study Aim
9	Selman, Bristowe, Higginson & Murtagh, 2019  Journal article  UK	20 patients with stage 5 chronic kidney disease who had made a decision for conservative management and were being conservatively managed  3 renal units at hospitals with conservative management services in London and South-East England	Purposive sampling until data saturation reached	Relevant sample n=20  9 females, 11 males  Median age=82 years (range=69-95)  18 White British, 1 Afro-Caribbean, 1 Other ethnicity  8 married, 9 widowed, 3 single  Median eGFR=12.3 ml/min/1.73 m <sup>2</sup> (range 6.5-14.9)	Cross-sectional, semi-structured qualitative interviews (some with spouses or family members present)  Part of a longitudinal study. Subtle realist paradigm. Inductive thematic analysis	To explore views and experiences of communication and information provision among patients with ESKD receiving conservative care, and their views of the treatment decision
10	Bristowe, Selman & Higginson et al., 2019  Journal article  UK	As in Selman (2019)	As in Selman (2019)	As in Selman (2019)	Method as in Selman (2019)  Secondary analysis of qualitative interviews. Inductive thematic analysis	To explore the experiences of older adults living with kidney disease that was being managed conservatively to examine: the impact of their illness, including the impact over time; and their understanding of the illness to inform clinical practice and policy
11	Han, Haldane & Koh et al., 2019  Journal article  Singapore	4 patients with end-stage renal disease on conservative management, 7 patients with end-stage renal disease on peritoneal dialysis, 5 patients with end-stage renal disease on haemodialysis, and 7 of their caregivers  Country's largest tertiary hospital	Purposive sampling to recruit patients, snowball sampling to recruit caregivers	Relevant sample n=4  2 females, 2 males  Age range=71-80 years  All Chinese	Semi-structured dyadic interviews (patient and caregiver)  Qualitative inductive and deductive thematic analysis, based on grounded theory and constant comparative method	To explore perspectives on decision making amongst older Singaporean patients with end-stage renal disease and their caregivers

**Table 7.** Representation of third-order and second-order constructs

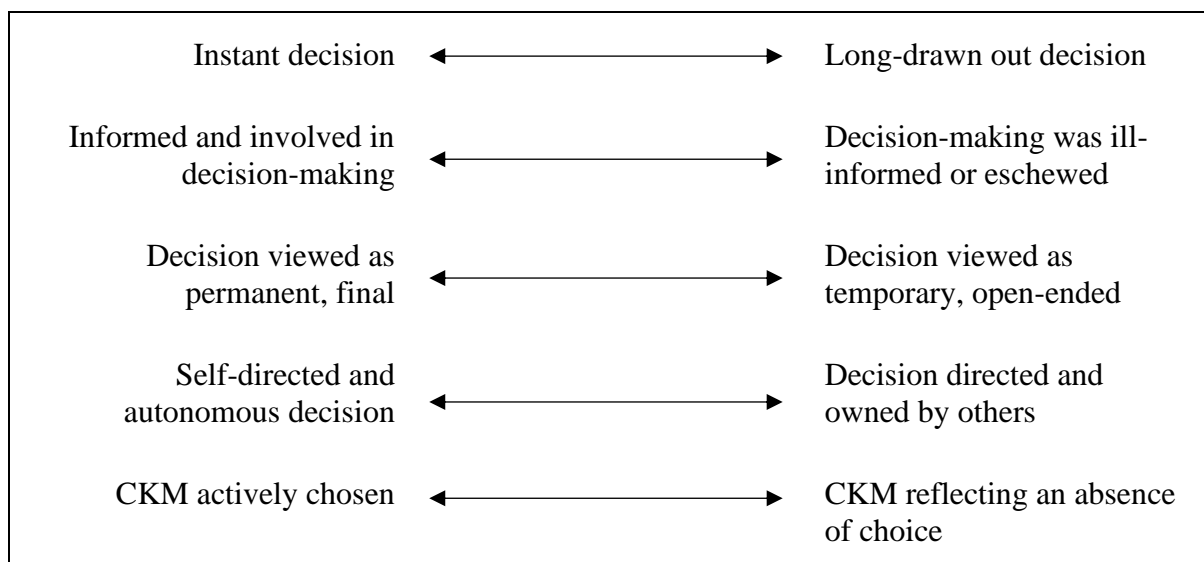
Domain	Third-order Construct	Second-order Construct	Contributing Studies
Experience of CKM decision-making and reasons for opting for CKM	1. The diversity of CKM decision-making	1.1. An autonomous decision	1, 2, 3, 4, 6, 7, 8, 9, 11
		1.2. The less informed or absent decision	1, 2, 3, 9, 11
	2. Choosing CKM goes against societal norms and expectations	2.1. Discussing the decision with others	1, 3, 4, 5, 6, 8, 9, 11
		2.2. Feeling pressured to start dialysis	1, 3, 4, 6, 7, 9, 11
		2.3. Patient-staff communication and information needs	3, 4, 5, 6, 7, 8, 9
	3. CKM offers congruence with life stage and personal priorities	3.1. Too old for dialysis	1, 2, 3, 5, 6, 7, 9
		3.2. Dialysis as reducing quality of life	1, 2, 3, 4, 5, 6, 7, 8, 9, 11
		3.3. Fear of becoming a burden	1, 3, 5, 6, 7, 8, 9, 11
Experience of living with chronic kidney disease and CKM	4. Chronic kidney disease as an ambiguous and amorphous entity	4.1. Invisibility and intangibility of chronic kidney disease	1, 4, 7, 9, 10
		4.2. Uncertainty and waiting to die	1, 4, 6, 8, 9
		4.3. Symptom burden and impact	1, 4, 10
	5. Maintaining personal continuity	5.1. Illness as an accepted consequence of old age	1, 4, 6, 8
		5.2. Experience of CKM	3, 4, 6, 8, 9, 10
		5.3. Not thinking or talking about illness and death	1, 4, 6, 8, 9
		5.4. Living in the here and now	1, 4, 6

## *Experience of conservative kidney management (CKM) decision-making*

### *1. The diversity of CKM decision-making*

CKM decision-making was idiosyncratic and diverse, aspects of which existed on distinct but intersecting continuums (see Box 1). Decision-making formed any combination of these aspects; experiences falling on either end of continuums did not necessarily confer more or less satisfaction or ease with the decision. While most patients saw themselves as having made an autonomous, informed and active choice for CKM, others, for example, viewed the decision as having been made by their clinicians, or otherwise perceived having no choice.

**Box 1.** The diversity of CKM decision-making, as it exists on multiple continuums



#### *1.1. An autonomous decision*

Most patients took personal responsibility for choosing CKM, presenting themselves as the final decision-maker even if they consulted with others (1, 3, 6, 8, 9, 11). Patients largely reported making informed and autonomous decisions, being fully involved and self-directed in their decision-making.

Choosing CKM was sometimes framed as a decision against dialysis, therefore perceptions of dialysis influenced decision-making (9). Some patients rejected dialysis almost instantly, sometimes before receiving dialysis information (1, 2, 6): “Well, the doctor did encourage me to go on dialysis, but I said ‘no’ I knew from the start that I did not want to go through dialysis if my kidneys ever failed” (6; p.1022). Others experienced the decision as long-drawn out and open-ended, alongside moments of reaffirmation of their choice (4). A minority viewed CKM as not an active choice, but a rejection of dialysis or intermediate step before dialysis (11).

Patients felt satisfied or comfortable with their decision (6, 8). While they generally stood by their decision to forgo dialysis, they felt empowered to change their minds later (4, 7), for example, if they “got really ill”, indicating a perception of CKM as a temporary choice that could change with deteriorating health (7; p.447).

### *1.2.The less informed or absent decision*

Some patients appeared to have made less informed decisions for CKM, or else reported having no choice (1, 2, 3, 11). A reluctance to consider the future or possibility of dialysis led some to experience initial doubts about declining dialysis, or conversely, great relief: “When you commit yourself to dialysis, it pretty much occupies you everyday; one day you go to the hospital, the following day you are already anticipating your next visit. I don’t like that. I even don’t want to consider whether the decision is ‘right’ or perhaps ‘wrong’ since I then have to live my life accordingly.” (2; p.797). Two patients with cognitive difficulties opted for CKM believing this would achieve similar outcomes to dialysis (1). Some patients felt that their clinicians either chose CKM for them or did not believe dialysis would benefit them, and consequently felt unhappy, uneasy or angry about the decision (1). Some appeared to accept their doctor’s (sometimes personal) recommendation unquestioningly, but were happy with the

advice offered (1, 3). Feeling low or depressed around the time of decision-making was associated with having initial doubts, being medically advised against dialysis, being clinically ineligible, or feeling that clinicians had poorly communicated why dialysis was unsuitable, though one patient preferred that her doctor decided for her as she no longer felt solely responsible (9).

## *2. Choosing CKM goes against societal norms and expectations*

Clinical practice and societal norms and values appeared biased towards extending life via dialysis. Through interactions with clinicians and family members, patients received messages (sometimes inadvertently) that their choice for CKM defied widely-accepted norms, potentially undermining perceptions of support around decision-making.

### *2.1. Discussing the decision with others*

Patients consulted with family members before or after coming to a decision and found them mostly supportive (3, 5, 6, 8, 9), though one reported resistance: “My wife wanted me to have it, she said, ‘You’ve got to have it [dialysis], you just can’t not have it.’ But I told her, it’s up to me, and I want to live ‘til I die, not stop in a taxi or sat in the waiting lounge half my life.” (9; p.8). Having family approval reinforced people’s decisions and offered reassurance that they would be supported in the future and that family wellbeing and harmony would be maintained (6). Clinicians’ recommendations reassured patients and influenced some (but not all) patients’ decision-making (1, 3, 8, 9).

### *2.2. Feeling pressured to start dialysis*

Conversations about dialysis dominated early experiences of chronic kidney disease. Patients reported being guided towards dialysis, the possibility of non-dialysis management being

unclear or sometimes not mentioned at all (3, 4, 7): “I didn’t know I had any options. I was told ‘you are going to be on dialysis, you have to have a fistula’. It didn’t dawn on me I didn’t have to have it... I was making myself ill thinking about it and then somebody said to me something about conservative management. But I hadn’t really taken that in because everyone in the medical profession said ‘YOU WILL BE ON DIALYSIS’ and I didn’t query it.” (4; p.52).

Feeling pressured to start dialysis (1, 3, 6, 9, 11), or fear of being coerced into dialysis (1) was commonly reported. Patients felt that clinicians, family and friends saw dialysis as best practice; they spoke as if choosing CKM placed them in an oppositional stance and challenged the ‘norm of dialysis’ (4 [p.55], 7). Some were strongly encouraged or persuaded by clinicians and family members to undergo dialysis (6, 11). This contributed to pressure to change their minds and reluctance to approach clinicians for decision-making support (6).

### *2.3. Patient-staff communication and information needs*

Patients received information mainly from renal nurses, supportive care or palliative care nurses and nephrology consultants (9). While they generally reported positive experiences with care co-ordination, medical consultations and access to information during decision-making, areas of poor communication were identified (3, 4, 5, 6, 7, 8, 9).

Patients usually received information about dialysis but not CKM, so chose CKM based on dialysis information (5). They had little impression of the subjective experience and impacts of dialysis (3). Patients from units with more (compared to less) established CKM pathways were more likely to believe that dialysis did not guarantee longer life (7). Patient-staff conversations around future deterioration and death trajectory were rare (7, 9), even for those on more-established CKM pathways, and patients rarely reported having discussed end-of-life

arrangements (4, 5, 7). Patients found that renal clinicians avoided, delayed, or struggled to have conversations about key issues including chronic kidney disease diagnosis and disease progression, creating uncertainty and worry about the future: "...if I ask something more... difficult [pause] ...like what's going to happen to me when... that, they don't know the answer to... but they don't always say." (9; p.6).

Patients' information needs and preferences were nuanced and evolved over time, they wanted staff to share unambiguous information proactively, while remaining sensitive, honest and personal (9). People desired information about their renal disease and treatment options, though some were ambivalent or against receiving prognostic information (9). While patients considered forgetfulness a challenge to retaining information, they also encountered clinicians being insensitive or brusque: "[Name of nephrologist] himself when I was still in the hospital, he said 'If you're still here in a few weeks or a few months, then I would be gobsmacked' he said, not a phrase we liked, 'If it lasted a year I would be surprised' would be better." (9; p.4). Use of unfamiliar technical language and abstract descriptions such as "percentage kidney function" confused people (4; p.52).

### *3. CKM offers congruence with life stage and personal priorities*

The choice for CKM was influenced by a complex interaction of personal values, beliefs and feelings towards life, death and suffering, potential risks or challenges of incorporating dialysis into lifestyles, and wider contextual and organisational factors including developmental life stage, cultural norms and values, and healthcare provision and policies.

### *3.1. Too old for dialysis*

The perception of being too old for dialysis was a common reason for choosing CKM (1, 3, 5, 6, 7). Patients saw dialysis as something to be avoided at their age (1, 5, 7), considering comorbidities (1, 3). They wanted to “let nature take its course” (3; p.1218). Having already lived a good and long life, they did not see dialysis extending life and accepted nearing the end of their natural lifespan (1, 2, 6, 9). Pragmaticism about the inevitability of approaching death (3, 6), plus a strong sense of life completion and of having achieved their life goals, was associated with contentment and reduced death anxiety: “I said no [dialysis], die never mind [sic], I’ve seen everything already, my children have grown up, my grandchildren. God has given me everything already, that’s more than enough” (6; p.1023). Patients also cited age-related loss of vitality, significant discrepancy between former and current lives, and dialysis being a disruption too far: “...dialysis is a trouble to go through, it is just a way to postpone death... I am already too weak, in particular physically. I am worn out!” (2; p.797). Indeed, some would have considered dialysis if they had been younger, healthier, or their spouse had been alive (2, 3, 9).

### *3.2. Dialysis as reducing quality of life*

Evaluating the relative advantages and disadvantages of dialysis, patients viewed CKM as maintaining status quo and quality of life, and dialysis as reducing quality of life (1, 3, 5, 7, 8, 9). Patients wanted to live as long as possible but not at any price (2).

Dialysis was seen as an arduous and onerous treatment (1, 3, 4, 6): “That’s no life at all, dragging up there three days a week four hours a time. It must drain you for the rest of the day. At least half the week or more you’re absolutely knackered” (4; p.52). Patients viewed dialysis as disruptive, invasive, constraining, and time-wasting (4, 5, 6, 7, 9), while CKM offered



continuity, requiring no changes to daily routines (4, 5). Patients believed dialysis would reduce their autonomy, freedom and time in the present (1, 2, 3, 4, 11). They did not want to depend on a machine to live (1, 2, 4). Avoiding the stress of daily medical treatment and living day-by-day, doing things they enjoyed at home with family was preferred (2, 5, 9): “Not at my age... it is better to go with all your dignity, doing things your way, not with tubes and machines and other people dictating... it makes it all on their terms, not my terms.” (9; p.8). Having satisfactory current health status, feeling well, and not being in severe pain meant some felt no need for dialysis, or questioned the seriousness of their illness (1, 2, 7).

Patients feared dialysis, their depictions including imagery of “snakes” and “monsters” (4; p.52). They were concerned about dialysis being unsafe (6) or shortening their lives (1), and potential suffering through infections and pain (5, 6, 11). Many based their perception and rejection of dialysis on seeing friends, peers and family suffer or die on dialysis (1, 2, 4, 5, 6, 11). Patients had observed the trauma and domestic upheaval associated with dialysis: “I have heard of others going through dialysis for a while, but they give up on it too. They stopped their dialysis treatment... they gave up because they couldn’t tolerate the pain. It was too painful... it’s a very painful process and it makes me scared after listening to it” (6; p.1024). One patient saw dialysis as worse than death: “I’ve seen many people here in wheelchairs who keep drooling and need people to feed them; to be honest it’s better to die than to lead such a life. What is the point of prolonging such a life?” (11; p.1106). Biased accounts from media, hearsay, and lay stories significantly contributed to negative impressions before people received dialysis education from clinicians (6).

Difficulties and impacts of travelling to hospital for dialysis influenced decisions (1, 2, 3, 5, 7, 9). Patients lived too far from dialysis centres and considered hospital transport to be time-consuming and tiring. They did not want to rely on family or friends for transport.

### *3.3. Fear of becoming a burden*

The fear or unacceptability of becoming a burden on family (1, 3, 6, 8, 11) or state healthcare resources (7, 9) was a common reason to reject dialysis. Patients did not want to place caregiving obligations on their family. They wanted to remain independent (5, 8) and feared becoming dependent (11). In Singapore, where families are required to contribute towards treatment costs, patients considered dialysis a family burden affecting the whole family's wellbeing and resources (6, 11): "If I go on dialysis, I will be a burden to my entire family. I rather not be a burden... their livelihood will be impacted... my son just got married, so I don't want to be a burden to him" (6; p. 1024). Given the potential to cause emotional stress and disrupt family routines, these patients chose self-sacrifice for the common good of the family (6).

## *Experience of living with chronic kidney disease and CKM*

### *4. Chronic kidney disease as an ambiguous and amorphous entity*

Separating the impacts of chronic kidney disease from the impacts of advanced age and existing comorbidities was challenging due to the ambiguous and amorphous nature of the disease. Deterioration and death were expected yet impossible to predict, contributing to uncertainty and a sense of lacking control.

#### *4.1. Invisibility and intangibility of chronic kidney disease*

An inability to perceive the effects of chronic kidney disease due to its lack of bodily expression through symptoms created challenges in attributing symptoms to the disease; patients felt they were ‘in the grip of something unseen’ (1, 4, 7, 10): “Like there’s something bubbling along in your blood that you don’t know quite what it will do, and you can’t see it.” (10; p.4). Chronic kidney disease was insidious and ambiguous, creeping up on people undetected (4). Patients described being asymptomatic or else losing the effects of the disease amongst symptoms of pre-existing conditions or old age: “it’s all related” (4; p.53). Their experience seemed incongruent with having a life-threatening disease, leading some to question the validity of their diagnosis (4, 7, 10). One patient described being ‘in the hands of a mystery’ as both they and renal clinicians struggled to identify the cause of symptoms (9; p.7).

For those with less troublesome comorbidities, chronic kidney disease diagnosis had little impact on quality of life as there were few reminders of the illness (1). For others, the “invisible” and “intangible” nature of the disease created a sense of ‘disconnect’; patients struggled to make sense of this unpredictable and formless disease, constructing it as having agency and control over their bodies (10). Compared to more ‘visible’ illnesses, people with chronic kidney disease had “nothing to show for it” (10; p.4), thus undermining their access to a ‘sick role’ with its rights and obligations: “With my kidneys... it’s, well... it’s hard to say, I just feel tired and no energy, and generally not myself, all vague and sounds like I’m just... complaining or something. Making a fuss about nothing [laughs]” (10; p.5). Chronic kidney disease challenged people’s sense of self and control, and ability to plan and engage in daily activities (10).

#### *4.2. Uncertainty and waiting to die*

Chronic kidney disease came with an uncertain prognosis. Patients had to learn how to live with not knowing when deterioration or death would come. One patient described organising his life around a poor prognosis, selling his clothes and furniture, before outliving this (1). People did not know what the decline would feel like or whether it would be painful, and one patient reported struggling to find a clinician who would discuss the final weeks: “I have absolutely no idea. I don’t know if it is peaceful, if you are sleeping or awake, or if you are in agony. But I haven’t found anyone to actually tell me what happens at the end. It may be that they don’t like talking about it or it might be that no one has training for it.” (4; p.54). Patients discussed waiting to die or at least waiting for deterioration (8). ‘Waiting to die’ was considered a normal part of ageing, though having a terminal disease changed the usual abstract concept of death associated with natural ageing as this signalled a concrete ‘end point’ (8; p.105).

While some expressed no distress about their current condition or future deterioration (6), others found the continued uncertainty of disease progression significantly disrupted their lives and familial relationships, contributing to unhappiness, depression and worry (1, 4, 9).

#### *4.3. Symptom burden and impact*

High symptom prevalence attributable to chronic kidney disease or comorbidities was reported (1). Patients commonly experienced: lethargy, fatigue (1, 4, 10), extreme weakness (4, 10), breathlessness, nausea, vomiting, bitter tastes, pain, bowel or bladder problems, oedema (1, 4), pruritis, insomnia, immobility (1), sores, infections, and emergency hospital visits (4).

Patients struggled to articulate the physical impact of kidney disease beyond tiredness or fatigue, but described being held down by a weight, and “lifelessness” (10; p.5). The effects of

illness were pervasive, impacting on all aspects of life and exacerbated by unpredictability. Patients could not predict deterioration from one day to the next as it typically came on suddenly: “The worst of it is, I never quite know how I’m going to be. Sometimes I can get up and I’ll be fine, it will be a good day, and that will carry on for a bit, and then out the blue, it all goes, like I’ve run out of petrol or something, and there’s nothing in the tank. I can feel unwell for days then, but I never really know why it’s like that” (10; p.5). Patients experienced their illness as debilitating and reported frustration, loss of independence, fear, distress, anxiety, stress, depression, isolation, and loneliness (1, 10): “It has affected me terrible [sic]. Yes, you know. Nothing is the same... I don’t have the strength or the energy anymore, it makes me feel useless” (10; p.5).

Patients avoided taking analgesia due to a belief that they were already taking too many tablets; they feared causing further kidney damage and did not trust clinicians’ advice (1). Patients also declined counselling or anti-depressants for depression, believing their problems could not be resolved by health professionals (1).

## *5. Maintaining personal continuity*

Patients accepted that life was coming to an end and wanted to live this limited time on their own terms. They maintained personal continuity by normalising and incorporating illness into personal narratives of old age, adjusting their expectations and staying focused on the present.

### *5.1. Illness as an accepted consequence of old age*

Adjustment involved making sense of chronic kidney disease in the context of current life stage and comorbidities (1, 4, 6). Following initial shock, patients moved into a relatively stable phase combining acceptance, resignation and stoicism (4, 6). Having relinquished their

independence and former lifestyles long ago to advanced age and other illnesses, patients adopted a new conceptualisation and state of health, normalising changes to their functioning and family and social life, and modifying their expectations of the future to accommodate the constraints of illness (4, 6). Chronic kidney disease was seen as ‘just another illness among many’ and patients accepted and normalised illness as the embodiment and inevitable consequence of old age: “As you get older you get things wrong with you. I don’t know many old people who haven’t got something wrong with them. Your body wears out and if you don’t accept it as it comes you’ll make yourself miserable” (4; p.52-53). Patients accepted that death was coming, regardless of kidney disease (1).

Patients tried to maintain a sense of normality (8), despite symptoms and illness intruding into their lives and destabilising their routines (4). Such episodes were frightening and reminded them of their poor health and uncertain future, which otherwise would be ignored or forgotten. However, they stayed positive by framing these as discrete episodes that accompany long-term illness and old age: “You have your good days and your bad days, don’t you. Everybody does... I can’t give in to it. You’ve got to keep going.” (4; p.54). By weaving expectations of illness into their narratives of ‘old age’, patients maintained biographical continuity (4).

### *5.2.Experience of CKM*

Patients generally felt well-supported on CKM (6, 8). They valued having meaningful patient-staff relationships and continuity in care (3, 6, 9). CKM was experienced as effective yet non-intrusive, offering greater flexibility and control and less pain than dialysis (6). Patients relied on medical appointments to gauge improvements and deterioration, these enabled them to feel monitored and maintain a sense of normality (4, 6, 10).

### *5.3. Not thinking or talking about illness and death*

Patients tried not to ruminate on worrisome future-related thoughts and did not wish to dwell on future deterioration (6, 8). While one patient was preoccupied with his prognosis, others rarely thought or talked about their kidney disease once they had firmly declined dialysis, preferring instead to focus on social and domestic activities: “I don’t worry. I honestly don’t give the kidney problem another thought.” (4; p. 53). Patients rarely discussed death (1, 4). Reasons for this included: finding death too difficult to talk about, believing that hope would be severed by talking about death, or feeling no need to dwell on the inevitability of death (1). While some expressed ambivalence or were against knowing how death might be experienced, one patient wanted honest discussions and spoke frankly about death and dying (9).

### *5.4. Living in the here and now*

Patients took stock of their lives and felt lucky and grateful to have reached old age before becoming seriously ill (1, 4). They lived in the present, concentrating on aspects unaffected by physical troubles and enjoying simple pleasures with loved ones (1, 4, 6): “I’m taking it day by day now. I have enough to eat and enough to wear, that’s good enough for me. My son treats me well, so I am very contented” (6; p.1021-2). Maintaining daily routines grounded them in the present and provided structure and certainty, away from future’s uncertainty (4).

## **Discussion and recommendations**

This meta-ethnography synthesised the cumulative experiences of 129 patients with advanced chronic kidney disease who had opted for conservative kidney management. The synthesis highlighted the diversity of decision-making experiences and the complex interplay of individual, developmental, social, contextual and organisational factors contributing to decisions to opt for CKM. For these older patients who commonly had comorbidities, dialysis

treatment intrusion was a major consideration; many prioritised continuity, autonomy and quality of life, over potential gains in longevity. Patients accepted that they were approaching the end of life, and CKM better facilitated living on their own terms. Prognostic uncertainty and unpredictable illness contributed to challenges of control; however, patients maintained continuity and a sense of normality by incorporating illness into expectations of old age and finding contentment in simple pleasures.

### *Clinical implications*

Patients emphasised personal responsibility and reasoned justification for choosing CKM, indicating the psychological importance of perceiving autonomous choice. This aligns with clinical practice guidelines for end-of-life care in advanced kidney disease, which encourage shared decision-making based on patients' reported goals, values and preferences (NHS Improving Quality, 2015). Negative feelings about decision-making were linked to perceptions of no choice or unclear rationale for CKM, highlighting the need to support patients to understand the relative risks, benefits and impacts of treatment options to make informed decisions.

Patients differed in their readiness to think about the future and the level of engagement and responsibility they wanted to have in decision-making. Some favoured their clinicians holding responsibility, while others purposefully avoided in-depth deliberation of treatment options. Similar findings have been reported with advanced cancer patients regarding end-of-life treatment decision-making preferences, with patients varying in how much they wanted to be involved in decision-making (Brom et al., 2014). In this Dutch interview study, influencing factors included how patients perceived their own (and their doctor's) roles and capabilities in decision-making, and patients speculated that they would want to take a more active decision-



making role as quality-of-life issues became more pertinent later on. Renal services should accommodate for diverse preferences by identifying the nature and extent to which patients wish to be involved in treatment decision-making and supporting patient autonomy, as appropriate. Given that some patients may seek dialysis as their situation evolves, practice should incorporate opportunities to review decisions, whilst ensuring that patients understand potential implications of delaying dialysis.

The tendency for patients to be guided towards dialysis without receiving sought-after information about CKM, disease progression and prognosis likely reflects the relative levels and lack of understanding of these topics. CKM is a relatively ‘young’ and under-researched treatment pathway, in part due to variation in definitions and provision, but also difficulties accessing this population. That patients based their choice for CKM on dialysis information and reported inadequate staff communication about future deterioration signals outstanding research and training needs. Our findings are consistent with existing evidence that doctors rarely discuss end-of-life issues with patients with advanced kidney disease (Davison et al., 2010). Research suggests that lack of confidence around discussing end-of-life issues contributes to renal clinicians avoiding discussing diagnosis and prognosis with patients (Bristowe et al., 2014). Indeed, clinicians have reported difficulties in relaying information about the uncertainty associated with treatment options, and deciding how much information to share (Noble et al., 2017). Given that uncertainty can negatively impact on patients’ adjustment to illness and that some illnesses are inherently uncertain in nature, communication training to support clinicians to convey this uncertainty to renal patients may aid adjustment (Bristowe et al., 2014). Of course, some patients do not wish to engage in end-of-life discussions, and these preferences should be taken into account.

Like those in previous systematic reviews, patients on CKM were more concerned with the impact of treatment on their quality of life than longevity, particularly dialysis treatment intrusion (Morton et al., 2010; Tong et al., 2014). Information about dialysis has a significant bearing on CKM decisions, and this review highlights a wider responsibility to convey accurate information about dialysis, including in mass media. Early education and conversations about how to maintain quality of life and autonomy on dialysis may counter common negative perceptions of dialysis, and expert patients living with dialysis may be well-placed to convey the benefits and subjective experience of dialysis.

The issue of patients feeling pressured by clinicians and family members to start dialysis is concerning given previous findings that older patients regret starting dialysis (Davison, 2010). While patients in this review were not swayed by others to start dialysis, it is possible that others were and subsequently experienced regret. Patients choosing CKM may experience resistance and invalidation and feel unable to seek clinicians' support around decision-making, raising the potential for decisional doubt and ambivalence. Given societal values around the sanctity of life and medical ethics on sustaining life where possible, patients' choices for CKM may not necessarily align with clinicians' professional or personal perspectives; yet clinicians potentially hold significant authority and influence over decision-making (Davison, 2010). Such circumstances, therefore, require a balance between providing appropriate information and supporting patient autonomy. Communication training for clinicians may help them to navigate these challenges whilst safeguarding against coercive practice (i.e. protecting patients from undue pressure to start dialysis). Clinicians could communicate more neutrally about dialysis and CKM and demonstrate an openness to understanding patients' perspectives and reasons for declining dialysis, including how patients personally define quality of life including the experience of dying.

Similarly, family members who are not psychologically prepared to face the prospect of their loved one's death may struggle to understand their choice for CKM. Attempts to persuade patients otherwise could be invalidating and lead to increased distress, guilt, isolation and relational conflict. Educating families and involving them in the decision-making process early on could facilitate mutual understanding.

The review highlighted some of the ways patients living with CKM maintained psychological wellbeing and coped with prognostic uncertainty and reaching the end of life. Referencing their current life stage and comorbidities, patients variously described acceptance, present-moment focus, contentment with simple pleasures, meaningful relationships, and a strong sense of life completion. These components align well with psychological interventions based on Acceptance and Commitment Therapy and Mindfulness-based approaches, and life story work, and should be explored further as potential interventions for older adults with end-stage kidney disease to adjust to illness and live well as they approach the end of life.

#### *Limitations and future research*

The studies in this meta-ethnography largely employed cross-sectional designs, exploring patients' perspectives at a single time-point following their decision to opt for CKM. As time and experience may have biased people's recall, we cannot infer how their perspectives may have evolved over time. Prospective longitudinal studies beginning earlier on in the decision-making process would provide insight into the evolution of beliefs and perspectives while reducing reliance on recall of previous events which, for this population, may be impacted by cognitive difficulties.

Some included studies reported that patients who declined participating were too frail to hold a conversation or did not want to talk about their choice for CKM, indicating that participants who agreed to participate may have had greater functioning or more positive experiences, and may have been more able or willing to discuss their experiences. The ethical challenges of accessing dying populations for research are noted (Seymour et al., 2005). However, patients reported a desire to know more about disease progression and the experience of dying, highlighting the clinical importance of researching diverse experiences on these topics.

Qualitative studies tend to be poorly indexed in databases, therefore it is possible that some studies were missed during systematic searching, however, attempts were made to minimise this by using a wide range of search terms. That only ten separate studies were identified highlights the lack of qualitative research in this area and inspires caution not to overstate the findings reported so far. Patient experiences are likely to reflect variation in CKM provision and organisational and sociocultural contexts. The majority of studies were conducted in cultures considered highly Individualistic, while half of all studies were conducted in the UK. Only two studies were conducted in a Collectivist culture (Singapore), therefore, it remains premature to draw conclusions from comparisons between patients' experiences in different cultures, though one would anticipate that cultural factors such as interdependence and the relative prominence of the family unit are likely to influence patients' experiences.

### *Conclusion*

This meta-ethnography forms the first known meta-synthesis focusing solely on the perspectives of renal patients who have opted for conservative kidney management. The decision to opt for CKM, while commonly framed as a rejection of dialysis, can be an optimal treatment option for older patients with end-stage renal disease. CKM aligns with patients'

personal priorities and developmental life stage, enabling patients to maintain quality of life and continuity, to live their life more on their terms. However, patients are not routinely provided with sought-after information about CKM and chronic kidney disease progression, and desire unambiguous information to be proactively shared by staff. Communication training for clinicians could improve these patients' decision-making experiences. Considerable further research with patients living with CKM in diverse cultures is needed to account for cultural differences in patients' experiences.

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## **Chapter Two**

### **Empirical Study**

Exploring the experiences of kidney transplant recipients one year after transplantation

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# **Exploring the experiences of kidney transplant recipients one year after transplantation**

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## **Abstract**

This cross-sectional qualitative study used interpretative phenomenological analysis to explore the experiences of adult kidney transplant recipients in north Wales one year post-transplantation, with a sub-aim of exploring how expectations may have shaped their experiences. Six recipients (two females, four males; mean age=62 years), who had received a first kidney-only transplant were interviewed 12-23 months post-transplantation. Participants reported minimal expectations for post-transplant life, however, challenges experienced post-transplantation were not necessarily anticipated by patients or their families. While transplantation restored vitality, recipients retained ongoing patient status. The first year was characterised by uncertainty, unpredictability and continued restriction, contributing to heightened vulnerability. Participants described conflicting emotions and pressure to demonstrate transplant's benefits. Interpersonal challenges indicated limited understanding by others, of the experience of kidney failure and transplantation. Transplant resilience appeared to take the form of 'radical acceptance' and present-moment focus. Finally, patients suggested areas for improving transplant experiences.

**Key words:** kidney transplantation; end-stage renal disease; chronic kidney disease; kidney transplant recipients; patient experience; transplant adjustment; expectations; qualitative

## **Introduction**

End-stage renal disease describes the final stage of chronic kidney disease, when kidneys can no longer sustain vital function and renal replacement therapies including kidney transplantation, haemodialysis or peritoneal dialysis are needed for survival. Kidney transplantation is the preferred treatment for most patients (Wainwright et al., 1999) and remains the ‘gold standard’ renal replacement therapy due to better survival rates, reduced risks and greater cost-effectiveness (NHS Kidney Care and Blood and Transplant, 2013).

Kidney transplant recipients report improved independence from restrictive dialysis regimes (Wainwright et al., 1999). Meta-analytic comparison has associated kidney transplantation with greater psychological wellbeing and lower emotional distress compared to dialysis (Cameron et al., 2000). However, recipients have reported psychological strain and symptoms of depression and anxiety, despite positive medical outcomes (Heck et al., 2004). In a meta-analysis comparing outcomes for kidney transplant and haemodialysis patients, transplant was linked to greater improvements in physical functioning and general quality of life, while improvement in psychosocial functioning was less consistently reported (Landrenau et al., 2010).

Indeed, recipients have reported ranging psychological responses specific to receiving a kidney, from mild anxiety concerning graft survival, to overwhelming fear of graft rejection (Gill, 2012). Following transplant, patients described uncertainty about the future (Kong & Molassiotis, 1999), feelings of inadequacy (Pillay et al., 1992), guilt (Griva et al., 2002), indebtedness (Achille et al., 2004) and ambivalence (Wiederhold et al., 2011), highlighting the complexities of psychological adjustment to kidney transplant.

Transplantation can present challenges for recipients and those around them. Aside from recovering from major surgery, patients must negotiate and adapt to the novel stressors, opportunities and demands of post-transplant life (Wainwright et al., 1999). Recipients require life-long immunosuppressant medication to prevent graft rejection, involving unpleasant side effects and increased susceptibility to illness, potentially intensifying feelings of vulnerability (Lonargáin et al., 2017). Sexual dysfunction and loss of libido, hair growth or loss, weight gain and bleeding gums all represent changes linked to decreased quality of life (Matas et al., 2002; Schipper et al., 2014).

Qualitative studies of transplant recipients' lived experiences provide insight into the personal meanings and impacts of living with a donated kidney. Receiving "the gift of life", a term frequently deployed by health professionals and the general public, may feel like both blessing and burden, resulting in psychological strain (Siminoff & Chillag, 1999). For recipients of living donor kidneys, emotional highs can accompany feelings of obligation akin to "grateful conduct" and "grateful use" of the kidney (Gill & Lowes, 2008; Gerrand, 1994; Murray, 1987). Recipients have reported extreme cautiousness about their health, fearing blame for a failed transplant (Crombie & Franklin, 2006). Responsibility to care for their kidney can manifest as pressure not to let themselves or others down, including staff or the donor's family (Orr et al., 2007). Recipients of deceased donor kidneys have reported conflicting emotions of gratitude and sadness for their donor's death (Lonargáin et al., 2017).

Individual and societal norms may shape how recipients experience kidney transplant outcomes, with positive emotions and physical improvements becoming challenging or precipitating maladaptive behaviour, including crossing personal boundaries (Schipper et al., 2014). In this Dutch interview and focus group study, 30 recipients of living and deceased



donor kidneys discussed post-transplant life's uncertainty, alongside psychological strain and fear of novel situations and risks. Recipients and families' high expectations of post-transplant life fostered unforgiving environments, with recipients feeling pressured to positively approach new roles and challenges. Patients experienced guilt and felt unable to express disillusion or disappointment, silenced by unspoken expectations that they should remain grateful.

In a UK interview study, six male recipients of deceased donor kidneys discussed how people's limited understanding or unsupportive judgements and interactions produced feelings of isolation (Lonargáin et al., 2017). Participants reported relational difficulties with family, friends and colleagues who treated them as 'healthy' and assumed they could "move on" with their lives, despite recent major surgery. Others experienced self-imposed pressures to "succeed in life" or over-exerted themselves at work to recoup lost time. Thus, expectations about post-transplant life stemming from both patients and those around them can become a source of emotional distress, with 'normative persuasions' and societal pressures creating additional challenges.

In a qualitative review of seven studies exploring experiences of directed living donor kidney recipients, Croft and Madison (2017) commented that recipients predominantly reported only positive expectations pre-transplantation, querying how well-informed patients were about potential risks and impacts. Crawford et al. (2017) suggested that some within their randomised controlled trial had unrealistic expectations about post-transplant life or underestimated the complexities of kidney maintenance, resulting in preoccupation with fear of kidney rejection and increased feelings of restriction and vulnerability. Expectations, realised or unrealised, may therefore influence adjustment.

Pérez-San-Gregorio et al.'s (2005) quantitative study suggested recipients face different post-transplantation challenges over time. Here, researchers compared depressive and anxious thoughts and body image perception in 59 kidney transplant recipients across three groups based on time since transplant: 0-1 year, 1-2 years, and >2 years post-transplantation. Participants in the first and third groups had significantly worse scores than those in the '1-2 years' group on items measuring depressive and anxious thoughts and physical self-esteem, with the '0-1 year' group scoring the worst. The authors speculated that during the first year, recipients negotiate more severe emotional and physical challenges surrounding readjustment, including "anxious waiting", with adaptation becoming more established as patients and their families adjust to their situation. Researchers have called for consideration of recipients' experiences within specific timeframes to gain insight into unique challenges and support needs at different stages (Lonergain et al., 2017). Interviewing recipients shortly after their first year post-transplantation would offer valuable perspectives while recall of memories is likely to be more recent, reliable and less biased by time passing.

#### *Rationale for current study*

Clinical practice guidelines largely focus on the medical and physical aspects of kidney transplant recovery, with little guidance on psychological and psychosocial domains (NHS Blood and Transplant, 2014). This likely reflects transplant research literature's current state (Croft & Maddison, 2017). As such, significant numbers of people live with the consequences of this potentially life-changing process, for which patients, families and health professionals may not be prepared.

Therefore, the aim of this study was to explore the perceptions, meanings and experiences of adult kidney transplant recipients following their first year of transplantation, with a sub-aim of exploring how expectations may have shaped their experiences. Exploring the psychological

and psychosocial aspects of transplant from recipients' perspectives would provide insight into the psychological and psychosocial implications of kidney transplantation. It was anticipated that this would draw attention to patients' experiences of challenges and adaptation to post-transplant life.

## **Method**

### *Methodology*

This qualitative cross-sectional study utilised an 'Interpretative Phenomenological Analysis' (IPA) framework (Smith et al., 2009). An idiographic and inductive approach, IPA seeks to describe and interpret how individuals make sense of their unique lived experiences, through their own words. While IPA concedes that direct access to participants' worlds is impossible, insights can be gained through interpretation. The aim, therefore, is to develop insight into the subjective experience of receiving a kidney, as opposed to establishing objective "truths". Through semi-structured interviews, personal meanings of receiving a kidney transplant were explored from recipients' perspectives, one year post-transplantation. IPA is ideal for understanding the psychological and psychosocial aspects of experiences, particularly within health psychology contexts, and considers participants' developmental, social and cultural contexts.

### *Recruitment*

Participants were recruited across three renal services within Betsi Cadwaladr University Health Board (BCUHB), covering north Wales. Renal transplant specialist nurses from these sites identified and recruited eligible participants through purposive sampling according to explicit criteria, to achieve an acceptably homogenous sample (Smith et al., 2009).

Inclusion criteria:

- Adults (aged 18 years+) who have received a first kidney-only transplant via living or deceased donor
- Accessed NHS care within BCUHB
- Between 12-24 months post-transplantation

Exclusion criteria:

- Individuals who have had non-renal allografts
- Not sufficiently fluent in spoken English to participate in interviews
- Lack capacity to consent due to impaired cognitive or mental health status.

During initial planning, the lead researcher (first author) met with nurses to discuss research questions and seek support with recruitment. Due to the global Covid-19 pandemic, telephone interviews (as opposed to face-to-face interviews) were chosen to comply with national restrictions and minimise infection risks for all parties. Following ethical approval, another meeting with the nurses clarified the study aims, eligibility criteria and recruitment procedures.

Two nurses from each site randomly identified five kidney transplant recipients from their patient databases and contacted them by telephone. They explained the study's aims and procedures, the voluntary nature of participation, and the study's independence from medical care to safeguard against coercion. Nurses posted prepared bilingual English and Welsh participant information packs to those interested, enclosing a participant information sheet, consent form, research opt-in slip and pre-stamped envelope addressed to the lead researcher. The lead researcher contacted patients who opted-in by telephone or email to provide further information, answer questions, gain written informed consent, and arrange a mutually

convenient date for the telephone interview. Recruitment took place from December 2020 to February 2021. Participants were offered a retail gift voucher as a token of appreciation.

### *Participants*

Six individuals (four males, two females) returned opt-in slips and consented to being interviewed. While small, six is considered sufficient given IPA's 'quality' over 'quantity' approach to data (Smith, 2003). To maintain anonymity, participants were assigned pseudonyms at the point of transcription. Potentially identifying details were removed. General demographics are reported in line with ethical considerations. Participants' ages ranged from early-50s to late-60s (mean=62 years). Time since transplant ranged from 12-23 months (mean=18.5 months). All experienced dialysis before transplantation. Five received a kidney from a deceased donor, one received a kidney from a living donor. Participants lived across north and mid Wales. All described their ethnicity as White British or White Welsh. Employment statuses and living arrangements varied, though most had children or were married.

### *Data collection*

The lead researcher conducted a single individual telephone interview with each participant, guided by a semi-structured interview schedule (Appendix 1), developed after reviewing existing qualitative literature and consulting with the research team, nurses and an expert patient who had received a kidney transplant. The interview schedule contained eight questions with supplementary prompts covering pre- and post-transplant experiences, transplantation expectations and impacts on relationships. Congruent with gathering information about individuals' lived experience, interviews were participant-led, exploring topics which seemed more personally significant in more detail.

The start of the interview aimed to build rapport and provide an overview of the interview process, including limits of confidentiality and right to withdraw. Telephone interviews took place in a private room in participants' own homes and were audio-recorded. Field notes made after interviews recorded initial thoughts and observations. Interviews lasted 1-2 hours (mean=82 minutes).

### *Data analysis*

IPA recognises research as a dynamic process between participant and researcher whereby initially, participants attempt to make sense of their experiences, followed by the researcher attempting to make sense of participants' accounts of their experiences. The researcher therefore engages in a 'double hermeneutic', acknowledging that their own subjectivities and experiences will influence analysis during and after data collection (Smith, 2003).

Interviews were transcribed verbatim (including pauses, sighs, stutters, tone and laughs) and analysed by the lead researcher in the same order as conducted. Transcripts were read and re-read to enable immersion in the data. Line-by-line analysis noted descriptive, linguistic and conceptual elements of the data (Smith et al., 2009). This facilitated the next stages of developing emergent themes within the transcript and identifying connections across them. Analysis continued consecutively across the remaining transcripts, before identifying patterns across transcripts to develop superordinate themes. Analysis was iterative and continued throughout analysis and write-up.

### *Ethics*

Ethical approval was granted by Bangor University School of Psychology Ethics Committee (Ref: 2020-16764) and London Brent Research Ethics Committee (HRA & HCRW approval: IRAS 283106), and subsequently gained site-specific NHS Research & Development approval.

## **Findings**

The main findings are presented below. Three broad themes, each with three sub-themes, describe interconnected aspects of participants' experiences of kidney failure and transplant. These themes are not mutually exclusive and participants' quotes reflect similarities and contrasts between accounts. Themes and subthemes are outlined in Table 1, along with descriptive summaries. Where verbatim quotes are presented, long pauses are conveyed by [pause], and [...] indicates that a small portion of extraneous text has been removed (for example, personally identifying details or superfluous text, as assessed by the lead researcher).



**Table 1.** Themes, sub-themes and descriptive summaries

## **1. Negotiating boundaries of the self**

*Captures the challenges of negotiating shifts in participants' and others' perceptions of themselves in response to illness and treatment.*

- 1.1. Self-identity undermined** - explores adaptive and maladaptive psychological responses to illness as they relate to participants' established identities and boundaries
- 1.2. A private experience made public** - captures participants' heightened sense of invisibility and visibility stemming from the hidden yet public nature of kidney failure treatment
- 1.3. Transplant as an ethical dilemma** - describes moral and ethical questions raised as participants considered transplant as an option

## **2. Transplantation as restoration of the self**

*Captures the restrictions and psychosocial impacts of life on dialysis and contrasts this with the "life-changing" and "life-giving" properties of kidney transplantation.*

- 2.1. Dialysis as restriction and loss** - describes the negative impact of dialysis on participants' sense of self and ability to participate in life activities
- 2.2. Transplant as freedom and vitality** - captures the restoration of participants' vitality and sense of self following transplant
- 2.3. The many sides of gratitude** - explores positive and negative impacts of transplant gratitude, including personal growth, altruism, guilt and pressure

## **3. Navigating uncharted territory**

*Captures the inherent uncertainty and unpredictability of kidney transplantation, and emergent coping strategies.*

- 3.1. Loosely held hopes and expectations** - considers participants' minimal expectations of post-transplant life as an adaptive response to uncertainty and lack of control
- 3.2. Continued cautiousness and restriction** - captures the uncertainty, anxiety, and heightened vulnerability that characterise the first year post-transplant
- 3.3. Acceptance in the absence of certainty** - describes transplant coping and resilience, namely pro-active strategies and 'radical acceptance' of aspects beyond personal control

## 1. Negotiating boundaries of the self

For some, coming to terms with kidney failure and requiring treatment unsettled well-established ideas held about their identities, autonomy and moral boundaries. Participants described challenges of negotiating shifts in their own and others' perceptions of themselves as they navigated health, illness and treatment.

### *1.1. Self-identity undermined*

Some participants perceived incongruity between kidney failure and their identities. Emma shared: "...when they said that my kidneys were packing up... I couldn't cope... I shouldn't be taking all these pills at this age...". They spontaneously distanced themselves from connotations of illness and frailty, for example, Paul described how he was "*not*... a typical transplant patient really", while Catherine humorously recalled rebuffing her family's suggestion of using mobility aids: "...there is *no way* I am using a walking stick! [laughs]". Mental distancing appeared adaptive to an extent, prompting self-management of illness. Catherine described feeling more motivated and hopeful after choosing home-based peritoneal dialysis: "...I stopped being a patient... and I became in my head a bit more proactive...". However, for Ifan, the shock of kidney failure led to extreme mental distancing, denial and avoidance:

"...I'm an active man, I just basically didn't accept that I had a problem...". As his health worsened on dialysis, he delayed registering for a transplant: "...I was still in denial that I was ill enough to have a kidney transplant..."

Undermined self-identity was a central theme of Ifan's experience; his increasing dependence on dialysis and gradual loss of his working role challenged his masculinity. Following surgery

to install a peritoneal dialysis catheter, persistent existential questions about essential aspects of his identity and quality of life arose:

“...it was like, oh my god... Is this my life? Am I gonna have to live with this pipe [catheter], hanging out of my body and how am I gonna cope? How am I gonna work? ...I sort of felt like I’ve lost my man-ship if you like, you know, being being a busy man and running a business... also for my [partner]... for her to live with somebody with that, it was quite upsetting.”

He alluded to an unease with ‘unnatural’ body modification when relaying his initial struggle to contemplate transplant: “...I’d *never* have myself cut open, major operation, have somebody else’s dead kidney, on ice, put inside me and revived...”

Ifan’s concept of transplant evokes the imagery of Frankenstein’s monster, an unnatural amalgamation of live parts belonging to him and “dead” parts belonging to another.

All participants spoke with admiration and fondness of renal staff, and some described developing close bonds, “...like meeting old friends” (Paul), a possible consequence of their dependence for care. Yet this could also be experienced as blurring the boundaries between ‘self’ and ‘other’. Referencing both attachment and loss, Ifan reflected:

“...they [dialysis staff] come quite close coz it’s quite an intimate thing really, isn’t it? connecting somebody to a to a machine... you have to lose all sort of [pauses], you know, I don’t know, whatever you have to lose whatever to, because you become a part of this dialysis team.”

Ifan’s use of the word “intimate” indicates a vulnerability and closeness in letting others into a usually guarded space. Though he struggles to articulate the essence of what was lost, an erosion of privacy, autonomy and identity is hinted at.

## 1.2. *A private illness made public*

While participants were keen to express gratitude for the practical and emotional support of renal and hospital staff, other renal patients, family, friends, and pets, the hidden yet public nature of kidney failure treatment contributed to a heightened sense of both invisibility and visibility. Negotiating their social selves and the perceptions of others carried additional pressures, leaving some feeling unsupported or undermined. Emma said:

“...I think they [adult children] just sort of, [casual tone] oh well, yeah we know mum’s got to have a kidney but [pauses] let’s put it bluntly [chuckles], she’s she’s still *alive*... I don’t think they actually realised the seriousness of it... because I suppose they couldn’t see anything [pauses] *happening*... I didn’t look any different [laughs]... it’s like I say... you don’t wear a kidney on the outside, do you?”

Emma’s casual phrasing of “she’s still *alive*” gives a sense of her family’s limited awareness of her illness’s severity. Her continuation with domestic obligations possibly reveals a pressure to be the dependable maternal figure who meets her family’s needs and expectations, at the expense of her own. Similarly, Ifan described the alienation and difficulty of conveying to friends and work colleagues how ill he was:

“...they just think, [casual tone] oh yeah you just get another kidney, don’t you? ...oh you just get some medication and, you know, you’ll be alright... and it’s quite jovial but they don’t understand... the sickness involved erm, is *really really*, you’re *really* ill...”

Ifan’s use of qualifier “*really really*” indicates the persuasion required to elicit people’s understanding, while “just” suggests that their reactions leave him feeling dismissed, his illness trivialised.

In contrast, Catherine was “unprepared” for her family becoming “*far, far*, overly protective” in response to her illness and transplant. Her family took “a *long* time to re-adjust”, she

explained: "...I think it was the position and how I was *perceived*, from being this, can cope with anything, to, we've got to protect her..." Attempts to assert her autonomy post-transplant were actively undermined as family members "took over", their involvement becoming intrusive and disempowering: "...it sort of got me down somewhat... it's as if everything was out of my control...". Catherine recalled the mismatch between her family's eagerness to help her return to activity and her own sense of vulnerability:

"My family were trying to be helpful in getting me *over* things... but I in my head I was thinking this is too soon, I don't feel quite ready, you know, but sometimes I felt I was doing it to please *them* rather than pleasing me."

Her family's paternalistic and conflicting responses of over-protectiveness and eagerness indicate a difficulty in gauging her vulnerability. Catherine seemingly regressed, in her family's eyes, to a child-like state requiring adult supervision.

### *1.3. Transplant as an ethical dilemma*

Accepting a kidney transplant was an emotional decision, carrying significant risks of physical or moral injury. For those considering living donation, concerns for their donor's health and wellbeing persisted and even deterred some from pursuing this option, especially when considering adult children as potential donors. Bryn, who received a living kidney donation from his adult child, felt solely responsible for resolving his illness ("It was *my* problem...") and worried about harming his donor. He "reluctantly" accepted a kidney and considered it one of his "most difficult decisions":

"I suppose the worst-case scenario would be that *you* would recover and *you* would feel much better, but you'd leave the donor in a similar position to you were when it *all* started... *that* would be psychologically very damaging."

Ifan was initially strongly against receiving a kidney from a deceased donor, citing moral unease and potential risk to his life:

“...it didn't seem right at the time erm for me, for my my moral thing, to take somebody else's or, even though they were dead... to have a *major* operation like that... you could die... it might *fail*...”

Both participants later went on to advocate for transplantation. Accepting a kidney, it seemed, necessarily prompted a re-examination of moral boundaries for some.

## 2. Transplant as restoration of the self

Participants sharply contrasted their restricted lives on dialysis with the freedom of post-transplant life. Transplant restored them to their former selves and gave them vitality and a greater appreciation for life. Gratitude and a desire to ‘give back’ featured strongly, with varied consequences.

### 2.1. *Dialysis as restriction and loss*

Most participants experienced daily restrictions and side effects on dialysis, including pain, breathlessness, exhaustion, weakness and malaise. While patients preferred the convenience of home-based (over hospital) peritoneal dialysis, for some, dialysis was intrusive, impacting on work, leisure, social and family life. Ifan reflected on his “lonely life” on dialysis:

“...I'd be going upstairs [to start dialysis] and [my family] would be downstairs... and it'd be my time to disappear again... you realise then... life has changed then for *me* as a *person*. ”

For Ifan, dialysis represented a treatment that “barely” kept him alive, while diminishing his vitality and personhood. By this point, he was “so desperate” for a kidney: “...I was willing to risk my life, to have *a* life...”

Transplant represented one of few ways to escape a life constrained by dialysis. Emma recalled her desperation:

“...I can’t carry on the way that I am... I’ve gotta try for the kidney coz as I say, I don’t feel I’m old... it was getting to a point where I thought... I *can’t* do this [dialysis]... forever...” Emma’s use of “can’t” and “gotta” suggests that she did not conceive any real alternative to transplant as life on dialysis was unbearable. In some ways, choosing transplant was as stark as choosing between life and death.

## *2.2. Transplant as freedom and vitality*

Receiving a kidney restored people’s wellness and sense of self. Some participants noticed immediate physical improvements, while some described an unexpectedly long period of physical and mental recovery. Participants expressively described transplantation as “life-changing” (Huw), and offering “freedom” (Bryn). Paul said: “...transplant gives you another crack at life, I feel *normal*... it's just brilliant to be alive... and to *feel well*...”. Participants reported improved mood and quality of life, with some reporting improved relationships. Huw felt “a lot happier... more relaxed”, his partner noticed a change in his “attitude to life” which he attributed to removing “...the stress of having to do dialysis every night”. Transplantation allowed Ifan to return to work and spend quality time with family, giving him his “*feeling of me back*”. Similarly, Emma reported being less serious and “more myself”.

Participants also discussed the Covid-19 pandemic, which brought varying degrees of restriction and frustration for some. Huw recalled feeling “depressed” due to ‘shielding’ (a requirement for all individuals deemed ‘clinically extremely vulnerable’ to not leave their homes and to minimise all face-to-face contact). Emma described feeling “hemmed in and

stopped from doing what we'd like" as she had to cancel personally significant post-transplantation plans. Bryn shared: "There wasn't much of a gap between getting better and the virus really". Participants' accounts gave a sense of having briefly experienced freedom or a '*normal* life' (Huw) via transplantation, before once again being restricted because of the pandemic.

### 2.3. *The many sides of gratitude*

Ongoing gratitude for receiving a kidney featured heavily in participants' accounts, with varying consequences on wellbeing and behaviour. Catherine shared: "...I have *really, really* benefitted... in my heart, spiritually as well...". Participants described increased appreciation for their lives and relationships, however, their accounts also hinted at inner conflict and pressure. Huw felt "very lucky" to have been given "...a second chance *very* late on in life", however, the nature of deceased kidney donation brought mixed emotions:

"...to start with, I was slightly emotional erm about knowing that somebody had had to die for me to have a kidney... The ones I feel for are the youngsters, the ones in their twenties and thirties that have to go through this without... hopefully getting one but maybe having to wait..."

Huw's words hint at sorrow and 'survivor's guilt', or a potential worry about justifying receiving a kidney before younger patients. Bryn was also conflicted about receiving a living donor kidney: "...I was conscious of the fact that people were willing to put their health at risk and I was incredibly grateful for that but it also puts an extra pressure on me as well." Receiving a kidney, therefore, elicited gratitude as well as pressure stemming from an awareness of the actual and hypothetical sacrifices involved in transplant.



Participants expressed ongoing gratitude towards their deceased donor, their donor's family and NHS staff. Many expressed gratitude and sorrow by writing to the donor's family. Catherine explained the importance of writing and taking personal responsibility to care for her kidney:

“...this is why I feel responsible to look after it and to show people the benefits of it... [recipients] have a responsibility in some ways to show that it's worth it, that it's *made* a difference...”

Transplant gratitude may have made it difficult to express disappointment or regret. Referencing an ongoing medical issue, Huw shared:

“...the only problem *now* is because of this [medical issue]... I'm *not* able to do as much again erm, *nothing* to do again with the transplant itself, it's another problem *because* of the transplant yes... I've said it to [partner] a couple of times and [she] didn't half give me a telling off when I'd tell [her] this, ‘Was it worth doing the transplant?’ ‘Yes’, she says, ‘It [whispered] *bloody* was!’”

Huw considered his transplant “worth it”, however, his hesitancy to attribute his difficulties to the transplant possibly reveal guilt over having momentary doubts and being unable to share his true experience with loved ones. His partner's firm response suggests a tension and pressure for both to remain positive and grateful for his transplant, as expressing negativity or disappointment could potentially undermine their experiences through transplantation.

Participants used their first-hand experience to promote kidney transplant and help other renal patients, recognising their value as expert patients and enjoying this role. Paul said:

“...I can explain *far* better than the renal specialist or the nurse that is there what it actually physically feels like to have these processes *done* to you... I can answer all the

questions... I see it as my duty to do that and I will *always* go and help them when I can... it's *my* way of paying back... I think that *that* is important and that we should *all* do that.”

Patients actively and willingly promoted transplant. However, this required accepting compromises to their privacy and understanding the potential impacts of what they shared, for example, not being “overly pessimistic” (Catherine). Catherine discussed the dilemma of balancing friends’ interest in her “high-profile” procedure and her own needs: “...it’s such a private thing in some ways... sometimes I just want to be quiet ... to take it all in myself...”. She appeared to resolve her dilemma by prioritising transplant promotion and embracing her duty as a recipient, concluding “...if it helps them to understand the benefits, *that’s* how I look at it too.”

### 3. Navigating uncharted territory

This theme captured the uncertainty, unpredictability and cautiousness of living with kidney failure and transplant, and the coping strategies patients adopted to regain a sense of control.

#### 3.1. Loosely held hopes and expectations

Participants reported having minimal expectations pre-transplant about post-transplant life. At most, they had tentative hopes of ceasing dialysis, gaining independence and feeling better. These scaled-down expectations appeared to be a way of adapting to minimal control over when a transplant might happen and ultimately whether it would be successful. Paul, explained:

“I believe in planning for the future but living in the *now*... you've *no* idea, when you're relying on a deceased donor, when [transplant] might happen... I found that I couldn't think to myself, ‘What will life look like when I've had a transplant?’ ... it's *all* a question of saying, I'm getting on fine with dialysis, and I *hope* one day, I'll get a transplant...”

Paul's present-moment focus was a necessary strategy to cope with unknown timeframes. The word "couldn't" suggests multiple possible meanings, that it was impossible for him to visualise post-transplant life, and that looking too far ahead would be futile and potentially create vulnerability to future disappointments.

For some participants, dialysis was complicated by infections and hospital admissions, exposing them to "upsetting" scenes "...watching other people deteriorate" on dialysis (Catherine), or meeting patients returning to dialysis following failed transplants. Such experiences may have offered unwanted glimpses into their own potential futures. Faced with a long and uncertain wait, hopelessness took over for Emma:

"...it seemed that I was never gonna get a kidney... of course I had to wait but I I was sort of getting to the point where I thought it's not gonna happen and I'm gonna be on this blummin' dialysis forever... I thought I can't cope..."

In similarly desperate circumstances, Ifan's expectations of post-transplant life were also minimal: "I had no expectations other than it must be better [pauses] than what's keeping me alive at the moment."

Participants related their lack of expectations to not having an explicit outline of "...what a transplant would be like... nobody actually sat down and told you, told me the whole process", as Catherine recalled, though she also reflected that she "only wanted to know so much", in case knowing the "*wrong* thing" would cause worry or put her off. Ifan and Catherine both cited a lack of prior contact with transplant patients as a reason for having limited expectations, although incidental contact could impact both positively (e.g. providing hope) and negatively, as Catherine explained:

“...I’d *seen* transplant patients in the waiting room... and they look really well... however it can also affect, when you’re in the waiting room, you meet people who it *hasn’t* gone very well... sometimes I think oh I wish I really didn’t hear that [referring to unsolicited conversation with said patient].”

Catherine continued:

“...I *did* hope that I would be a *lot* lot better... so I *really* was hoping, but I didn’t *overly* hope... I didn’t *purposefully* think I’d be miraculously different, you know?”

Patients seemed, therefore, to intentionally or instinctively limit their hopes and expectations as a way to cope with uncertainty and to protect against the disappointment of unsuccessful transplant outcomes.

Many wished they had been offered more contact with transplant patients, transplant staff and the transplant centre itself pre-transplant, to gain “insight” (Ifan) and reduce uncertainty. Bryn explained how sharing a ward with other transplant patients during a minor rejection helped him, as their comments put his worries “into perspective”:

“...you think, well you’re not alone, alone with the worries... [and] ...with having these problems... it’s a bit like the back room I suppose, the barracks, isn’t it? You know, you get to be discussing things... it sort of calms you down... the value of the the [sic] experience of other patients shouldn’t be undervalued... the guys on the ward tell [chuckles] you as it is, you know, they give you the the [sic] nuts and the bolts of what to expect... so it doesn’t come as a shock...”

Bryn’s war-time comparison of the ward as “barracks” hints at the no-holds-barred conversations, gallows humour and camaraderie built between transplant patients sharing their stories, which he contrasts with the “very clinical” approach of his doctors.

### 3.2. Continued cautiousness and restriction

While most participants reported current stable kidney functioning, kidney failure and transplant were experienced as an “emotional rollercoaster” (Ifan), with “ups and downs” (Catherine). The first year was characterised by new forms of uncertainty, restriction and disruption resulting from the threat and experience of complications (e.g. serious infection), continued tests and consultations, unanticipated hospital admissions, and uniquely for this cohort, the introduction of Covid-19 pandemic restrictions and shielding. Feelings of vulnerability, fear of graft rejection and continued cautiousness were common. Bryn described the unpredictable nature of graft rejection:

“...you buy a lottery ticket and you don’t know... you might be feeling ok... but... you just didn’t know what the blood was gonna say, that was a constant worry really... no matter how careful you are... your eGFR, your kidney function goes up and down.”

Bryn’s likening of transplant to “lottery” suggests potential jackpots to be won, with transplant success being determined more by chance than agentic action. An inability to trust his intuition contributed to his sense of worry and lacking control.

Emma referenced the psychological toll of transplantation, as transplant recipients retained ongoing patient status unlike other patients. She compared this with patients undergoing amputation:

“...it’s not just your body... when we go to hospital *now* for blood tests, I’m still sat there with everything crossed, waiting for them to ring me to say... [that] the kidney’s working ok... I think that will take a little bit of time before I’ve sort of stopped panicking about, well not panic but worry about coming to the hospital...”

“...if they chop my leg off today, they’d probably say you’d be in hospital for a fortnight, give you a pair of crutches, go home and that’s it, it’s finished with basically whereas

[pauses] to some extent I feel that this, it's still going on, if you get me? Coz I'm still going to the hospital regularly and which I will *always* be going to the hospital... I will always be on [pauses] medication...”

Emma’s description of adjusting to wellness after transplantation gives a sense of wanting to be well and a desire to move on with her life. Yet, anxiety surrounding her kidney functioning loomed one year on, the absence of an ‘end point’ constantly reminding her of her patient status with its connotations of being fragile and unwell.

Post-transplant tests and consultations were particularly “disrupting” (Bryn), “a *bind*” (Huw), given appointments and travel could take an entire day (patients in north Wales are transplanted across the border in England). Many relied on friends and family for transport, and some considered the distance and cross-border nature of transplant care a potential threat to the success of their transplant, should they require urgent specialist treatment. Ifan discussed knowing “every day that [his] kidney could fail”:

“...it's still an ongoing treatment, this is what I didn't understand when they'd say to me having a kidney transplant is not... it's not the end of the problem... I understand what they *mean* now because it's not, it's not a *cure* [pauses] it's a treatment...”

Ifan’s revelation here suggests incongruence between expectations and experiences of post-transplant life. While he reported no disappointment, he referenced others calling transplant “the golden ticket”. Such impressions could have created overly optimistic expectations.

The “balancing act” of keeping complex life-long immunosuppressant medication regimes led to ongoing fears of serious illness such as skin cancer - “...in the back of your mind all the time” (Bryn), or fears of damaging the kidney. Bryn discussed his feelings of ‘protectiveness’ and personal responsibility to look after the “precious kidney”:

“...the last thing I wanted to happen was to [pauses] erm for my for the kidney that had been taken from my [adult child] to be rejected because it it would seem like erm betrayal in some ways... there was no way I wanted to do anything that would put the kidney at risk...”

Bryn related his cautiousness to the human and resource costs of his transplant, including potential harm to his donor. The emotive word “betrayal” hints at the potential for him to cause significant moral injury should his transplant fail. He described staff being “...hyper careful... making sure that you don’t lose the kidney because you know, it [transplant] costs a lot of, takes a lot of time and effort *and* money”. Similarly, Ifan spoke of ‘respecting’ and taking great care of his kidney, as to “mistreat” it would be “dishonourable” to him and the donor. Thus, patients may experience internal and external pressures to prevent transplant failure, a challenge given the unpredictability of graft rejection.

### *3.3. Acceptance in the absence of certainty*

Many participants sought information pro-actively and made lifestyle choices to maximise their transplant chances, while accepting that they had little control over certain aspects. Paul said: “...the more you learn about your disease... the easier it is for you to handle it...”. Bryn took a pragmatic approach to managing treatment choices and transplant challenges, with practical considerations (e.g. arranging work cover) taking precedence over emotional concerns. Explaining his stoic attitude, he said:

“...I’m a bit of a realist... there’s nothing much you can do about it at that stage really anyway... you just get on with it... if it’s [transplant] gonna happen then it’s gonna happen...”

Participants discussed “positive attitude” (Paul) and the need to be “incredibly strong-minded” (Catherine). Evoking war imagery, Catherine discussed the cyclical nature of transplant recovery and necessary “warrior” mindset:

“...it’s *bound* to be hard... you have *this* little battle and and then... stages of peace and calm, and then *another* little battle erm and perhaps that’s how it will always be...”

At the same time, ongoing gratitude and appreciation of life’s transience enabled Catherine to cope with inevitable future challenges, offering “peace of mind” and perspective:

“...my mindset is I’m still here and I’m *glad* I’m here, and [pauses] I’m fortunate... I can counterbalance, you know, if this goes wrong well I, doesn’t matter, it’s nothing really in the shape of things, all this will be left behind when I’m gone.”

Given the continued uncertainty and lack of control over transplant outcomes, coping necessarily took the form of acceptance. Transplant resilience therefore combined pro-active strategies, for example, becoming experts of their illness and treatment, while accepting aspects beyond their personal influence.

## **Discussion**

This study explored the experiences of kidney transplant recipients in north Wales following their first year post-transplantation, with a sub-aim of investigating how expectations may have shaped their experiences. Participants reported minimal expectations of post-transplant life but were not necessarily prepared for post-transplantation challenges. While transplant was largely restorative, the first year was characterised by uncertainty, unpredictability and continued restrictions, leading to heightened vulnerability and fear of graft failure. Transplant gratitude was associated with increased appreciation and a desire to ‘give back’; although it could bring inner conflict, guilt or pressure to demonstrate positivity and gratitude. Transplant resilience included information-seeking and ‘radical acceptance’ in the absence of certainty.

Participants’ accounts highlighted the uncertainty and fear experienced pre-transplant and during the first year post-transplantation. For those who experienced extreme sickness and



restriction on dialysis, distress and hopelessness characterised the pre-transplant waiting period. Conversely, when dialysis felt less consequential, a present-moment focus on day-to-day activities emerged; hopes for a transplant remained in the background. This appeared to be an adaptive response to the uncertainty of unspecified transplant waiting times and outcomes, emanating from a need to balance hope with the daily challenges of living with long-term illness. This aligns with previous findings whereby patients waiting for a deceased donor kidney placed transplant in the back of their minds, focusing instead on everyday life while believing that one day they would have a successful transplant (Nielsen et al., 2019).

Many participants felt they underwent transplantation without knowing what to expect. Participants typically reported having minimal expectations or preconceptions about post-transplant life and held their hopes and expectations lightly, perhaps to protect against disappointment. Intentional or otherwise, this enabled patients to balance optimism with the uncertainty of their receiving a transplant and its success. These findings seemingly conflict with Crawford et al.'s (2017) suggestion that recipients have unrealistic expectations. However, that some reported an unexpectedly long recovery, or did not initially understand the ongoing nature of transplant treatment indicates that implicit expectations may have been overly optimistic.

The role of societal expectations and normative persuasions is elaborated upon by this study's findings of conflicting emotional responses (Schipper et al., 2014; Lonargáin et al., 2017). Explicit and unspoken expectations to maintain their kidney and demonstrate the benefits of transplant, alongside gratitude and awareness of the costs and sacrifices involved, created additional pressure, guilt and isolation for recipients.

Recipients were protective of their new kidney, yet some felt pressured to prioritise their families' needs and wishes above their own, implying the role of social pressures. Perhaps in acknowledging the challenges faced by their family and the support provided throughout dialysis treatment, both recipients and their families felt a need to 'move on' and return to some form of normality following transplantation. Patients then, may have felt little choice but to ignore feelings of vulnerability to engage in behaviours they considered premature or risky. This could lead to feelings of anger, resentment, regret, guilt, or shame, which could potentially be exacerbated in the event of transplant failure.

### *Clinical implications*

Recipients' expressions of vulnerability, sadness or disappointment were not necessarily met with empathy or understanding from others. Social interactions resulting in patients feeling alienated, dismissed or undermined indicate a lack of understanding or mismatch between the expectations of others and patients' realities of living with kidney failure and transplant. Public perceptions that patients can be easily 'mended' with a replacement kidney and societal discourses marketing organ transplant as the 'gift of life' potentially underpin such incongruity, failing to mentally prepare patients and families for the challenges and restrictions of post-transplant life (Waldron et al., 2017). Established literature on hidden disabilities in the context of chronic and invisible health conditions could be utilised to help families and patients understand the impacts of living with an 'invisible' illness (Lyons et al., 2006). Transplant campaigns and pre-transplant educational interventions could better prepare patients and their families for the inherent uncertainties and likely mixed outcomes of transplantation.

Adopting a stance of 'radical acceptance' (Linehan, 1993) and a present-moment focus seemed to empower recipients to adopt pro-active approaches including self-management, while

coping with lack of control over transplant success. This supports Petre et al.'s (2020) suggestion that recipients of deceased donor kidneys focus on present-moment living in response to post-transplant life's perpetual uncertainty, and the prospect of losing their freedom or dying. Indeed, studies have shown that emotion-focused coping strategies are beneficial in contexts where the stressors are uncontrollable, which can be said of kidney transplant (Folkman & Lazarus, 1985; Nicholls et al., 2012). Psychological interventions encouraging acceptance and connection with the present moment, for example, Acceptance and Commitment Therapy, Mindfulness-based Stress Reduction and Mindfulness-based Cognitive Therapy may help patients to find positive ways to live with long-term illness and prepare for post-transplant life.

Participants identified unmet needs from their own transplant experiences, including transplant information not routinely offered by services. They craved opportunities to discuss concerns and experiences with transplant patients. Further, they advocated for earlier contact with transplant teams and the transplant centre itself, for example, through practice transplant 'run-throughs', to counter the inherent stress and uncertainty of the transplant process. Many were keen to help renal patients in similar positions, driven by a desire to 'give back' and improve transplant experiences. Renal teams could signpost patients to existing high-quality and balanced educational resources promoted by third sector organisations. While self-education is generally considered to empower and offer a sense of control and confidence (Orr et al., 2007), renal staff should also ensure that educational interventions are patient-led, considering that some patients, particularly those waiting for a deceased kidney, may not be in a position to relate to ongoing transplant education (Nielsen et al., 2019).

Expert patients have immense value and may benefit too from helping other patients. Renal staff could encourage honest discussion with patients and families about the potential

implications of receiving a kidney and becoming public ambassadors for kidney transplant. This could include: acknowledging hidden pressures, clarifying what is expected of recipients and expert patients, and validating and normalising less-publicised negative aspects of transplant and emotional responses such as disappointment or guilt. This could reassure and safeguard recipients from pressures such as sharing personal or confidential experiences, or feeling unable to disclose or seek support for negative experiences related to feelings of gratitude or personal responsibility.

### *Limitations and future research*

This study provided a snapshot of transplant experiences at a particular point in time; the cross-sectional retrospective nature required participants to rely on recollections of their pre-transplant expectations. As experience and time likely influenced people's beliefs, memories and emotions, a prospective longitudinal study following the development of expectations before, during and after transplant could reduce bias and provide insight into how expectations are shaped and realised over time. Future studies could explore recipients' perspectives at other time-points, for example, 3-5 years post-transplantation, when patients may have further settled into post-transplant routines, or otherwise experienced continued complications or graft failure (Pérez-San-Gregorio et al., 2005).

Participants in this study were recruited by renal transplant specialist nurses and were keen to assist. They were incredibly grateful for their transplant and may have been more biased towards reporting positive impacts. However, that participants shared some of their personal challenges suggests they were comfortable to speak candidly about the downsides to transplant. Due to the lead researcher not speaking Welsh, interviews only reflected English-speaking recipients, excluding those whose Welsh language and cultural identities may have contributed to qualitatively unique experiences given the cross-border nature of transplantation in north

Wales. Explicit questions exploring cultural beliefs and norms, and recruitment of non-White recipients would offer more socioculturally-attuned perspectives. To maintain anonymity, we omitted some personal details which would have provided further context and insight into patients' transplant experiences. Emergent findings from this study could be elaborated using specific eligibility criteria to explore factors including gender identity, cultural identity, spirituality and religious faith, socio-economic context, pre-transplantation family dynamics, and prior experiences of illness.

### *Conclusion*

Receiving a kidney transplant restores the vitality and sense of self eroded by kidney failure and dialysis. However, recipients and families may not necessarily anticipate post-transplant challenges or that recipients retain ongoing patient status. The first year post-transplantation is a time of specific uncertainty and continued restriction; patients may experience conflicting emotions, heightened vulnerability and pressure. Adopting a stance of 'radical acceptance' and present-moment focus may help post-transplant adjustment. Patients desire (timely) transplant information in preparation for transplant; recipients often want to 'give back' and are well-positioned to address recognised information gaps, which may best be provided through conversations with those who have undergone transplantation. Renal services can facilitate transplant adjustment by facilitating contact with expert patients, and initiating honest and balanced discussions with patients and their families about the potential benefits and negative impacts of transplant. This would help normalise conflicting emotions and help patients and families to manage their expectations to better cope with the challenges and restrictions of the first year following transplantation.

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## **Chapter Three**

Contributions to Theory and Clinical Practice

## **Contributions to Theory and Clinical Practice**

The present research project sought to develop further understanding of psychological and psychosocial aspects of living with end-stage renal disease, exploring the experiences of two groups of patients who, arguably, are at very different stages within the illness trajectory of chronic kidney disease. This chapter considers the contributions of the literature review and empirical study as they relate to theory and clinical practice.

### **Implications for future research and theory development**

The literature review forms the first known meta-synthesis and meta-ethnography focusing solely on the perspectives of patients who have chosen conservative kidney management (CKM). While small in number, the ten separate studies together highlighted patients' positive perceptions of CKM as a treatment offering congruence with their personal priorities and life stage, and simultaneously, experiences of bias in clinical practice and social interactions which explicitly and implicitly guided patients unwillingly towards dialysis.

Preferences for CKM appeared related to a need to maintain personal autonomy, independence and continuity in old age (Perrig-Chiello et al., 2006); all associated with how successful ageing is evaluated within Individualistic cultures (Coleman & Iso-Ahola, 1993; Ford et al., 2000). The advance of old age and illness, with their associated physical limitations, threaten the feasibility of these valued aspects of living. Therefore, patients' constructions of themselves as the final decision-maker and emphasis of their agency when choosing CKM likely reflect attempts to achieve 'personal control' in the face of deteriorating health (Roberti et al., 2018). This aligns with findings of patients' perceptions of dialysis as removing their personal autonomy and increasing dependence (on a dialysis machine, staff and family members).

Patients' reports of a strong sense of life completion and achievement of life goals, contentment and reduced death anxiety while living with CKM can be conceptualised using Erikson's (1963) eighth stage of psychosocial development, 'integrity versus despair'; applicable to late adulthood from the mid-60s until the end of life. These patients had seemingly resolved the tensions of this stage and were able to reflect on their lives with little regret, and satisfaction equating to a "coherence or wholeness" (Erikson, 1982), or 'ego-integrity'. This was prominent in older people's accounts of choosing CKM, who reported savouring simple delights such as spending time at home with family, seemingly satisfied with having lived a good life and accepting their limited remaining time.

In other ways, both patients living with CKM or a transplanted kidney described challenges representing an 'ego-dystonic' regression to tensions of previous life stages, akin to the ninth stage of psychosocial development (Erikson & Erikson, 1997). Physical and social changes often associated with ageing arguably mirrored changes caused by the physical and psychosocial impacts of end-stage renal disease. For example, the tensions of stage two, 'autonomy versus shame and doubt', were recognisable in one patient's likening of dialysis, with its "tubes and machines and other people dictating", to a loss of "dignity" (Selman et al., 2019). Here, the shame of lacking physical autonomy is implied. Ego-dystonic elements highlighted by kidney transplant recipients' accounts also included mistrust, relating to transplant uncertainty, fear and unpredictability; role confusion, relating to ongoing patient status following transplantation, and loss of work role; isolation, relating to being unable to express one's true experience, and loss of participation in social and family life; and stagnation, due to unexpectedly long recovery, and continued restrictions. Exploring experiences of illness through this lens may offer theoretical underpinning to interventions facilitating patients' resolution of such tensions in alternative ways. For example, identifying sources of social

support - such as other renal patients - may reduce feelings of isolation; preparing adjustment to ongoing patient status after their transplant potentially reducing role confusion and normalising negative emotions associated with the long recovery period (emotions which they may feel are unwelcome or necessitating suppression around family members).

Interpersonal, organisational and systemic factors contributing to challenges and adjustment were highlighted by patients' accounts in both studies. Experiences of kidney failure and transplantation can be better understood using Lehman et al.'s (2017) dynamic biopsychosocial model of health. Borrowing concepts from Bronfenbrenner's ecological systems theory (1979; 1986), this model provides a more contextualised approach to health, particularly with regard to interpersonal dynamics and the passage of (historical and developmental) time.

Using Lehman et al.'s (2017) model, lack of understanding on the part of family members, peers and clinicians contributed to patients' feelings of distress and invalidation at the 'microsystem' level. Reciprocal influences such as patients being unable to express themselves truly (possibly due to fear of undermining the support provided by others) may have also contributed to the maintenance of challenges through feedback loops. The model also makes it possible to locate how the immediate environment influenced the experience of decision-making and living with conservatively managed kidney disease. These included observations of family members and peers suffering and dying on dialysis, interactions with family and clinicians persuading them to start dialysis, and lack of information about CKM, disease progression and prognosis. Indirect 'exosystem' factors such as mass media depictions of dialysis and clinician familiarity with CKM, and 'macrosystem' factors (also termed 'contextual dynamics') such as state healthcare policies, distance to dialysis centres, and societal norms and values, could also be identified as influencing patients' choices for CKM.

A dynamic biopsychosocial model allows identification of potential points for intervention, for example, working at the level of the ‘mesosystem’, clinicians could provide information about CKM or transplantation to family members or workplaces to facilitate understanding of treatment impacts; working at the ‘exosystem’ level, communication training for clinicians could improve patients and families’ experiences by facilitating clear and timely communication about treatment options and disease progression.

### *Recommendations for future research*

People’s illness experiences are likely to be influenced by intersecting aspects of identity and their sociocultural contexts. Transplant recipients highlighted challenges potentially relating to their gender and family roles (e.g. as parents). For example, one participant spoke about the difficulty of accepting a kidney from his adult child, with moral connotations of violating his parental duty to protect and provide. Another participant related the loss of his working role and increasing dependence on dialysis to an erosion of his masculinity and sense of self. Findings such as these point to the importance of considering the role of relational and sociocultural factors (e.g. societal attitudes towards illness and dependence, neoliberal ableism), and warrants further research to explore, for example, gendered experiences of illness. Research may also explore the socially constructed nature of biographical narratives, and ways to reconstruct these so that illness is experienced as less of an existential threat (i.e. less ‘biographically disruptive’ [Bury, 1982]). Such research could draw on work within critical disability studies, for example, raising awareness of stigmatising societal norms, attitudes and structures, and exploring ways to address these (Goodley, 2020).

Patients from both studies reported unmet needs including information provision. Transplant recipients advocated for increased opportunities for patients preparing for transplantation to

meet with former recipients to gain emotional support and insight into the process. They also described both positive and negative impacts of their own experiences as expert patients helping new renal transplant patients. With expert patients being recognised as valuable sources of insight and support, there is a need to understand the diverse impacts of this role, for ‘newer’ patients and for themselves. Future research should explore the reciprocal influences of expert patient interactions from the perspectives of patients on both sides of the interaction, their families, and healthcare professionals. This would help to identify areas of support to identify the benefits and risks of such interactions and facilitate patients to engage in this role. This is likely to include formalising the role and developing clear expectations of both patients’ roles, to safeguard against undue pressure and distress which might arise through role ambiguity or overstepping personal boundaries.

Patients from both studies alluded to psychological aspects of coping similar to psychological flexibility, which is a broad objective of Acceptance and Commitment Therapy (ACT) (Hayes et al., 2006). For example, acceptance, gratitude, present-moment focus (mindfulness), and committed action, were identified in participants’ accounts. ACT interventions have been adapted for use with patients with wide-ranging chronic health conditions including cancer, type 2 diabetes, multiple sclerosis, cardiac disease, and epilepsy, with positive impacts on self-management and adjustment (Graham et al., 2016). While its application and evidence base for renal patients is still ‘young’, early findings from pilot studies suggest that ACT and mindfulness-based approaches such as mindfulness-based resilience training for patients and caregivers may facilitate adjustment, potentially when offered before transplantation (Stalker et al., 2018; Stonnington et al., 2016).



## **Implications for clinical practice**

The literature review highlighted that personal priorities for people with end-stage renal disease are related to perceptions of reaching the end of their natural lifespan, for whom the maintenance of independence, autonomy, and quality of life take precedence over longevity. These findings support a growing body of research indicating that for older people, quality of life is equally or more important than longevity (Parker et al., 2007; Lewis et al., 2019). Societal discourse and medical emphasis on the sanctity of life and the prolonging of life at all costs has arguably filtered into ideologies about what is valued in old age (Russ et al., 2007), not necessarily aligned with what older people view as important at the end of life when presented with terminal illness. Clinical practice and societal attitudes could be more accepting and understanding of older people's reasons for choosing CKM. Facilitating conversations between patients, families and clinicians, about what constitutes quality of life for each patient, may help to promote shared understanding and acceptance of diverse definitions of quality of life and acceptance of CKM. Definitions are likely to evolve as physical health deteriorates and people reach different life stages, however. Our findings that older patients wanted to spend more time at home rather than in hospital, and to have timely, unambiguous conversations with clinicians about diagnosis, disease progression, and CKM, are consistent with Lewis et al.'s (2019) findings that end-of-life priorities for older adults with terminal illnesses include; having a sense of personal control through meeting personal standards, expectations and aspirations; being able to do what they enjoy; maintaining a sense of self through these activities; and having honest and transparent communication between patients, caregivers and healthcare providers. In choosing CKM, patients maintained a sense of personal control and continuity, therefore, communicating these benefits to family and clinicians may encourage more positive attitudes towards conservative management, and reassure clinicians that it can very much align with patients' needs and values.

Our findings indicate that patients want health professionals to offer information about end-of-life issues and CKM so that they can prepare for future deterioration. That some patients perceived clinicians as avoiding or struggling to have specific conversations suggests a need for communication training for clinicians, to increase their confidence about discussing these topics. Collaboration with palliative services could improve clinician confidence about approaching these topics.

Findings from the empirical study indicate that the uncertainty of transplantation is a source of distress for recipients. Providing additional information about the transplant process could help patients to prepare. Participants made suggestions such as opportunities to meet with transplant recipients in the run-up to transplant and being signposted to existing high-quality resources from third sector organisations such as Kidney Wales and Kidney Care UK. This indicates that greater collaboration between the healthcare sector and third sector organisations would benefit patients. Participants also recalled watching a television programme depicting a live kidney transplant operation being completed with a living donor and a kidney transplant recipient, in the run-up to transplant. This helped patients to familiarise themselves with the procedure and go into their own transplant operations feeling more prepared, suggesting that mass media can play a role in raising transplant awareness in the public realm.

### **Personal reflections**

In outlining principles of quality in evaluating qualitative research, Yardley (2000) discusses ‘sensitivity to context’. This refers to an awareness of the sociocultural context in which research is situated, both with regard to the participants and phenomena investigated, and the researcher’s potential role in influencing data collection and analysis. Making explicit, as far

as possible, the researcher's own (fluctuating) motivations, contexts, and biases, allows readers to interpret research findings considering such influences. This section therefore offers personal reflections on the research process and outcomes as part of researcher reflexivity.

The motivation to explore people's experiences of living with end-stage renal disease came from personal and professional interest. Previous work with individuals with neurological conditions drew my attention to the psychological and psychosocial impacts of living with 'invisible' chronic health conditions, and their reciprocal influences on individuals, people around them, and the systems in which they are embedded. Experience of family members' long-term health conditions also fuelled my interest in the diverse ways in which illness and its associated lifestyle changes, becomes integrated into identities and individual and group narratives.

I approached the topic of chronic kidney disease from a largely naïve, outsider's perspective, having no personal experience of the illness. Conducting the research alongside a new clinical placement in renal medicine and inherited bleeding disorders, I entered the recruitment phase of the empirical study with limited clinical experience and a working knowledge of the medical, psychological and psychosocial aspects of chronic kidney disease and renal replacement therapies. Going into research interviews with little subject-matter expertise, I noticed a tension between portraying myself as a competent health professional with the appropriate expertise to hold and contain what participants were sharing with me (extending also to my clinical practice), for example, expressions of distress, and a desire to be explicit about my curious naivety, so that opportunities to elaborate and gain access to rich and meaningful data were not missed. Early on, I experienced an opportunity to acknowledge my ignorance, on the topic of dialysis 'drain pain'. While I was nervous to admit this, the participant responded generously

by elaborating on details that, had I not flagged up as being novel, may have led me to proceed with the rest of the interview with a superficial understanding and later, to make more speculative interpretations of their account based heavily on assumptions. The encounter gave me confidence to be open about the limits of my understanding, which hopefully signalled to participants my curiosity and desire to understand them, also giving them licence to articulate their experiences in detail.

My experience of developing an ‘invisible’ long-term health condition in my early twenties likely sensitised me to picking up certain themes during analysis and synthesis. Accounts relating to alienation, altered relational dynamics, restriction and loss of control resonated with me more as a result of my personal history. There was a risk of over-identifying with participants about particular aspects of their experience, or projecting my own feelings and beliefs onto them. Therefore I had to be alert to opportunities where I might intervene to minimise making assumptions. However, in discussing with my research supervisor the analysis process and the development of themes, I came to further understand how my subjectivities and experiences are inherently bound to my interpretations; and that the aim is not to separate the data from the context but to make explicit where these elements interact and influence what eventually is reported. Participants offered enlightening accounts and I felt responsible to accurately represent what people had highlighted as personally significant. For example, I was drawn to delve further into themes highlighting crisis of identity and fluidity of boundaries between ‘self’ and ‘other’, which felt prominent for one participant. However, I was reminded in supervision of my responsibility to report as widely as possible across participants’ accounts and to keep in mind the wider implications of the research.

My identity as a British-born, Chinese second-generation immigrant, gives me access to two arguably opposing cultures, Collectivism and Individualism. While conducting the meta-ethnography, I was interested in the cultural interpretations that researchers based in Singapore emphasised in their findings, particularly that cultural ideology based on Confucian concepts of personhood and autonomy filtered through into state healthcare policies and ultimately influenced patients' CKM decision-making. The researchers argued that due to cultural values of harmony and interdependence, patients' decisions were deeply embedded into the family context, and that inter-relational dynamics and family involvement in decision-making needed to be attended to in Collectivist cultures. While I was inclined to agree, I had to be mindful of the fact that only two studies in the meta-ethnography were conducted in Collectivist cultures, and the risk of over-generalising these findings due to personal biases. Still, this process made me consider how the application of Eurocentric concepts in Clinical Psychology continues to favour thinking and intervening on an individual level, and that working more closely with disciplines which more readily apply systems-level thinking could be beneficial regardless of alignment with Individualism or Collectivism.

I had hoped to elevate the voices of recipients given that their perspectives are less represented in research compared to donors. However, not being able to speak Welsh myself, I was acutely aware of being unable to offer interviews in people's mother tongue, thus excluding Welsh voices and complicitly perpetuating a system of not meeting basic language needs (Welsh Government, 2019). Given the recognised challenges of speaking about personal experiences in a second language, research conducted through the medium of Welsh, and more generally, in people's first language, is needed. This may help to identify culturally distinct aspects of experience, translating into more culturally-attuned healthcare practices.

Due to the global Covid-19 pandemic, interviews coincided with a prolonged period of ‘lockdown’, the full impacts of which are yet to be understood. As participants relayed their frustration with the restrictions of post-transplant and pandemic life, for example, missing out on personally significant post-transplant plans and family milestones, I considered how the timing of the interviews created a rare context in which I was able to more readily relate, in an embodied way, to their experiences of restriction, uncertainty, vulnerability and deviation from life plans. While some participants reported solitude and relief from challenging social interactions, others discussed heightened vulnerability and a sense of ‘missing out’, highlighting the diversity of pandemic responses. Another participant shared how difficult it was to separate his emotions relating to the pandemic from those relating to his transplant. This led me to consider the methodological limitations of asking people to isolate and articulate specific phenomena or experiences, and the need to situate their experiences within developmental, social, cultural, political and historical contexts.

Interviewing individuals who had been in close contact with serious illness and death and reviewing the literature on the experiences of patients with conservatively managed kidney disease offered a chance to reflect on what constitutes quality of life and quality in dying. Participants spoke about acceptance, gratitude, the transience of life, and the importance of meaningful relationships. Their perspectives made me examine my own and I hope that their accounts encourage the same for others.

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## **Appendix 1. Semi-Structured Interview Schedule**

### **SEMI-STRUCTURED INTERVIEW SCHEDULE**

#### **Pre-ample:**

Thank you very much for agreeing to take part in this research study. We are interested in hearing about your experience of kidney transplantation. You have given your consent to be interviewed by telephone, and I want to make it clear that your participation is entirely voluntary, meaning you can withdraw from the interview and research study at any time, without giving a reason. This will not affect your care or legal rights in any way. It is important for me to stress that you do not have to answer any questions that you do not want to, and you do not have to discuss any topics that you feel are sensitive or upsetting. There are no right or wrong answers to the questions being asked and you can stop the interview at any time. Please also feel free to take as many breaks as you need during this interview. It's expected to take between 1 and 2 hours, but do let me know if you start feeling too tired or unwell to carry on.

All the information you provide will be kept securely, and the content of this interview will be kept confidential. While the content of this conversation is confidential, you have given permission for anonymised quotes to be used as part of the research. If you share anything that gives me cause for concern regarding your own safety or the safety of another person, I may have to break confidentiality. In the event of such a situation, I will discuss this with you. Do you have any questions that you would like to ask me?

#### **Interview questions:**

##### **Experiences**

#### **1. I'm interested in hearing about your experience of the work-up to receiving your kidney. What was that period like?**

*Potential prompts:*

- What stood out?
- What worked well?
- What were some of the challenges you faced?

#### **2. What was the first year after receiving your transplant like, from the time you woke up in the hospital, through your recovery and the later stages of that first year?**

*Potential prompts:*

- Were there any significant milestones for you?
- What has helped you through the challenges you faced?

### **Expectations (self)**

- 3. In the run-up to receiving an organ transplant, some people have expectations about what life will be like after transplantation. What were your own expectations of what life would be like after getting your kidney transplant?**

*Potential prompt:*

- What did you base your expectations on? Did anything or anyone influence those expectations?

- 4. Some people find that life after transplantation can differ from what they expected and this can result in both positive feelings and feelings of disappointment. Looking back, how has your experience compared to any expectations you had before your transplant?**

*Potential prompts:*

- How do you feel about having had your transplant knowing what you now know?
- Have your views about having a transplant changed over time?

### **Expectations of others and relationships**

- 5. Do you think the people around you had any expectations of what life would be like after getting your transplant and how did this affect you?**

- 6. How has your transplant affected your relationships with the people in your life, such as friends, family, partners and colleagues?**

*Potential prompt:*

- Do you think people see you or treat you any differently since your transplant?

### **Being an expert**

- 7. Reflecting on your experience, what would have made your kidney transplant experience better?**

*Potential prompt:*

- Is there anything that you felt was missing or you would have liked at any stage?

- 8. Thinking about what you know now having reached this stage of the process, what advice would you give to another renal patient who was at start of the process of receiving a kidney transplant?**

*Potential prompts:*

- Is there anything you weren't aware of that would have been helpful to know when you began the process?
- What would you tell your pre-transplant self if you had the chance?

- 9. Is there anything else you would like to add?**

## Appendix 2. Research Protocol

### RESEARCH PROTOCOL

#### Study title

The experiences of kidney transplant recipients one year post-transplantation

#### Researchers

Rebecca Chan, Trainee Clinical Psychologist, BCUHB

Dr Beth Parry-Jones, Consultant Clinical Psychologist, BCUHB Central & East Renal Services

Dr Paul Gardner, Consultant Clinical Psychologist, BCUHB West Renal Services

#### Background

##### *Kidney transplantation*

End-stage renal disease (ESRD) describes the last stage of chronic kidney disease, when the kidneys can no longer sustain vital function and renal replacement therapies (RRT) such as kidney transplantation, haemodialysis or peritoneal dialysis are needed for survival (DoH, 2004). In the UK alone, 64,887 adult patients were receiving RRT at the end of 2017, with kidney transplantation being the most common treatment (55.2%) (UK Renal Registry, 2019). Kidney transplantation is viewed as the ‘gold standard’ treatment for ESRD, with 3280 adult kidney-only transplants completed in the UK in the financial year of 2018/19 (NHS Kidney Care and Blood and Transplant, 2013; NHS Blood and Transplant, 2019; UK Renal Registry, 2019). Transplantation offers significant potential physical and functional benefits, namely, improved independence and quality of life, longer life expectancy, and greater freedom from the restrictive complications associated with chronic kidney disease (DoH, 2004). However, despite the potential benefits, post-transplant quality of life for kidney transplant recipients still appears to be lower than that of ‘healthy’ populations (Landreneau, Lee & Landreneau, 2010).

##### *Psychological impact of kidney transplantation*

The process of receiving a kidney can give rise to additional challenges for patients and their families. Aside from the physical challenges of recovering from a major operation and managing post-transplant regimens, transplant recipients must negotiate and adapt to novel challenges, stressors, opportunities, roles and demands (Fallen, Gould & Wainwright, 1997; Wainwright, Fallon & Gould, 1999; Zimmermann, Pabst, Bertram et al, 2016). Immunosuppressant medication side effects have been reported to give rise to a high sense of vulnerability for some recipients, while others have reported sexual dysfunction and undesirable changes to physical appearance (Lonergain, Brannigan & Murray, 2017; Schipper, Abma, Koops et al, 2014; Matas, Halbert, Barr et al, 2002). Depressive symptoms and anxiety have also been reported despite positive medical outcomes, suggesting that the process of adjustment may not be straightforward (Heck, Schweitzer & Seidel-Wiesel, 2004).

Quantitative questionnaire studies examining recipients’ psychological and behavioural responses to transplantation have reported inconsistent findings with regard to elevated levels of anxiety, depression and guilt, compared to ‘healthy’ populations and other RRT modalities such as haemodialysis. For example, prevalence studies of depression in kidney transplant recipients have reported figures ranging from 12% to 75% (Vásquez, Navarro, Valdés et al, 2013; Anvar-Abnavi & Bazargani, 2010). Psychological responses both specific to the experience of receiving a kidney and varying in intensity have been reported following transplant, from mild anxiety concerning the viability of the kidney graft, to “extreme” pervasive fear of graft rejection, and feelings of guilt, gratitude, anger

and indebtedness (Kong & Molassiotis, 1999; Griva, Ziegelmann, Thompson et al, 2002; Pillay, Sclebusc & Louw, 1992; Orr, Willis, Holmes et al, 2007). Recipients of cadaveric (as opposed to living) donor kidneys are also more likely to report experiencing a sense of having taken on the characteristics of their donor, raising questions about how the individual's sense of wellbeing and identity may be affected by transplantation (Sanner, 2003). It has, therefore, been argued that quantitative surveys may fail to capture the complexity of the emotional responses and experiences of transplant recipients, and that qualitative methods may be better suited to exploring the individual meanings of living with a donor kidney (Dobbels, De Bleser, De Geest et al, 2007; Lonargáin et al, 2017; Schipper et al, 2014).

#### *Qualitative research on kidney transplant experiences*

Health psychology is a relatively new area in renal care and qualitative studies on kidney transplant experiences have traditionally focused on living donors as opposed to the lived experience of recipients (Ummel, Achille & Mekkelholt, 2011). This can be considered in the context of continued shortages of donor kidneys, preference for living (over cadaveric) donor kidneys due to superior clinical outcomes, and strategic drives within the NHS to increase the numbers of living kidney donors. All of these may contribute to a 'privileging' of donors' perspectives on the experience of receiving a kidney transplant and an imbalance in research agendas (i.e. targeted efforts to demonstrate the benefits and low risks of living kidney donation) (Johnson, Bradbury, Martin et al, 2014; NHS Blood and Transplant, 2014). A growing body of qualitative research exploring the psychological wellbeing, adjustment and lived experience of kidney transplant recipients is beginning to redress this imbalance and shine a light on the complexities of living with a donated kidney (e.g. Croft & Maddison, 2017; Schipper et al, 2014; Lonargáin et al, 2017).

#### *Conflicting emotions towards kidney transplantation*

Qualitative studies looking at how living donor kidney transplant recipients negotiate the transplant process have begun to highlight how ambivalent and conflicting emotional responses can cause recipients psychological strain (Ummel & Achille; 2016, Ummel et al, 2011). Receiving a kidney can be accompanied by emotional highs and a sense of being given a new lease of life (Ummel & Achille, 2016). However, receiving this "gift of life" – as kidney donation is often described by both health professionals and the general public, can also be challenging, leaving some recipients feeling obligated to always be grateful, while others become extremely cautious about their own health, for fear of being held responsible in the event of graft failure (Gill & Lowes, 2008; Ummel & Achille, 2016). One Dutch study identified that normative persuasions can be influential in shaping how recipients respond to both positive and negative outcomes of transplantation, such that even physical improvements or positive emotions can confront patients with challenging problems and emotions (Schipper et al, 2014). For example, transplant recipients may experience psychological strain due to uncertainty about how to approach new roles and opportunities following transplantation, or they may have feelings about not being able to sufficiently express their gratefulness to donors. Such findings may point towards a role for individual and societal norms and obligations influencing how people respond to transplantation.

#### *Post-transplantation expectations*

Expectations about life following transplantation may be a source of emotional distress for some recipients, and may stem from transplant recipients themselves as well as those around them. Recipients have described how a lack of understanding from others and unsupportive judgments and interactions can affect their wellbeing. For example, some individuals have reported relational difficulties with family, friends and colleagues treating them as if they are fully 'healthy' and assuming

that they should be able to “move on” and “carry on as normal” despite having just undergone major surgery (Lonergain et al, 2017; Schipper et al, 2014). Others have talked about self-imposed pressures to “succeed in life” or push themselves further at work to make up for time lost to hospital appointments, thus transitioning from “fighting to survive a major operation, to fighting the pressures that society is placing on them” (Lonergain et al, 2017).

Crawford and colleagues’ (2017) observational commentary of Australian kidney transplant recipients involved in a study of theirs suggested that recipients may have unrealistic expectations about what life after transplant may involve and that they may underestimate the complexities of maintaining their graft. For example, some did not anticipate that their medication would make them feel more sick and unwell, and others anticipated a quicker return to “normalcy” and were not prepared for obstacles or complications in the first few months. The researchers observed that transplantation had the opposite intended effect on some recipients who were highly aware and anxious about the threat of graft rejection, were living in fear and perhaps feeling more restricted and vulnerable than before transplantation. The researchers also emphasised a range of responses to complications, from psychological distress to increased resilience and determination to adhere to medication regimens. Notably, Croft and Maddison’s (2017) review of existing literature observed that kidney transplant recipients tended to have only reported positive pre-transplantation expectations. The researchers questioned how informed patients might be regarding the potential risks of transplantation and whether patients were offered adequate psychological provision in the run-up to the operation. Expectations (both realised and unrealised) therefore appear to be a common theme in qualitative studies of transplant recipients’ experiences and may help explain emotional adjustment during the post-transplantation period.

#### *Influence of time on psychological adjustment*

While little research has explored how time influences psychological adjustment to kidney transplantation, one cross-sectional study suggested that the psychological status of kidney transplant recipients varies with the passage of time (Pérez-San-Gregorio, Martín-Rodríguez, Galán-Rodríguez et al, 2005). The authors compared depressive and anxious thoughts and body image perceptions of recipients at distinct time points post-transplantation (1 year, 1-2 years and 2 years) and found a ‘U-shaped’ pattern, whereby participant reported more depressive and anxious thoughts and lowered physical self-esteem in the first 12 months post-transplantation, followed by a drop in these symptoms in the year after, only to increase again after 2 years post-transplantation. They proposed that patients during the first year post-transplantation must cope with severe emotional and physical challenges surrounding readjustment, returning to work, fear of kidney rejection and ‘anxious waiting’, and after the first 12 months, adaptation becomes more established as patients and families adjust to their new situation. After 2 years post-transplantation (‘exhaustion’ stage), psychological disturbances may increase, potentially brought on by a return of fear of graft failure, disappointment or a growing tiredness with their situation (such as not having a ‘normal’ life or needing continual medical monitoring). These findings indicate that kidney transplant recipients may negotiate specific challenges at each stage of the transplantation process, therefore targeted research which explores recipients’ experiences at specific time-points may further our understanding of psychological wellbeing and adjustment to kidney transplantation.

#### *Rationale for current study*

Clinical practice guidelines from The NHS Blood and Transplant Strategy (2013) focus more heavily on the medical and physical aspects of recovery from kidney transplantation, as opposed to the psychological and psychosocial domains, and this may be reflective of the relative lack of understanding of the psychological impacts of receiving a kidney (Croft & Maddison, 2017). As such,

significant numbers of people live with the consequences of kidney transplantation, while relatively little is known about how transplant recipients may experience this potentially life-changing process.

Qualitative research in this area is starting to broaden our understanding of this process, though the existing literature has traditionally focused more on the perspectives of kidney donors rather than recipients. Qualitative research on kidney transplant recipients' experiences has been conducted in Germany, Denmark, the Netherlands, Canada, Australia and more recently, the UK. To the author's knowledge, no qualitative studies have investigated the experiences of kidney transplant recipients in Wales (or North Wales specifically). Given the potential differences in culture, ethnic diversity, socio-economic diversity, socio-political factors and NHS service provision, experiences of receiving a kidney in North Wales may differ qualitatively. As research indicates that kidney transplant recipients may face qualitatively different challenges during the first 12 months of transplantation, compared to later stages (Pérez-San-Gregorio et al, 2005), researchers have called for targeted research to explore recipients' experiences within distinct time-frames (Lonargáin et al, 2017). There has not yet been a qualitative study in North Wales focusing on kidney transplant recipients' experiences, despite the large region covered by its Health Board (Betsi Cadwaladr University Health Board). Given that kidney transplant recipients may face more severe challenges of adjustment during the first year post-transplantation, interviewing them about their experiences of this first year shortly after this period may enable patients to reflect on this phase and offer valuable perspectives on the nature of challenges and adjustment, and potential ways to improve this post-transplantation period for future patients.

Understanding the transplant experience from the perspective of recipients may inform service delivery in terms of highlighting what information, care, support and advice recipients and their families may need, and how this may be delivered to help prepare them for the transplant process and for life beyond transplantation.

### **Research aim**

This qualitative study seeks to explore the perceptions, meanings and experiences of kidney transplantation in adult kidney transplant recipients, with a focus on their first year post-transplantation and a sub-aim of investigating how pre or post-transplantation expectations may shape these experiences. This will be done by directly asking patients to give a detailed and subjective account of what life is like for them following kidney transplantation and what impact kidney transplantation has had on aspects of their life, emotionally, psychologically and socially. Topics may include: self-identity, expectations of life post-transplantation, relationships, and aspects of their care and treatment; however, as this is an exploratory study, the content and direction of discussion topics will be ultimately led by what participants feel are significant and meaningful to them.

The study aims to develop understanding of transplantation processes and to draw attention to the possible implications of kidney transplantation on individuals' psychological wellbeing and identity. Findings may contribute to the development of information and support for kidney transplant recipients in North Wales Renal Services and across the UK.

### **Methods**

#### **Design**

This small-scale qualitative study will employ a cross-sectional design. Single semi-structured telephone interviews will be conducted with a purposively selected sample of participants, following the principles of 'Interpretative Phenomenological Analysis' (IPA) (Smith, Flowers & Larkin, 2009).

IPA involves interviewing individuals most concerned by the phenomenon being studied, in order to identify the unique perceptions and narratives that communicate people's subjective understanding of events. In this case, it will involve interviewing kidney transplant recipients about their experiences of receiving a donor kidney transplant. IPA is concerned with describing and interpreting how individuals make sense of their lived experiences and providing a detailed account in which participants' experiences are expressed in their own words. The approach aims to gain access to participants' personal meanings and interpretations, and to develop insight into major life experiences, as opposed to trying to establish objective "truths" about experiences, or defining experiences in absolute ways. IPA is therefore said to be idiographic, employing a 'constructivist-interpretivist' paradigm. IPA is considered a useful method for understanding the impact of experiences in psychological, emotional and social terms, and is ideally suited to exploring health psychology and lived experience (Brocki & Wearden, 2006; Smith, 2011).

IPA recognises research as a dynamic process between participant and researcher whereby initially, participants attempt to make sense of their experiences, then the researcher attempts to make sense of, and interpret, the participants' accounts of their experiences (Dancyger, Wiseman, Jacobs et al, 2011). This process of engagement is known as the 'double hermeneutic' (Smith et al, 2009; Osborn & Smith, 2008). In this way, IPA readily acknowledges that the researcher's own beliefs and experiences will influence (and therefore potentially bias) analysis during the process of data collection and afterwards. IPA concedes that while direct access to participants' worlds is impossible, insights can be gained by interpreting this world, while recognising that participants' contextual and cultural contexts will be relevant too (Reid, Flowers & Larkin, 2005).

### **Participant criteria**

#### *Study inclusion criteria*

Participants who meet the following criteria will be eligible to participate in the study:

- Must have received a kidney-only transplant via living or cadaveric donor
- Must have received care from the NHS within a BCUHB Renal Service
- No restrictions on kidney transplant recipient's relationship with donor - can be live/cadaveric; related (e.g. sibling/parent-to-adult child/adult child-to-parent, spouse) or unrelated (e.g. friend, colleague, altruistic)
- Are at least 12 months post-transplantation, ideally not more than 2 years post-transplantation
- Adults (aged 18 years+, no upper age limit)
- No restrictions on gender
- No restriction on whether the kidney transplant was successful or not.

#### *Study exclusion criteria*

Participants who meet the following criteria will be excluded from participating in the study:

- Unable to speak English to a sufficient level for participating in in-depth interviews
- Impaired cognitive or mental status which compromises ability to provide informed consent (capacity to consent will be determined by the individual's renal healthcare clinicians)
- Have had non-renal allografts.

#### *Sample size*

For IPA, a small sample of 4-10 participants is recommended (Smith et al, 2009). This study will therefore seek to recruit 5-8 individuals to take part in single semi-structured telephone interviews (a maximum of 10 participants will be recruited). For the purposes of maintaining confidentiality and



improving generalisability, recruitment will take place across all three renal services managed by Betsi Cadwaladr University Health Board (BCUHB).

### **Participant recruitment**

Renal Transplant Specialist Nurses (RTSNs) associated with the three renal services across BCUHB will assist in the identification and recruitment of participants, and they have provided initial consent and agreement to assist the study in this way. The RTSNs will be familiar with potential participants as they are members of individuals' renal healthcare teams, and will already have clinical authorisation to access patient records as part of their clinical roles. They will identify potential participants by looking through patient databases and reviewing patient medical records against the study's inclusion and exclusion criteria.

Prior to recruitment, the Principal Investigator will meet virtually with the RTSNs to brief them on the study and answer any questions. RTSNs will be provided with written information sheets about the study, which will cover research goals and protocol, study inclusion and exclusion criteria, and an outline of their roles in identifying and recruiting participants.

RTSNs will first approach eligible participants by written, telephone, or face-to-face contact, and ask participants if they would be interested in receiving written information about an upcoming research project. Those who respond affirmatively will be provided with written information packs about the study. These will contain:

- A participant information sheet with details about the study, including research goals and protocol
- A copy of the participant consent form
- An opt-in slip with space for patients to provide contact details and consent to be contacted by the Principal Investigator, if interested in participating
- A pre-paid envelope for returning the opt-in slip to the Principal Investigator
- Contact details of the Principal Investigator

When contacting potential participants, the RTSNs will make it clear that they have no direct involvement in the study besides recruitment and that patients' care will not be affected by their decision to participate or not. RTSNs will be clear that they are not members of the research team and that they will not have access to any interview data collected. Consent will be obtained from interested participants prior to the Principal Investigator contacting participants to discuss the study and arrange interviews, as indicated by them signing and returning the study opt-in slip and providing their contact details. The Principal Investigator will not contact participants without this consent. RTSNs will be instructed to contact 5 potential participants each initially (each RTSN recruiting from one of the 3 renal services across BCUHB), to control the rate of recruitment, however, this may be revised depending on demand.

### **Procedure**

Participants will be invited to take part in a single semi-structured telephone interview, conducted by the Principal Investigator. Participants will provide written consent prior to interviews taking place. Interviews will take place individually, and will likely take place in participants' own homes. It is anticipated that interviews will last 90-120 minutes and will be completed in one sitting. However, as the participants have chronic health conditions and may be affected by fatigue or fluctuating concentration, some may prefer or require a shorter interview, or wish to complete the interview in several sittings. The Principal Investigator will work flexibly, monitoring participants' levels of engagement, physical discomfort and consent throughout the interview. This may include pausing or

finishing the interviews early following discussion and consideration of participants' wishes. Participants will be asked to take the interviews alone in quiet, private rooms, away from distractions, interruptions and other household members.

Time will be allocated at the start of interviews to discuss the limits of confidentiality, right to withdraw and the interview process, as well as building rapport and putting participants at ease. In line with IPA guidelines, a flexible interview schedule will be used to guide interviews towards areas of interest based on the study's aims, though the actual content and direction of interviews will be determined by participants (Smith et al, 2009).

Potential areas of exploration during the interviews include:

- Participants' experiences of the renal services throughout the transplant process
- Participants' experiences during the first year following transplant
- Participants' expectations of the transplantation process (including pre and post-operation expectations; realised and unrealised expectations)
- Impact of transplant on self-identity, including relationship with donated kidney
- Impact of transplant on relationships (particularly with the donor/ donor's family, but also friends, family, colleagues)

Active participation will end on completion of the interview, though participants will be given the opportunity to contact the Principal Investigator should any research-related questions or concerns arise following the interview.

### **Measures**

Some demographic information will be collected from participants, including: age, gender, type of kidney transplant received (e.g. living/non-living, related/non-related), relationship to donor (e.g. spouse, parent), and time elapsed since transplant procedure. No formal psychometric measures will be administered.

### **Data Analysis**

Data will be analysed by the Principal Investigator following the principles of IPA, which comprises six main stages (Smith et al, 2009; Osborn & Smith, 2008). In the first stage, the researcher reads and re-reads the first interview transcript with the aim of becoming familiar with the data and immersed in it. The second stage is initial note-making, whereby the researcher examines semantic content and language use, making notes on the transcript and adding descriptive, linguistic and conceptual comments about what the interviewee is communicating. Thirdly, 'emergent themes' are developed in such a way that the volume of data is reduced but the complexity and meaning are retained. The fourth stage involves the researcher looking for connections across themes, and creating a 'map' of how the themes may be positioned in relation with one another (for example, 'clusters' of themes). The development and refinement of themes is a continual process. In the fifth stage, the next interview transcript is examined, following the first 4 stages described above. This continues systematically for all interview transcripts. The sixth stage involves searching for patterns across all the interview transcripts, and identifying similarities and differences between interviewees' responses and experiences. A narrative account of major and minor themes is modelled up and written up, such that the experiences of the interviewees are presented in varying levels of interpretation and complexity. Analysis and interpretation continues throughout the write-up process as emerging patterns are identified. The researcher also keeps a reflective journal throughout the entire research process, which may include thoughts and feelings that arise in relation to the work.

In IPA research, it is recommended that an independent audit method is followed to improve the validity and reliability of the research (Smith et al, 2009). As such, data will be organised and presented in such a way that a 'chain' of evidence can be followed, starting from the original data (for example, the interview transcripts) and continuing on to the finished written research report. In this project, the supervisors will inspect anonymised annotated transcripts and master documents of quotes and themes, as well as written reports of how ideas for themes have been constructed and the final narrative write-up. The aim of this will be to provide a level of transparency to show how thoughts and ideas have shaped the analyses at each stage of the process, thus offering a 'credible' account of the data. Supervision will involve the lead supervisor reading over anonymised transcripts and theme constructions, and facilitating the Principal Investigator to extend their interpretation.

### **Data Management**

The Principal Investigator will comply with BCUHB and Bangor University and data protection policies and procedures at all times (including Data Protection Act, 1998). All interviews will be audio-recorded using a digital voice recorder, transferred to an encrypted password-protected pen drive and then immediately deleted from the digital voice recorder. Audio-files will then be transferred to and stored on a secure BCUHB-owned computer or laptop. Interview transcripts will be assigned anonymised participant numbers at the point of transcription. Potentially identifying details will be described in more general terms or removed from interview transcripts to preserve anonymity. These may include, though are not limited to, names, ages, dates, occupations, locations and services. Similarly, any published quotations will have had potentially identifying details redacted or altered so that general terms are used over specific terms, and participants' confidentiality is maintained. Identifying details will be removed from contemporary field notes and managed similarly. All electronic files will be stored on a BCUHB-owned computer system, and will only be transferred to the Principal Investigator's personal laptop when all data has been anonymised and confidential or potentially identifying details have been removed. Only fully anonymised participant data will be stored on the Principal Investigator's personal laptop. Electronic data will remain encrypted and password-protected, and all audio-recordings will be destroyed once transcription is complete. Only the research team will have access to audio-files, interview transcripts and field notes.

Personal information relating to participants such as names and contact details will be stored as paper records for 6 months following completion of the study, in a locked filing cabinet at the lead supervisor's clinical base that is only accessible to the lead supervisor, and kept in a locked office accessible only to BCUHB renal clinical staff. This information will be required to post out written summaries of study findings to participants as requested. After 6 months, the lead supervisor will destroy all paper records in line with BCUHB procedures.

On completion of the project, all anonymised electronic data will be stored on a secure Bangor University-owned computer system for 10 years, after which it will be destroyed in line with Bangor University procedures and data protection legislation.

### **Feedback**

Participants will be asked if they would like to receive a summary of the main findings of the study. Those who request this will be provided with a 1-2 page written summary of the main findings once the study is complete.

## **Risk assessment**

### *Risks to participants*

Due to the sensitive subject matter of the interviews, participants are likely to be discussing highly personal and emotive information which may potentially elicit difficult emotions or distress for them. Participants will be fully informed about the topics that may be covered in the interviews. They will be reminded that they are under no obligation to discuss any topics that are particularly distressing and that they may stop or withdraw from the interview at any point. Participants will be assured anonymity and confidentiality, and personal risks will be discussed prior to being interviewed, to enable advance consideration and open discussion about potential difficulties. In line with the principles of Interpretative Phenomenological Analysis (IPA), an interview schedule will be used to guide the interviews, however, participants will remain in control of the topics and direction of the interview at all times.

If, during the interviews, participants experience distress, the Principal Investigator will provide space for this to be explored together, and collaboratively, a decision will be made with regard to managing any risk. The Principal Investigator will also be in a position to provide useful contact numbers for participants as required. Participants may also be referred, with their expressed consent, into the clinical psychology service, for which the lead supervisor oversees as a consultant. If a participant discloses suicidal thoughts with intention or planning, or discloses planning or knowledge of potential harm to other people, it will be necessary for the Principal Investigator to inform the appropriate professionals.

At the end of interviews, the Principal Investigator will check to ensure that participants are not left in a state of distress. Participants will be invited to discuss how they found the interview process and time will be allocated to provide a debrief and to manage any negative affect.

### *Risks to researcher*

The Principal Investigator is a trainee clinical psychologist and is therefore skilled in managing their own and other people's distress. However, they will seek regular supervision from the lead supervisor to discuss any issues arising that may relate to distress caused by the interview or research process.

Telephone interviews will be arranged at a mutually convenient time for the participant and Principal Investigator, which may mean that some interviews will be scheduled to take place out of usual '9-5' office hours, or on weekends. As such, the Principal Investigator will adhere to BCUHB lone worker policies and seek supervision from the lead supervisor.

## **Diversity**

Efforts will be made to ensure that the research study is open and accessible to all patients satisfying the study's inclusion criteria. To this end, British Psychological Society (BPS) research guidelines and 'codes' of ethics will be consulted to ensure that the research is carried out as ethically as possible.

Written participant information sheets, opt-in slips and consent forms will be available in both English and Welsh, as will written summaries of the main findings provided to participants who request these.

It is an acknowledged limitation that the lead researcher is English-speaking only, therefore unfortunately it will not be possible to complete the interviews in Welsh. Any issues arising from this will be brought to supervision with the lead supervisor for discussion.

## **Funding**

Participants will be offered £20 cash for their participation in a single semi-structured interview. Expenses will be covered by North Wales Clinical Psychology Programme.

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## Appendix 3. Participant Information Sheet



### PARTICIPANT INFORMATION SHEET

***Research Study: The experiences of kidney transplant recipients one year post-transplantation***

#### **Research Team**

Rebecca Chan, Trainee Clinical Psychologist  
Dr Beth Parry-Jones, Consultant Clinical Psychologist  
Dr Paul Gardner, Consultant Clinical Psychologist

We would like to invite you to take part in a research study which aims to explore the impact of kidney transplantation on the lives of adult kidney transplant recipients. We hope to extend invitations to renal patients across North Wales who have recently had a donor kidney transplant within Betsi Cadwaladr University Health Board (BCUHB) Renal Services.

Before you make a decision about whether or not you would like to take part, it is important that you understand why this research is being done and what it involves. Please read this information sheet carefully and take as much time as you need to consider it. We are happy for you to contact us if anything seems unclear. You will find the contact details for the lead researcher, Rebecca Chan, at the end of this information sheet. You can also contact your Renal Transplant Specialist Nurse for more information. If they are unable to answer any questions, they will contact Rebecca on your behalf.

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

The aim of this study is to explore in depth the experiences of people who have received a kidney through transplantation. While previous research has explored the experiences of kidney donors, less research has looked at the experiences of people who have received a kidney. No studies so far have looked at the experiences of renal transplant recipients in North Wales.

We would like to ask you about your experiences of receiving a donor kidney within BCUHB Renal Services and what life has been like since having a kidney transplant. This information will be used to help people working in renal services to better understand the experiences of kidney transplant recipients and their families, with the hope of improving renal services, support and information for renal patients in North Wales and elsewhere.

This study will form part of a doctoral thesis in Clinical Psychology for Rebecca Chan, who is studying at Bangor University and is employed by BCUHB. The project is being supervised by Dr Beth Parry-Jones and Dr Paul Gardner, both are Consultant Clinical Psychologists currently working within the BCUHB Renal Psychology Service.



**Why have I been invited to participate?**

We have asked the Renal Transplant Specialist Nurses to approach individuals aged 18 years and above who have received a kidney-only transplant within the last 2 years at one of the North Wales Renal Services in BCUHB. We are seeking a maximum of 10 people to take part.

Although all the information about the study will be available in Welsh and English, we are sorry that the telephone interviews will have to be conducted in English as unfortunately Rebecca does not speak Welsh.

**Do I have to take part?**

Not at all. You do not have to take part or give a reason for not doing so. Participation in this study is completely voluntary and it is completely up to you to decide whether or not you would like to take part. If you do decide to take part, you will be asked to sign a consent form.

Also, if you decide to take part, you can change your mind about participating and withdraw from the study at any point, without giving a reason. Withdrawing from the study will not affect your care at the renal service or any other part of the NHS, nor will it affect your legal rights. You can also ask for your data to be removed after you have participated in the study. This will not affect your medical care or legal rights in any way.

**What would taking part involve?**

If you agree to take part in this research, you will be asked to do a single telephone interview with the lead researcher, Rebecca Chan, where you will be invited to talk openly about your experiences of the kidney transplantation process, and what life has been like since getting a transplant. This interview will be arranged at a time and date that suits you, and can take place in the evening or weekend if you prefer. It is important to be aware that you do not have to answer any questions that you do not want to and you do not have to discuss any topics that you feel are sensitive or upsetting. There are no right or wrong answers to the questions being asked and you can stop the interview or withdraw from the study at any time if you do not feel it is right for you. You will not need to explain your reasons for doing so.

At the start of the interview, Rebecca will ask you some short questions including your age, time since transplant, your relationship to the kidney donor (e.g. relative or unrelated) and the type of kidney received (e.g. living donor or cadaveric). Following this, Rebecca will ask you a series of questions that will encourage you to talk openly about life following kidney transplantation. We are particularly interested to know if and how kidney transplantation has affected various aspects of your life, whether it has affected the way you feel about yourself, and how you experienced aspects of your treatment and care. The research questions have been designed by the research team and have been approved by Bangor University and BCUHB. Rebecca will use a digital audio-recorder supplied by Bangor University to record your interview.

We estimate that the interview will take approximately 60-120 minutes to complete. You will be able to take as many breaks as you need throughout the interview. If you feel tired or unwell during the interview, you will have the choice of completing it over 2 sessions (i.e. on 2 different days). It is important that the interview takes place somewhere comfortable, quiet and private so that it is confidential and free of interruptions. You may find that doing the interview at home is most suitable, however, if you feel you may be more comfortable in a hospital clinic room, this could be arranged.

**What will happen to my interview?**

All interviews will be audio-recorded and then typed up into written transcripts of what was said. These transcripts will be anonymised to remove your name and any other information that might make it possible to identify you. The audio-recording of the interview will be erased as soon as the transcripts have been typed up. Only the research team will be able to listen to these recordings.

After transcribing all the interviews, we will summarise into 'themes' how participants have described their experience of receiving a kidney transplant and what life is like for them. We will use direct quotes (i.e. things that people have said in the interviews) to illustrate these themes and we may use your words for this purpose. However, we will follow strict guidelines to ensure that it is not possible to identify you through your words; we will not include any names or personal details, and will replace specific terms with more general ones to ensure your anonymity. We will then let people know what we have found, and potentially publish the results of the research. We would be happy to provide a written summary of our main findings if you would like this, once the study is complete.

**What about confidentiality?**

Your interview will be audio-recorded and then this recording will be destroyed after being transcribed. Your personal information and audio-recorded interview will be treated as confidential and stored securely. We will not share your personal information with anybody outside of the research team. Your data will be given an anonymised participant number at the point of transcribing the audio-recordings and pseudonyms (different names) will be assigned so that your details are fully anonymised from this point onwards. We will remove or replace any specific terms that may identify you (including names and personal details). Any published information will also be anonymised, in line with the Data Protection Act (1998). Electronic data such as interview transcripts will be stored securely on an encrypted pen drive supplied by the North Wales Clinical Psychology Programme, Bangor University (NWCPP).

Your consent form with your details on will be kept at the Renal Psychology Service where they will be kept locked away safely and destroyed within 6 months of completing the study. Interview transcripts will be stored securely at the Renal Psychology Service and destroyed after 10 years, in accordance with the Data Protection Act (1998). The information you provide may be used in further research conducted by BCUHB Renal Services but your details will remain anonymous.

If, during the interview, you say something which makes us concerned about your safety or the safety of others, we may have to break confidentiality and share this information with other people, in line with our duty of care. We would make all efforts to discuss this with you beforehand if we did think we needed to share any information with anyone.

**How will we use information about you?**

We will need to use information from you for this research project. This information will include your name, age, sex and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- by asking one of the research team
- by sending an email to [rbc18hns@bangor.ac.uk](mailto:rbc18hns@bangor.ac.uk)

**Will the use of my data meet GDPR rules?**

Yes. GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data, including this study, must follow UK laws and rules.

**Will I be able to get a copy of the study's findings?**

If you have requested a summary of the main findings, you (along with other participants who have requested this) will receive a written summary about the study's main findings and how these may influence clinical practice or future research. We will post this to you once the study has ended. We will also let you know how you can find a copy of the project in its entirety at Bangor University Library. Alternatively, you can contact us to request a copy of the study.

**What will happen to the results of the study?**

As the project forms part of a thesis for a Doctorate in Clinical Psychology, it will be written up and submitted to Bangor University. Rebecca will present the findings of the study at the annual stakeholders' meeting for the North Wales Clinical Psychology Programme. The results of the study will be shared with BCUHB Renal Service Teams across North Wales, and may be used to inform the development of renal services. The findings may also be submitted for publication in a scientific journal for other professionals to read.

**What will I get out of taking part?**

You may not benefit directly from taking part in this study, however your participation has the potential to benefit people in the future by helping us to better understand the experience of renal transplant patients. It is hoped that the understanding and insight gained from learning about these experiences will help improve the experiences of others going through the transplantation process. You may also find it helpful or enjoyable to share your experiences, and you can request a copy of the results of the study which you may find interesting. As a token of our appreciation, we are offering participants a £20 Amazon gift voucher as a thank you for sharing your time and your experiences with us.

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

We do not anticipate any physical risks associated with taking part in this study, however, it is possible that you may find it upsetting to talk about your kidney transplant experience. As the interview questions will invite you to talk openly about your experiences, there is a very small risk that this may raise distressing thoughts or feelings for you. Rebecca is a Trainee Clinical Psychologist and has the skills to manage difficult emotion responses. We would like to reassure you that you do not have to reply to any questions you feel uncomfortable answering, and that you may end the interview or withdraw from the study at any stage, without giving a reason. If your responses during the interview suggest that you are currently experiencing some level of emotional distress, Rebecca will discuss this with you at the interview stage, and offer to contact your GP or refer you to a Clinical Psychologist within the renal service (but only with your expressed permission). Rebecca will also be able to signpost you to different services for support and provide you with further information. If, following the interview, you are feeling distressed, please do contact Rebecca or a member of your medical care team for further support.

It is worth being aware that if you feel you are struggling to adjust to the transplantation process, you can approach any member of your usual medical care team (e.g. your Renal Transplant Specialist Nurse or GP) and ask them to refer you to a Clinical Psychologist in the renal service, at any time.

**Who is involved in this research?**

This research project is being undertaken by Rebecca Chan, a Trainee Clinical Psychologist from Bangor University. The project is being supervised by Dr Beth Parry-Jones and Dr Paul Gardner, and both are Consultant Clinical Psychologists working in renal services across Betsi Cadwaladr University Health Board.

The project is organised and funded by the North Wales Clinical Psychology Programme, at Bangor University, in partnership with Betsi Cadwaladr University Health Board.

**Who has reviewed this research study?**

This study has been reviewed and approved by the School of Psychology, Bangor University Research Ethics Committee (reference number: 2020-16764) and the NHS Research Ethics Committee (reference number: 283106). The study is being sponsored by Bangor University.

**What if something goes wrong?**

If you have a concern about this study, please contact a member of the research team (Rebecca Chan, Dr Beth Parry-Jones or Dr Paul Gardner). You will find our contact details at the end of this information sheet.

If you are still not happy and would like to raise a formal complaint about any aspect of the study, including the way that you have been approached or treated during the course of the study, you can do this by contacting Huw Ellis, who is the Bangor University contact for complaints regarding research. His contact details are as follows:

Huw Ellis,  
School of Psychology Manager,  
School of Psychology,  
Brigantia Building,  
Penrallt Road,  
Bangor,  
Gwynedd,  
LL57 2DG.

Telephone: 01248 383229

Email: [huw.ellis@bangor.ac.uk](mailto:huw.ellis@bangor.ac.uk)

You can also contact staff at the North Wales Clinical Psychology Programme (NWCPP) directly. All contact details can be found at the end of this information sheet.

### **What next?**

If you decide that you would like to take part in this study, please return the 'Research Opt-in Slip' that accompanies this sheet. A pre-paid envelope is provided so that you can either post this to us or hand it to staff in the renal service - they will ensure it reaches us. If you opt-in to the study, we will contact you directly using the contact details you have provided. Only patients returning an opt-in slip will be contacted. We will then arrange a mutually convenient time to complete the telephone interview. Before taking part in the interview, you will be asked to read and sign a consent form - a copy of this is included in this pack. You will be given a copy to keep.

We aim to contact you within 3 to 6 weeks of receiving your opt-in slip. However, if you have not heard from us within that time, please feel free to contact us.

Thank you for taking the time to read this information sheet, we hope that it has been helpful and look forward to answering any questions you may have.

Kind regards,

Rebecca Chan  
Trainee Clinical Psychologist

Supervised by:

Dr Beth Parry-Jones  
Consultant Clinical Psychologist

Dr Paul Gardner  
Consultant Clinical Psychologist

## Further information and contact details

### Research Team

If you have any further questions or are unsure about anything, please contact Rebecca Chan by email or phone: [rbc18hns@bangor.ac.uk](mailto:rbc18hns@bangor.ac.uk) or 01745 445655.

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LL57 2PW.

Email: [Paul.Gardner@wales.nhs.uk](mailto:Paul.Gardner@wales.nhs.uk)

## Complaints

If you would like to raise a formal complaint about any aspect of the study, including the way that you have been approached or treated during the course of the study, you can contact Huw Ellis or Mike Jackson below:

School of Psychology Manager:

Huw Ellis,  
School of Psychology Manager,  
School of Psychology,  
Bangor University,  
Brigantia Building,  
Penrallt Road,  
Bangor,  
Gwynedd,  
LL57 2DG.

Email: [huw.ellis@bangor.ac.uk](mailto:huw.ellis@bangor.ac.uk)

Telephone: 01248 383229

North Wales Clinical Psychology Programme Research Director:

Dr Mike Jackson,  
Research Director,  
North Wales Clinical Psychology Programme,  
Bangor University,  
Brigantia Building,  
Penrallt Road,  
Bangor,  
Gwynedd,  
LL57 2DG.

Email: [mike.jackson@bangor.ac.uk](mailto:mike.jackson@bangor.ac.uk)

Telephone: 01248 388746

## Appendix 4. Participant Consent Form

### PARTICIPANT CONSENT FORM

**Title of Study:** The Experiences of Renal Transplant Recipients One Year Post-Transplantation

**Name of Researcher:** Rebecca Chan, Trainee Clinical Psychologist

**Supervised by:** Dr Beth Parry-Jones, Consultant Clinical Psychologist and  
Dr Paul Gardner, Consultant Clinical Psychologist

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

- |    |  |                          |
|----|--|--------------------------|
| 1. | I confirm that I have read and understand the participant information sheet dated 19/7/2020 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions about anything I don't understand, and have had these answered satisfactorily.  | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.   | <input type="checkbox"/> |
| 3. | I understand that specific quotes from my interview may be included in the final report, however these will be anonymised and carefully selected to ensure that I cannot be identified through these.  | <input type="checkbox"/> |
| 4. | I understand that participating in this study involves taking part in an interview and I agree for this to be audio-recorded.  | <input type="checkbox"/> |
| 5. | I understand that any information collected about me will only be identifiable by the research team. Information collected about me will be anonymised and stored securely on the Betsi Cadwaladr University Health Board computer system in accordance with standards outlined under the Data Protection Act (1998).  | <input type="checkbox"/> |
| 6. | I understand that the anonymised information collected about me may be used to support other research in the future within the North Wales Renal Service.  | <input type="checkbox"/> |
| 7. | I understand that if the information I provide during this study indicates to the researcher that I am currently experiencing some level of distress associated with my psychological wellbeing, the researcher will contact me within 3 weeks to discuss this. The researcher may notify my GP or make a referral to the Renal Clinical Psychology Service, with my permission. | <input type="checkbox"/> |
| 8. | I agree to take part in the above study.   | <input type="checkbox"/> |



9. Please indicate if you are happy for the research team to notify your GP of your participation in this study.

☐

**Please delete as appropriate:** I DO / DO NOT agree for my GP to be notified of my participation in this study.

Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

Name of Researcher: Rebecca Chan Date: \_\_\_\_\_ Signature: \_\_\_\_\_

**Further information about the study** If you have any further questions or require more information about this study please contact: Rebecca Chan via e-mail: [rbc18hns@bangor.ac.uk](mailto:rbc18hns@bangor.ac.uk)

**Complaints:** Any complaints concerning the conduct of this research should be addressed to: Huw Ellis, School of Psychology Manager, Manager, School of Psychology, Bangor University, Brigantia Building, Penrallt Road, Bangor, Gwynedd, LL57 2DG. You may also contact Huw by telephone: 01248 383229 or e-mail: [huw.ellis@bangor.ac.uk](mailto:huw.ellis@bangor.ac.uk)

*Please note: One copy is to be given to the participant, and one copy is to be retained by the researcher.*

## Appendix 5. Research Opt-In Slip

### RESEARCH OPT-IN SLIP

**Study:** *The experiences of kidney transplant recipients one year post-transplantation.*

Thank you for reading the participant information sheet and completing this opt-in slip. Returning this slip indicates that you are interested in taking part in the research. We would like to remind you that you can still change your mind about taking part at any time.

I have read the participant information sheet and have decided that I **would like** to take part in this research study.

My name is: \_\_\_\_\_

Signed: \_\_\_\_\_

Please contact me on:

Telephone:  \_\_\_\_\_

Mobile:  \_\_\_\_\_

Email:  \_\_\_\_\_

Address:  \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

My first language is:                      English ☐                      Welsh ☐

(Please note that all interviews will be conducted in English.)

I **would like** to receive a summary of the results when the study is completed: ☐

**Thank you!**