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Exploring the experiences of dialysis in young adulthood

Piggin, Lucy

Award date:
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**Exploring the Experiences of Dialysis in
Young Adulthood**

Bangor University
2014

Lucy Helen Piggin

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Thesis Summary

This thesis explores the experience of dialysis in young adults across three papers: the first paper, a systematic literature review, evaluates the evidence for direct and indirect relationships between social support and adherence to treatment regimens – including prescription, medication, dietary restriction, and fluid intake. It reviews the quantitative evidence, finding no consistent relationship between these two variables. The second paper presents findings from an empirical study, qualitatively exploring the lived experience of dialysis in patients aged 18-35 years. This cross-sectional study was undertaken according to the principals of interpretative phenomenological analysis (IPA), with semi-structured interviews undertaken with four male patients. Two interconnected aspects of experience were identified, forming two broad categories of themes: *biographical disruption* and *biographical repair*. Biographical disruption described the immediate and ongoing negative impact that dialysis had on patients' lives, including failure to complete developmental tasks and difficulty maintaining a place within social networks. Patients also perceived multiple barriers to initiating and sustaining intimate relationships (e.g. sexual dysfunction and body-image disturbance). Biographical repair revealed a process of adjustment and adaptation, with patients finding new meaning in life on dialysis through efforts to reconnect with lost peers and seek alternative interests. This study suggested that age – and developmental life-stages – are important determinants of illness experience and outcome. The third paper discusses implications for theory and clinical practice emerging from the first two papers. It emphasises the importance of considering the intersection between illness and age in both research and clinical contexts. The difficulties that young people have in maintaining a place within social networks is discussed in relation to social support structures, whilst the difficulties faced in establishing and maintaining intimate relationships are also considered within a developmental framework. This paper also contains personal reflections on the research process and outcomes.

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Acknowledgements

I would like to thank a number of important people who have helped and supported me in completing this thesis. Firstly, I am extremely grateful to my supervisors – Dr Beth Parry-Jones and Dr Paul Gardner – both for providing the opportunity to undertake this research and for their expert guidance throughout. I am also indebted to Dr Renee Rickard for her continued support and encouragement and for her tireless efforts in checking and rechecking drafts to keep me on track.

As ever, I am also thankful for the support of my amazing family – Rebecca, Kate, and Gordon and my wonderful parents – all of whom have encouraged and inspired me throughout. And yes, I promise that this is the last one...

Finally, I would like to thank the inspiring young people who participated in the research; I am indebted to each of you and have learned so much – thank you.

Word Count

Paper 1: Literature Review

Social Support and Treatment Adherence in Adult Dialysis Patients: A Systematic Review of the Quantitative Literature

Word count without references:	7453
Word count with references:	9888
Tables, Figures, and Appendices:	4585

Paper 2: Empirical Study

The Lived Experience of Dialysis in Young Adulthood: Exploring the Impact of Treatment in Young Adults Aged 18-35 Years

Word count without references:	6985
Word count with references:	7854
Tables, Figures, and Appendices:	2821

Paper 3: Contributions to Theory and Practice

Word count without references:	4982
Word count with references:	5506

Overall thesis word count:

Total: without references:	19,425
Total with references:	23,248
Total of Tables, Figures Appendices:	7406

Paper 1: Literature Review

Social Support and Treatment Adherence in Adult Dialysis Patients: A Systematic Review of the Quantitative Literature

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Abstract

Background: Dialysis patients are required to make substantial lifestyle adaptations: attending regular treatment sessions, taking medication, modifying diet, and severely restricting fluid intake. The degree to which patients adhere to these behavioural demands has an appreciable impact on treatment outcomes; however, rates of non-adherence remain high. *Aims:* This paper systematically reviews the literature to establish whether social support has any direct/indirect effects on adherence behaviours. *Methods:* The online databases PsycINFO, Web of Knowledge, and Medline were searched for quantitative studies reporting statistical relationships between measures of social support and all forms of adherence in adult dialysis patients (i.e. prescription, medication, diet, and fluid restriction). *Results:* Twenty-three papers met inclusion criteria, variously assessing: perceived social support (emotional/instrumental), instrumental support from informal carers, the presence of supportive dyadic relationships, the size of social networks, and family dynamics. Adherence was measured objectively and subjectively across all adherence domains. There was found to be no direct relationship between social support and adherence behaviours; however, the presence of instrumental support did appear to have a positive impact on dietary adherence and there was evidence to suggest that social support may mediate/moderate the effects of additional variables (e.g. depression) on adherence. These results are considered alongside an appraisal of research methods used to explore adherence in dialysis populations, with recommendations made for future research design. *Conclusions:* There does not appear to be a direct relationship between social support and adherence in dialysis populations; however, there is sufficient evidence to recommend that social context be considered in research exploring adherence in this population.

Keywords: adherence, compliance, dialysis, renal, social support, family, review.

1. Introduction

Timely implementation of dialysis saves and sustains the lives of many patients experiencing end-stage renal disease, ameliorating the immediate physical symptoms of renal failure and affording a significant survival advantage (Wright et al., 2010). It is, however, understood that dialysis is a complex and challenging intervention, demanding prolonged and effortful commitment from recipients. Dialysis patients must make substantial lifestyle adaptations in order to achieve optimal results: undertaking frequent dialysis sessions, following complicated medication regimens, observing rigid dietary restrictions, and severely limiting fluid intake (Sharp, Wild & Gumley, 2005). The degree to which patients successfully engage with these behavioural demands has an appreciable impact on treatment outcomes; poor adherence in any domain significantly increases mortality and morbidity risks (Leggat et al., 1998), hospitalisation rates (Saran et al., 2003) and healthcare costs (DiMatteo, 2004); it also causes patients immediate physical side-effects (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte & De Geest, 2007) and is associated with dramatic declines in quality of life (Pang, Ip, & Chang, 2001).

Despite the myriad associated risks and consequences, poor adherence is frequently and consistently reported in this population. Indeed, it is estimated that around half of all dialysis patients are routinely non-adherent in at least one aspect of care, with 1-35% skipping sessions, 7-32% prematurely shortening the dialysing process (Denhaerynck et al., 2007), 40-67% demonstrating poor adherence to medication regimens (Schmid et al., 2009; Arenas et al., 2010), and 50-80% failing to observe diet and/or fluid restrictions (Lee & Molassiotis, 2002; Kugler et al., 2011). Qualitative studies confirm that pressure to maintain adherence across multiple domains is a source of intense frustration for patients, with the pervasive nature of 'additional' lifestyle restrictions felt to significantly compound the sense of treatment burden (Leggat, 2005).

Reducing non-adherence improves immediate illness experiences and optimises long-term clinical outcomes for dialysis patients (Clarke, Farrington, & Chilcott, 2014); however, understanding the *causes* of non-adherence has proved challenging. Early research in this field focused on the influence of demographic and clinical variables, consistently identifying younger age, non-white ethnicity, single status, lower levels of education, higher rates of co-morbidity (e.g. diabetes), and living a greater distance from the dialysis unit as variables that increase the risk of non-adherence (Curtin, Svarstad, Andress, Keller, & Sacksteder, 1997; Leggat et al., 1998; Di Matteo, 2004; Kugler, Maeding, & Russell, 2011). It is, however, recognised that these factors alone do not explain all of the variance in adherence rates and a range of psychological variables have also been explored: personality (Christensen & Smith, 1995), affective disturbances (Khalil & Frazier, 2010), coping-styles (Christensen, Benotsch, & Wiebe, 1995), self-efficacy (Zrinyi et al., 2003), health and treatment beliefs (Krespi, Bone, Ahmad, Worthington, & Salmon, 2004), illness representations

(O'Connor, Jardine, & Millar, 2008), and health locus of control (Cukor, Rosenthal, Jindal, Brown & Kimmel, 2009) have all been considered as potential determinants of non-adherence – though with notably inconsistent results. Many of these studies have focused on single intrapersonal variables without considering important contextual factors (e.g. interpersonal and environmental stressors); this distortion unhelpfully presents patients as living in a 'social vacuum' (Gallant, 2003). An increasing number of researchers recognise the importance of the wider social context and have explored how adherence behaviours might also be shaped by both the interpersonal networks that surround patients and the support that they provide (Oh, Park, & Seo, 2013).

The important role that social support plays in facilitating positive health outcomes is well documented in the wider literature (DiMatteo, 2004; Marmot, Allen, Bell, Bloomer, & Goldblatt, 2012), where it has been observed to buffer against the effects of illness-related stress (Cohen, 1988), positively influence affective states (DiMatteo, Lepper, & Croghan, 2000), bolster self-esteem and self-efficacy (Amir, Roziner, Knoll, & Neufeld, 1999), and moderate 'sick role' behaviours (Wallston, Alagna, DeVellis, & DeVellis, 1983). It is also acknowledged that supportive individuals can provide practical help, offer information and guidance, and model positive health behaviours that facilitate adherence in patients (DiMatteo, 2004). Certainly, robust relationships between good adherence to treatment regimens and high levels of satisfaction with social support have been established in patients living with other chronic illnesses, including diabetes (Miller & DiMatteo, 2013), hypertension (Criswell, Weber, Xu, & Carter, 2010), cardiovascular disease (Reutlinger et al., 2009), and following organ transplantation (Chisholm-Burns, Spivey, & Wilks, 2009).

It should be noted, of course, that there are aspects of social and familial relationships that may also exert a negative influence on health outcomes (Rosland et al., 2008); for example, patients may express guilt for the perceived burden that the provision of support places on members of a social network and can feel strongly criticised by family members in response to poor adherence (Carter-Edwards, Skelly, Cagle, & Appel, 2004). Competing motivations, goals, and demands between patients and family members may also pose barriers to adherence; especially where patients are attempting to make lifestyle changes that not all members of a family wish to engage with (e.g. dietary modification). Indeed, attempts to adhere to complex treatment demands alongside efforts to maintain relationships and fulfil other family roles can generate considerable stress for patients (Gallant, Spitze, & Prohaska, 2007).

Having a clear understanding of how social support influences adherence in renal patients seems particularly important given the level of self-care expected outside of the dialysis unit, where patients must implement and maintain challenging lifestyle adaptations without direct supervision or support from healthcare professionals. Non-adherence occurs far more frequently at home than in hospitals, with adherence to dietary restrictions and fluid intake consistently identified as being the

most challenging task for patients (Iborra-Molto, Lopez-Roig, & Pastor, 2012). There is already evidence linking good social support with positive illness experiences in this population – including superior adjustment to dialysis, higher levels of treatment satisfaction, improved quality of life, fewer hospitalisations, and lower mortality risks (Christensen, Wiebe, Smith, & Turner, 1994; Kimmel, 2001; Kimmel et al., 1998) – it seems important to clarify what role social support might also play in shaping adherence.

A number of studies have considered social support as a potential determinant of adherence in dialysis patients; however, there has been no attempt to systematically synthesise and review the evidence: this is the primary focus of this review.

1.1 Aims

This paper will evaluate the relationship between social support and adherence in adult dialysis patients, considering adherence to prescription (i.e. attendance and fulfilment of prescribed time on dialysis per session), medication, dietary intake, and fluid restriction. Due consideration will be afforded to both direct effects (i.e. where social support directly relates to adherence outcomes without the influence of additional variables) and indirect effects (i.e. where social support appears to be related to adherence outcome measures through the influence of one or more additional variables). The utility of existing research methods will also be appraised, with recommendations made for future research.

2. Methods

2.1 Definitions

The definition of adherence adopted in this review concurs with that used by the World Health Organisation (WHO), describing “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider.” (WHO, 2003; pg. 18). The concept of *social support* is defined as the quality of, and satisfaction with, support available from family and friends; this identifies not only whether support is available but also how effective and meaningful it is considered by those seeking/receiving it. This will include support that is *emotional* (e.g. empathy, trust, and positive affect), *instrumental* (e.g. practical/physical assistance), and *informational* (e.g. advice or instructional guidance; Schwarzer, Knoll, & Rieckmann, 2004). Due consideration will also be afforded to the influence of *social networks* where relevant, defined as the presence, number, and depth of contacts that a patient has (i.e. how many people they have regular contact with and how closely these

individuals are linked); this will be restricted to consideration of informal networks (i.e. family and friends) and will not include formal relationships (i.e. with healthcare professionals).

2.2 Measuring Adherence

Accurate assessment of adherence in dialysis patients is complicated by the lack of any accepted ‘gold standard’ measure (Kaveh & Kimmel, 2001); the literature describes both *objective* methods (i.e. biochemical, physiological, and behavioural indices) and *subjective* methods (i.e. self-report), with acknowledged limitations to each (Clarke et al., 2014).

A recent methodological review found that objective measures are used far more frequently in a research context, with most studies utilising the physiological data collected in routine clinical practice as proxies for adherence (Clarke et al., 2014). Table 1 describes the most commonly used physiological indices within each adherence domain, noting potential confounds associated with each. It also summarises various ‘corrections’ recommended to optimise accurate interpretation of these data. These physiological measures offer only indirect means of appraising adherence and, as such, their reliability and validity cannot be assumed; however, all are recognised as vitally important clinical outcomes – indeed, the primary purpose of adherence is to optimise these outcomes – and they will, consequently, form a central component of this review. Objectively estimating adherence to dialysis *prescription* requires a different approach; it is most often measured by counting attendance at sessions and calculating time spent dialysing as a percentage of total time prescribed (Kimmel et al., 1995). This measure will also be included.

There is a relative paucity of studies using subjective measures to assess adherence; however, numbers have increased as more population-specific scales have been developed (e.g. the Dialysis Diet and Fluid Non-adherence Questionnaire [Vlaminck, Maes, Jacobs, Reyntjens, & Evers, 2001] and the Renal Adherence Behaviours Questionnaire [Rushe & McGee, 1998]). Estimates of adherence are found to be higher on self-report scales than on objective measures, with a lack of statistical association between the two often reported (Clarke et al., 2014). Patients consistently overestimate adherence, even where this is assessed in a non-threatening and non-accusatory way (Liu, Golin, & Miller, 2001); however, they rarely overestimate *non*-adherence (Lamping & Campbell, 1990). Combining objective and subjective measures should increase confidence in estimates of adherence: evidence from both will be considered.

2.3 Search Strategy

A systematic search for relevant papers was conducted using the following electronic databases between October 2013 and February 2014: PsychINFO, Web of Knowledge, and Medline. The search terms ‘adherence’, ‘compliance’, ‘concordance’, ‘dialysis’, ‘renal’, ‘kidney’, ‘CKD’, ‘ESRD’ and

associated derivations (e.g. *adher** and **dialysis*) were inputted in various combinations. Restrictions were imposed on date parameters (1990 – 2014) as it was considered that earlier studies would not reflect medical advances in treatment provision over recent years (Port et al., 2006). Only English language papers were included. After the initial search, abstracts were reviewed and retained according to more specific inclusion/exclusion criteria:

Inclusion:

- Recruited adult patients successfully established on dialysis.
- Reported quantitative measures of both adherence *and* social support.
- Evidenced statistical analysis of the relationship between these two variables.

Exclusion:

- Non-empirical papers, case studies, or dissertations/theses.
- Not peer-reviewed.
- Contained participants <18 years old.

The review process is outlined in Figure 1, which includes the numbers of papers retrieved and accepted/rejected at each stage. There were 70 papers reporting psychosocial variables, with 23 of these including measures of social support. The reference sections of these papers were hand-searched to identify additional papers: no further studies were found.

2.4 Data Extraction and Quality Assessment

Data extraction forms were devised to enable systematic summation of key findings and to facilitate quality assessment (Appendix 1a). Most quality assessment tools are designed to assess randomised-controlled trials and intervention studies, with no universally accepted framework for reviewing observational designs (Sanderson, Tatt, & Higgins, 2007). To overcome this noted obstacle, a modified version of the Downs and Black (1998) checklist was used: inappropriate items (i.e. those only pertinent to intervention studies) were removed and quality scores calculated as percentages – where higher scores indicate superior quality (Appendix 1b). These scores are reported in Table 2.

2.5 Data Synthesis

Due to the variety of methods, measures, and outcomes employed, it was considered appropriate to present the results in a narrative form rather than as a meta-analysis. Results are presented in three sections: the first provides a descriptive overview of study designs and methods, whilst the final two sections report direct and indirect effects of social support on adherence.

3. Results

3.1 Description of Studies

Table 2 summarises designs, methods and key outcomes extracted from each paper; a more detailed description of participants is provided in Table 3. All studies used convenience samples of dialysis outpatients recruited from hospital units. Patients' ages spanned at least five decades in all cases: ages ranged from 18 to 84 years. The duration that patients had been on dialysis also varied greatly, from 1.2 to 340 months (<1 to >28 years). In most studies ($n=17$) males outnumbered females, with three samples containing $\geq 70\%$ males. Sample sizes were ≥ 100 in only fourteen studies, in total ranging from 20 to 32,332 – the latter sample coming from the Dialysis Outcomes and Practice Patterns Study (DOPPS), an international survey (Untas et al., 2011). It was noted that studies were conducted across numerous countries and cultures; however, fewer than half of all studies ($n=11$) reported the ethnicity of patients. In these studies the majority were described as Caucasian or African-American, although one sample was composed of only Chinese, Malay, and Indian patients (Yu et al., 2012). There were only three prospective designs; most studies ($n=20$) were cross-sectional and only one of these was a case-control study (Cicolini et al., 2011).

3.1.1 Adherence

Studies included measures of adherence to prescription ($n=6$), medication ($n=4$), dietary restriction ($n=17$), and fluid intake ($n=11$). One study combined these domains to assess 'general' adherence using a self-report scale, though did not report statistics that enabled differentiation between types. Adherence was established using objective measures ($n=11$), subjective measures ($n=7$), and a combination of both ($n=5$). In most instances, objective measures were physiological outcomes: serum potassium (K; $n=12$), interdialytic weight gain (IDWG; $n=12$), serum phosphate (P; $n=11$), blood urea nitrogen (BUN; $n=2$), and serum albumin (SA; $n=1$). Four studies measured adherence to prescription in terms of skipping and prematurely shortening dialysis sessions. Studies using subjective measures primarily used standardised questionnaires designed specifically for use with this population; however, one study (Untas et al., 2012) asked patients to rate adherence on Visual Analogue Scales (VAS) and another study (Yu et al., 2012) devised its own Likert-type scale.

Only two of the five studies that combined objective/subjective measures reported inter-correlations between the two. Fincham et al. (2009) found no significant relationships, whilst Kara et al. (2007) reported several significant positive associations: frequency and degree of self-reported *dietary* non-adherence was significantly correlated with K, P, IDWG and SA and *fluid* non-adherence with K, IDWG, and SA.

Seven of the fifteen studies that used physiological outcomes reported having made corrections in analysis to control for differences in dry weight, adequacy of dialysis, or residual renal function (Table 4). Ten studies treated the physiological values obtained as continuous data, whilst six transformed them into categorical data using cut-off points that labelled patients as either adherent or non-adherent – there was variable agreement as to the criteria by which these labels were assigned (Table 4). Nine studies provided prevalence rates for non-adherence within samples; these are reported in Table 5 and show levels within the range described in wider population studies (e.g. Denhaerynck et al., 2007).

3.1.2 Social Support

Most studies ($n=18$) focused on the concept of *perceived social support* provided by family and friends; a general measure of satisfaction with combined instrumental and emotional support. In all cases this was measured by standardised self-report scale. Half ($n=9$) used the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988), which explores perceptions of the availability and adequacy of this support. Other scales were conceptually similar, all measuring instrumental *and* emotional support: e.g. the Social Support Questionnaire ($n=2$; Siegert, Patten, & Walkey, 1987), Social Provisions Scale ($n=1$; Cutrona & Russell, 1987), and Support from Family Scale ($n=2$; Munakata, 1982). Three studies used scales devised by the authors to measure similar concepts: e.g. capturing perceptions of “practical and emotional support” and including items addressing “reciprocity of support” (Sensky et al., 1996; pg. 37). Two studies analysed items from the Kidney Disease Quality of Life Scale (KDQoL; Hays et al., 1997) measuring satisfaction with support but also perceptions of feeling like a burden and feelings of isolation – psychological consequences associated with either receiving support or an absence of support.

Two studies investigated whether the presence of a carer providing *instrumental* support influenced adherence. Two further studies explored whether the presence of any stable dyadic relationship influenced adherence; these studies also used the Dyadic Adjustment Scale (DAS; Spanier, 1976) to investigate whether the *quality* of these relationships – assessed in terms of satisfaction and levels of conflict – was also important. Two studies measured the dynamics of family relationships using the Relationship Index of the Family Environment Scale (FES; Moos & Moos, 1994), a measure that defines family relationships along three domains: *cohesion* (i.e. the degree to which family members are supportive and help each other), *expressiveness* (i.e. the extent to which family members are encouraged to act openly and express their feelings directly), and *conflict* (i.e. the extent to which the open expression of anger and conflictual interactions are characteristic of the family). Two studies (Pang et al., 2001; Zrinyi et al., 2003) considered the absolute size of supportive social networks.

Only four studies measured social support alone: all other studies additionally measured combinations of depression ($n=12$), anxiety ($n=4$), health/illness beliefs ($n=5$), self-efficacy ($n=4$), locus of control ($n=4$), general mental health ($n=2$), adjustment ($n=2$), acceptance ($n=2$), personality ($n=1$), stress ($n=1$), treatment beliefs ($n=1$), and self-repression ($n=1$). Only eight of these studies reported inter-correlations between variables to allow relationships between social support and these additional variables to be considered.

3.2 Direct Effects of Social Support on Adherence

Table 6 summarises the frequency of significant/insignificant results in each adherence domain in respect to the *direct* links between social support and adherence. It considers each aspect of social support identified: perceived social support, instrumental support, quality of supportive dyadic relationships, social networks, supportive family relationship dynamics, and psychological consequences of receiving support. As physiological outcomes provide the clinical rationale and incentive for adherence, Table 7 offers a summary of the significant direct effects of each aspect of social support on individual physiological indices.

3.2.1 Perceived Social Support

Amongst the eighteen studies exploring the direct effects of perceived social support on adherence there were inconsistent results. Three studies focused on prescription: only one found a significant relationship between social support and adherence – a positive relationship between greater perceived social support and better *attendance* at dialysis sessions. This relationship, however, was not observed in the sample as a whole: Kimmel et al. (1996) found that social support significantly explained 5% of the variance in attendance for *prevalent* patients (i.e. those who had been using dialysis for ≥ 6 months) but observed no significant effect of social support on attendance in *incident* patients (i.e. those who had been using dialysis for < 6 months). The remaining two studies (Kimmel et al., 1998; Kimmel et al., 2000) failed to replicate this result despite presenting samples that contained only prevalent patients.

Two studies (Boyer et al., 1990; Kimmel et al., 1996) focused on the relationship between perceived social support and adherence to medication regimen: both returned insignificant results. It was noted that Boyer et al. (1990) did find significant correlations between social support and physiological measures of medication adherence; however, these relationships were no longer significant once demographic variables (e.g. gender, age, and time on dialysis) were statistically controlled for in the analysis. In this study, being younger, male, and having been on dialysis for a longer time all increased the risk of non-adherence; this indicated that adherence to medication regimen was most strongly influenced by demographic/clinical variables, though does also suggest that satisfaction with social support may itself vary with factors such as age and gender.

Thirteen studies explored the relationship between perceived social support and adherence to dietary restrictions. Four of these studies (Kara et al., 2007; Oka & Chaboyer, 1999, 2001; Vardanjarni et al., 2012) reported significant results, all indicating that greater social support predicted better adherence. Interestingly, all of these studies measured adherence using self-report scales: none of the nine remaining studies – all using physiological measures – found any significant relationships. This suggests that greater perceived social support increased the likelihood of patients *reporting* better dietary adherence, yet did not directly influence the clinical outcomes believed to be shaped by dietary adherence behaviours.

Ten studies explored direct links between perceived social support and fluid adherence. Four papers – all assessing adherence objectively via IDWG – reported significant relationships: three (Kara et al., 2007; Pang et al., 2001; Untas et al., 2011) found positive relationships, indicating that greater perceived social support was related to better adherence. However, Moran et al. (1997) found a *negative* relationship that appeared to be mediated by levels of trait conscientiousness. This study observed that higher levels of social support were significantly related to poorer adherence in patients with lower levels of conscientiousness, yet found no significant relationship between social support and adherence in patients with higher levels of conscientiousness. Six studies found no significant relationship between perceived social support and fluid adherence. Of these, three used subjective self-report measures and three combined self-report scales with objective measures of IDWG. There was, therefore, no consistent pattern of influence noted for social support and adherence to fluid intake guidelines – whether measured objectively or using self-report measures.

3.2.2 Instrumental Support

Two studies explored whether carer presence impacted on adherence behaviours, where carers were defined by *instrumental* support provided on a daily basis (e.g. meal preparation). In a prospective case-control study Cicolini et al. (2011) followed two groups of consecutive patients for four months: those identified as having one consistent carer and those without named support. These carers were spouses, parents, siblings, and friends. Results indicated that patients *with* carers were more likely to present with superior clinical outcomes and to demonstrate ‘excellent’ adherence in respect to diet and fluid intake. It was concluded that instrumental support had a positive influence on adherence behaviours, with this effect particularly pronounced for dietary adherence. These results were replicated by Yu et al. (2012), who observed that the presence of a family carer providing support in treatment-related tasks was significantly related to self-reported dietary – though not fluid – adherence.

3.2.3 Supportive Dyadic Relationships

Two studies explored whether the presence of a stable dyadic relationship influenced adherence; both additionally considered whether the *quality* of that relationship was also important. Kimmel et al. (1996) found no significant associations between having a stable supportive relationship, levels of dyadic satisfaction/conflict, and any objective measures of prescription, medication, dietary, or fluid adherence. Kimmel et al. (2000) found no significant association between social support, dyadic adjustment, and any objective measures of prescription adherence in the sample as a whole; however, did note that attendance rates were positively correlated with relationship satisfaction and negatively correlated with intra-relational conflict for females only. Females reporting higher levels of satisfaction and lower levels of conflict were significantly more likely to attend dialysis sessions.

3.2.4 Social Network

Two studies considered the size of supportive social networks, one focusing on diet and the other fluid adherence. Zrinyi et al. (2003) observed that as the number of cohabiting family members increased, patients' dietary adherence *decreased*. The authors suggest that greater numbers of family in the home may increase temptation to deviate from dietary restriction, as it may be easier for a single carer (e.g. a spouse) to provide and even share dietary adaptations, though much harder for whole families to make changes. This result, however, was not replicated by Pang et al. (2001), who found that whilst greater satisfaction with social support was significantly related to better fluid adherence, absolute numbers of individuals in a social network did not influence adherence behaviours - positively or negatively. It was further noted by Kutner et al. (2002) that 'living alone' neither increased nor decreased the risk of shortening or skipping sessions.

3.2.5 Family Relationship Dynamics

Two studies focused specifically on the characteristics of supportive family relationships. Christensen et al. (1992) used the FES to explore whether relationships between family members impacted on physiological outcomes. 'Good' support was defined as that which was 'emotionally supportive', characterised by high levels of cohesion and expressiveness and low levels of intra-family conflict – indeed, the authors sought to isolate the effects of this 'optimal' environment. This study additionally aimed to clarify whether social support buffered against the effects of stress or proved equally beneficial regardless of stress experienced: physical impairment was used as an indicator of illness-related stress and the effects of both impairment and social support were explored. The results indicated that family support was a significant predictor of fluid but not dietary adherence, with patients reporting higher levels of family support presenting with significantly lower IDWG. There was no main effect of impairment on fluid adherence, suggesting that emotionally supportive families exerted a uniformly positive influence, rather than acting as a

buffer against stress. There was, however, a significant main effect of impairment in relation to dietary adherence – which was not related to social support – with higher levels of impairment predictive of poorer dietary adherence.

These results suggest that social support does not buffer against the effects of stress, even where it is related to better adherence. One might query whether levels of physical impairment offer an accurate gauge of ‘stress’ in dialysis populations, as patients with relatively low levels of physical impairment may still find treatment demands extremely stressful; however, the veracity of the conclusions drawn are substantiated by evidence from Hitchcock et al. (1992), who also reported no significant interaction effects between social support, self-reported stress, and adherence – this study found that minor stressors significantly predicted variance in dietary adherence outcomes once the effects of social support had been controlled for, indicating that social support did not protect patients from the disruptive influence of daily stress on adherence outcomes.

In a more recent prospective analysis of family dynamics, Untas et al. (2012) used the FES to identify different patterns of family interaction. Hierarchical cluster-analysis identified three distinct profiles: *conflict* families (low cohesion, low expressiveness, and high conflict), *communicative* families (high cohesion, high expressiveness, low conflict), and *supportive* families (high cohesion, mid-range expressiveness, low conflict). At one, six, and twelve months after starting dialysis, significantly more patients from conflict families demonstrated clinically problematic dietary and fluid adherence, whilst there were no significant differences between communicative and supportive families; this suggests that family dynamics can influence adherence behaviours. It is unclear, however, whether there is something added or something taken away between these families: i.e. whether communicative/support families protect and/or support patients to facilitate adherence or whether conflict families deplete resources and generate additional stresses that negatively impact on adherence behaviours.

3.2.6 Psychological Consequences

In addition to exploring whether satisfaction with perceived social support was related to adherence outcomes, the DOPPS survey – based on data from 32,335 patients – also measured perceptions of feeling like a burden and feelings of isolation; these are considered as psychological consequences to receiving support or the absence of support (Untas et al., 2011). It was observed that patients who reported greater feelings of being a burden to family were both more likely to prematurely shorten sessions and had higher rates of dietary non-adherence, as measured objectively through K and P levels. This result was observed consistently throughout Europe, Australia, and New Zealand. There were no significant relationships between feelings of social isolation and adherence outcomes.

3.3. Indirect Effects of Social Support on Adherence

Of the eight studies reporting inter-correlations between variables, six provided sufficient information to show whether social support was significantly correlated with variables that were themselves significant predictors of adherence (i.e. reported whether social support was related to another variable *and* whether that variable predicted adherence outcomes). Such relationships are cautiously considered here as potential indirect effects, reviewed with the understanding that associations are tentatively inferred from the available statistics: only one study (Oh et al., 2012) performed path analysis to formally test whether social support exerted any indirect mediator/moderator effects – all other studies relied on simple correlations.

Two studies reported that greater satisfaction with perceived social support was significantly correlated with both positive attitudes towards adherence (Fincham et al., 2009) and perceptions of the importance of adhering to guidelines (Vandanjarni et al., 2013) – both variables found to be predictive of better fluid and dietary outcomes. Relatedly, of the four studies that measured self-efficacy (defined as patients' belief in their own ability to execute health-related behaviours), two found it to be positively correlated with adherence outcomes and social support: in these studies self-efficacy was the largest significant predictor of self-rated dietary adherence (Oka & Chaboyer, 2001) and general adherence across domains (Oh et al., 2013). A third study (Zrinyi et al., 2003) found a negative correlation between the number of family members living with patients and dietary self-efficacy (i.e. greater numbers of co-habiting family members associated with poorer adherence), which was the largest significant predictor of objective measures of dietary adherence. Eleven studies measured depression as a possible predictor of adherence: eight found significant negative effects and three reported non-significant results. Two studies (Oh et al., 2013; Vandanjarni et al., 2013) found that perceived social support was negatively correlated with depression, which in turn negatively correlated with adherence. These results suggest that social support may indirectly influence adherence outcomes via its effects on other psychological variables – notably attitudes towards adherence, self-efficacy, and depression.

4. Discussion

This paper has collated research exploring both the direct and indirect effects of social support on adherence amongst adult dialysis patients. The accumulated evidence suggests that social support can play an important role in shaping adherence and determining clinical outcomes – especially where its effects are moderated and/or mediated by demographic, clinical, and psychological variables – and that this influence can be positive or negative. It was not, however, possible to identify a *consistent* pattern of direct influence, either across or within adherence domains. This contrasts somewhat with the results of similar reviews in other illness populations (e.g. diabetes), where clear links between social support and positive self-care behaviours have been established

(Gallant, 2003). The evidence reviewed here confirms the importance of considering patients within a wider social context, whilst acknowledging the need for further research. Findings are discussed alongside a number of methodological limitations that may have contributed to the variable pattern of results identified.

Different aspects of social support were identified within the dialysis literature, which replicates the findings of reviews in other illness populations (e.g. DiMatteo, 2004). Social support was most often conceptualised as instrumental *and* emotional; however, the evidence for a combined effect on adherence was limited. In some instances there was strong evidence to suggest that perceived social support was an important determinant of adherence outcomes; however, in other cases no statistical link was found – this variable pattern was replicated within each adherence domain.

The evidence for a direct effect of social support seemed most compelling where support was *instrumental*. It was chiefly for dietary adherence that these effects were observed. This makes intuitive sense, as practical help buying and preparing appropriate food might be expected to facilitate adherence. Indeed, if only appropriate foods are available to patients, it is possible that directive support removes the option of non-adherence altogether. Scaffolding to support adherence in this way may also increase self-efficacy, especially where it provides patients with experiences of success. Consistent evidence indicated that social support was positively associated with self-efficacy, encouraging the conclusion that social support indirectly facilitates adherence by helping strengthen patients' beliefs in their ability to adhere. An alternative explanation might be that patients high in self-efficacy report greater satisfaction with social support because they do not need as much external support; though it is probable that only further research will be able to clarify the nature of this relationship.

Positive effects of instrumental support were most apparent where it was provided by an individual designated as a carer; the mere presence of a stable dyadic relationship was not noted to influence adherence and greater numbers of cohabiting family members were observed to reduce dietary self-efficacy. These findings highlight the importance of looking not just at whether potential supporters are available to patients but also who these individuals are and what they actually do. Having many people within a network does not necessarily mean there is more support; indeed, Zrinyi et al. (2003) suggest that having greater numbers of people in a household increases temptation, with social support quickly turning to social pressure. On a practical note, buying and preparing meals for whole families – possibly including children – may also mean that different foods have to be bought into houses and offered/available at mealtimes, giving patients access to different foods. In busy households it is possible that carer time and resources are also divided. No study assessed how the *structure* of the household impacted on adherence: e.g. whether having younger children at home, who also require practical care and support, influenced adherence. It is also unclear whether there are differential outcomes for male/female carers or those in paid employment, and whether there

were differences due to the type of relationship that carers had to patients (e.g. spousal relationships compared to parental).

Instrumental support was not significantly associated with prescription, medication, or fluid adherence outcomes, which is somewhat surprising. Overall, significant relationships between social support and adherence outcomes were most often reported within the domains of diet and fluid adherence. This may, in part, reflect the fact that non-adherence rates were higher in these domains, with greater variability in the data to be explained; however, there are also identifiably 'social' components to eating and drinking that should be considered, with cultural context especially relevant here. Studies were conducted across a diverse range of countries, yet few reported the ethnicity of participants or considered the impact of culture on either social support or adherence. Kara et al. (2007) observed that drinking black tea is an important aspect of social interaction in Turkish communities, noting that fluid restrictions may have prevented patients in their sample from participating in this social exchange. Having social relationships may increase opportunities for food and drink to be consumed *and* sustaining those relationships may be harder when patients are unable to take part in social rituals that involve food and drink. These issues have not yet been explored in a research context.

Family support structures, expectations around support provision, and satisfaction with social support may also have varied according to differing cultural norms: Kara et al. (2007) noted strong ideals about protecting the health of family members in close Turkish families, questioning whether such attitudes and values may be less prevalent in more individualistic Western societies. These cultural nuances are important, not only as clinicians seek to generalise the results of studies across cultures, but also because many clinical populations will contain patients from varied cultural backgrounds. Of related importance, specific family dynamics were highlighted as playing an important role in shaping adherence behaviours: cohesive families, providing emotionally supportive environments, facilitated adherence, whilst conflict in families was associated with poorer adherence. Untas et al. (2012) noted that adherence was superior in patients belonging to families where there was encouragement to openly express emotions and a propensity for members to support and help each other. There was no evidence to suggest that social support buffered patients from the effects of stress; however, there were links between support and lower levels of depression: it is possible that emotionally supportive family environments protect patients from depression and/or reduce the likelihood of patients perceiving themselves to be a burden – both associated with poor adherence. Of course, these relationships have only been established in correlational studies and it is consequently difficult to make confident assertions about causation: it is important to recognise that whilst social support may help to 'protect' patients, depression may also *cause* patients to dismiss/reject available support, fail to recognise where it is available, or underestimate its strength

and meaning. Depression may also discourage those around patients from offering support – again, further investigation is advised.

The explicit communication of support from families and carers, either through supportive interpersonal dynamics or instrumental support, may indeed shape patients' psychological approaches to adherence and to wider illness experiences. The evidence suggests, however, that patient variables – clinical, demographic, *and* psychological – have the potential to interact with social support in a reciprocal manner, both influencing and being influenced by. It is important to consider these potential interactions; Christensen et al. (1992) observed that social support only impacted on adherence in patients with low levels of conscientiousness – arguably those less likely to have self-motivation and/or self-discipline to maintain adherence in the face of temptation. Conscientiousness itself may be conceptually linked to other variables (e.g. health locus of control and self-efficacy) that might also influence the type of support that patients' seek and receive and its impact on adherence. Few studies convincingly explored interactions between psychological and social variables and this should be addressed more comprehensively in future. Existing studies provide interesting avenues for researchers to explore but do not allow firm conclusions to be drawn about interactions or indirect effects.

Across all adherence domains, inconsistencies in results were most apparent where studies used comparable physiological outcomes. Although caution was urged given that physiological measures are only indirect indices of adherence behaviours, it is these standardised clinical outcomes that adherence is intended to optimise and the lack of consistency across studies using physiological outcomes is, therefore, itself an issue that should be carefully considered. Conflicting results may reflect the fact that social support does not reliably influence these measures or that there are other variables interacting with social support to determine its effects; however, it is also important to be mindful of methodological and statistical limitations that may account for differences. For example, few studies controlled for extraneous medical factors known to confound analysis, including residual renal function, pre-dialysis dry weight, and dialysis efficiency, all of which could have distorted results. It is recommended that researchers account for these factors. A number of studies also transformed physiological data into categorical form, often by applying arbitrary cut-off scores, and it is likely that transforming data in this way led to a loss of information. The use of different criteria to define levels of non-adherence also inhibits comparability across studies and it is recommended that physiological values be treated as continuous data to avoid these potential distortions. Indeed, until researchers account for all of these potential confounds, it will remain extremely difficult to accurately interpret and compare physiological data in this field – the 'noise' generated within datasets by these extraneous variables may explain a significant proportion of the variation in results observed across studies, potentially masking the effects of social support.

In this review, significant relationships between social support and adherence outcomes were most often noted where patients subjectively reported adherence. It is possible that patients did perceive adherence to be better or worse than clinical measures suggested. This might, to some extent, reflect knowledge deficits (i.e. patients' misunderstanding of what is expected in respect to adherence and how best to follow guidelines); however, bias towards overestimation of adherence is often observed in self-report measures seemingly to promote a positive image of being a 'good' patient (Liu et al., 2001). These reports may have reflected desired or ideal behaviours rather than actual behaviours and the same motivation – to project a socially desirable impression – may also have encouraged patients to report satisfaction with social support. Social support significantly correlated with positive attitudes towards adherence and these attitudes also correlated with self-rated adherence; it is unclear whether attitudes did actually translate into positive behaviours, as they were not reflected in objective outcomes. Exploring the relationship between subjective and objective measures is clearly another important task for researchers and until more is known about this relationship it seems prudent that studies include both.

It was noted that few studies employed prospective or longitudinal designs. Cross-sectional datasets offer a useful snapshot of relationships between variables; however, they do not allow researchers to explore changes over time. It is possible that perceptions of social support, and the effect that the presence or absence of support has on adherence, may evolve or interact with different variables in different ways over time. This may also explain some of the inconsistencies in the results obtained. Certainly Kimmel et al. (1998) noted differences in the direct effects of social support between incident and prevalent patients that indicated changes in the effects of social support with time on dialysis. Many samples demonstrated vast heterogeneity in respect to demographic and clinical variables with few attempts to explore how these variables interacted with social support and adherence outcomes. Patient age is another prominent example: although a number of studies noted that non-adherence was more likely in younger patients, there were no attempts to establish whether social support had different meaning – and whether needs changed – at different life stages. Patients' ages ranged from 18-84 years and it is likely that the nature of support being provided varied, even if only in respect to relationships between patients and carers: it is likely that parents, spouses, peers, and even adult children offered support to patients of different ages, yet no attempts were made to investigate these factors. It is understood that many studies used small convenience samples and where multiple variables were already being considered it would have further reduced statistical power to undertake this finer analysis: this suggests that research with larger samples is required. There are clearly important variables – especially clinical and demographic variables – that were not considered, despite evidence to suggest that they do shape adherence behaviours and may also influence both need for and perceptions of social support.

5. Conclusion

Social support does appear to play an important role in shaping adherence in dialysis populations, confirming the importance of considering patients within a wider social context; however, existing research does not provide sufficient evidence to clearly define this role. There is vast scope for further research to help clinicians understand and address non-adherence in this challenging patient group. In other illness populations evidence linking social support and adherence behaviours has been used to design interventions to improve adherence – and thus improve clinical outcomes – including the provision of group consultation, structured support groups, internet and telephone peer-support networks, and direct therapeutic work within families to target communication and problem-solving (McDonald, Garg, & Haynes, 2002; van Damet al., 2005). There is certainly potential for such approaches to be considered with dialysis patients, with further research likely to enable these interventions to be targeted more effectively in this population. In seeking to establish a comprehensive model of adherence in dialysis patients, researchers are advised to: further explore what meaning patients attach to social support; recruit larger samples and employ longitudinal designs; include both objective and subjective measures; treat physiological data as continuous and control for confounding medical effects; include independent variables that span demographic, clinical, psychological *and* social domains and to plan, a priori, tests of interaction between these variables. It is most likely that a clear understanding of adherence behaviours will only emerge when researchers and clinicians come to consider them in a truly bio-psychosocial context.

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Note. Studies reviewed in this paper are indicated by an asterisk.

Table 1. The most commonly used physiological indices within each adherence domain, as identified by Clarke et al. (2014), alongside potential confounds associated with each and ‘corrections’ recommended for researchers seeking to optimise accurate interpretation (adapted from Denhaerynck et al., 2007).

Adherence	Physiological Indices	Potential Confounds	Recommended Corrections
<i>Fluid</i>	Inter-dialytic weight gain (IDWG): weight gain between two dialysis sessions or average weight-gain over multiple sessions	<ul style="list-style-type: none"> • Results can vary depending on whether a single reading or an average across sessions is used. • Values may be influenced by other variables (e.g. residual urine volume or kidney function and nutritional status). • Values may be distorted if they have not been corrected for a patient’s body mass; adjustment for a patient’s dry weight is necessary to avoid this. • IDWG is also influenced by the characteristics of dialysis (e.g. duration between sessions). • Arbitrary cut-off values are often used to classify patients as adherent or non-adherent. • High IDWG can indicate poor fluid adherence; however, it can also indicate good nutritional status, which is a protective factor. 	<ul style="list-style-type: none"> • Correct for body mass, residual renal function, interval between dialysis sessions, and nutritional status. • Take average values across >6 sessions rather than relying on single readings.
<i>Diet</i>	<p>Pre-dialysis serum levels of potassium (K), phosphate (P), and blood urea nitrogen (BUN).</p> <p>Sodium intake may also be estimated by IDWG, as excessive sodium increases thirst (i.e. fluid intake).</p>	<ul style="list-style-type: none"> • P/K levels may also reflect residual renal function, dialysis adequacy, acid-base and hormonal status, and adherence to medication. • There is a lack of consensus over clinically validated cut-off values (i.e. what level of non-adherence is related to increased risk for poor clinical outcomes). 	
<i>Medication</i>	Serum phosphate (P) levels, used as an estimate of adherence to phosphate binding medication.	<ul style="list-style-type: none"> • Poor discriminative reliability: it is difficult to accurately extrapolate the degree to which results reflect adherence to phosphate-binding medication compared to other aspects of medication regimen (e.g. cardiovascular drugs). • Factors other than medication (e.g. dietary adherence, residual renal function, dialysis adequacy, and hyperthyroidism) also effect P levels. • Individual differences in fractional phosphate absorption and dialytic phosphate removal may also influence readings. 	

Table 2. Summary of study designs, country of origin, mode of adherence (i.e. prescription, medication, diet and/or fluid), aspects of social support investigated, additional variables considered, a summary of the findings and a quality assessment rating.

No.	Study	Country	N	Design	Adherence		Social Support		Variables	Summary Findings	Quality (%)
					Domain	Measure	Subtype	Measures			
1	Boyer, Friend, Chlouverakis & Kaloyanides (1990)	USA	61	CS	Medication Diet	<i>Objective:</i> P, K, BUN	Perceived Social Support	Novel Scale		When demographic variables were controlled for there were no significant relationships between social support and adherence. Demographic/situational variables explained most variance in adherence: female patients' demonstrated better adherence than males and older patients better than younger; adherence deteriorated with time on dialysis.	75
2	Christensen, Smith, Turner, Holman, Gregory & Rich (1992)	USA	81	CS	Fluid Diet	<i>Objective</i> IDWG, K	Family Relationships	FES-RI	Sickness Impact	Greater family support - greater cohesion and expressiveness and less conflict - predicted lower IDWG (better adherence). Low levels of support predicted higher IDWG (poorer adherence). There was no relationship between family support and K. Higher levels of perceived impairment were related to higher K, indicating poorer adherence. Patients who perceived themselves as having better family support showed better fluid adherence but no difference in dietary adherence.	88
3	Cicolini, Palma, Simonetta, & Di Nicola (2012)	Italy	72	P/L	Fluid Diet	<i>Objective</i> P, K, IDWG	Instrumental Support (Carer)			Patients with carers providing instrumental support had lower P levels - indicating better adherence - compared to those without. The numbers with 'excellent' P levels were higher for patients with carers. There was a non-significant trend for lower K and IDWG in patients with carers. It was concluded that diet/fluid adherence was enhanced by carer presence.	100
4	Fincham, Kagee, & Moosa, (2009)	South Africa	62	CS	Diet Fluid	<i>Objective</i> P, K, IDWG <i>Subjective</i> RAAQ RABQ.	Perceived Social Support	MSPSS	LoC Attitudes Knowledge	Social Support did not predict any subjective or objective measure of adherence. It was concluded that the nature of the relationship between perceived social support and adherence was complex and should not be assessed in isolation from other determinants of behaviour (e.g. preference for control). There were no significant correlations between objective/subjective measures.	69
5	Hitchcock, Brantley, Jones & McKnight (1992)	USA	55	CS	Diet	<i>Objective</i> K, BUN	Perceived Social Support	SSQ-SF	Stress	Social support was not significantly correlated with either outcome measure, indicating it did not directly influence adherence. Only minor daily stressors predicted physiological outcomes after social support and baseline measures of K and BUN were controlled for: minor stresses appeared to predict <i>changes</i> in adherence rather than absolute levels. Major life events did not predict either baseline or changes in physiological outcomes. There was no evidence to suggest that social support buffered the effects of stress.	69

No.	Study	Country	N	Design	Adherence	Social Support	Variables	Summary Findings	Quality (%)		
					<i>Domain</i>	<i>Measure</i>	<i>Subtype</i>	<i>Measures</i>			
6	Kara, Caglar, & Kilic (2007)	Turkey	160	CS	Fluid Diet	<i>Objective</i> IDWG, K, P, SA	Perceived Social Support	MSPSS	Most support came from immediate family, significant others, and friends. Unmarried patients were significantly less likely to adhere in diet and fluid. Low levels of family support were significantly related to dietary and fluid non-adherence; fluid non-adherence was more likely amongst young and married patients.	88	
7	Khalil, Frazier, Lennie, & Sawaya (2011)	USA	100	CS	Diet Fluid	<i>Objective</i> IDWG, P, K BUN	Perceived Social Support	MSPSS	Depression	Perceived social support not correlated with or predictive of either subjective or objective measure of adherence. Moderate to severe depression was predictive of dietary and fluid non-adherence.	76
8	Khalil, Darawad, Al Gamal, Hamdan-Mansour, & Abed (2013)	Jordan	190	CS	Diet Fluid	<i>Subjective</i> DDFQ	Perceived Social Support	MSPSS	Depression Health Beliefs	No variables were significantly related to self-rated dietary and fluid adherence, including measures of perceived social support.	82
9	Kimmel, Peterson, Weihs, Simmens, Boyle, & Verme (1995)	USA	149	CS	Diet Fluid Medication Prescription	<i>Objective</i> IDWG, K, P Shortening Skipping	Perceived Social Support	MSPSS DAS	Illness Beliefs Depression	In 'incident' patients (on dialysis <6 months), depression negatively correlated with social support and marital satisfaction. There were no significant relationships between social support, presence of a stable relationship, satisfaction with relationships, and adherence. In regression analysis, social support did not significantly predict adherence for 'incident' patients but predicted 5% of variance in attendance for 'prevalent' patients (on dialysis >6 months). Stable relationships positively correlated with satisfaction with social support in 'prevalent' but not 'incident' patients.	83
10	Kimmel, Peterson, Weihs, Simmens, Alleyne, Cruz & Veis (1998)	USA	295	P/L	Prescription	<i>Objective</i> P, K, IDWG Shortening Skipping	Perceived Social Support	MSPSS	Depression Adjustment Satisfaction with Life	Levels of social support were significantly correlated with depression, perceptions of illness effects, and satisfaction with life but not with adherence. Younger patients were less adherent to prescription. There were significant negative correlations between depression and adherence, with greater depression associated higher levels of session skipping and shortening.	88
11	Kimmel, Peterson, Weihs, Shidler, Simmens, Alleyne, & Phillips (2000)	USA	174	CS	Prescription	<i>Objective</i> K Shortening Skipping	Perceived Social Support Marital Relationship	MSPSS DAS	Depression Illness Perceptions	Social support and dyadic adjustment measures (satisfaction/conflict) were not significantly correlated with adherence to prescription. In females only, attendance rates were positively correlated with satisfaction in dyadic relationships and negatively associated with conflict. Increased social support was associated with decreased mortality risk for males and females.	100

No.	Study	Country	N	Design	Adherence	Social Support	Variables	Summary Findings	Quality (%)		
					<i>Domain</i>	<i>Measure</i>	<i>Subtype</i>	<i>Measures</i>			
12	Kutner, Zhang, McClellan, & Cole (2002)	USA	170	CS	Prescription	<i>Objective</i> P Skipping Shortening	Perceived Social Support	KDQOL-SF	Depression LoC Illness Beliefs	There were no significant correlations between social support, satisfaction with care, and any measure of adherence. Living alone was not associated with any form of non-adherence.	100
13	Moran, Christensen, & Lawton (1997)	USA	56	CS	Fluid Diet	<i>Objective</i> IDWG, P	Perceived Social Support	SPS	Personality	There was a significant interaction between social support and conscientiousness: for patients with low levels, greater social support was associated with <i>poorer</i> fluid adherence, while for patients with high levels, high/low social support was not related to adherence. There were no significant relationships between social support and dietary adherence.	88
14	Oh, Park, & Seo (2013)	Korea	150	CS	Diet Fluid Medication Regimen	<i>Subjective</i> TCSHP	Perceived Social Support	MSPSS	Health Beliefs Self-Efficacy Acceptance Mental Health	Family support did not have a direct effect on adherence but seemed to mediate the relationship between depression and self-efficacy. Self-efficacy mediated the relationship between family support and adherence. Perceived barriers to adherence, self-efficacy and health-related knowledge were direct predictors of adherence, with self-efficacy the most significant predictor.	81
15	Oka & Chaboyer (1999)	Japan	325	CS	Diet	<i>Subjective</i> DBS	Sources of social support and satisfaction.	SFS		Married patients reported greater satisfaction with social support. A longer time on dialysis was associated with lower levels of perceived support; patients using dialysis for <3 years reported the highest levels of support. Dietary adherence was significantly correlated with all measures of social support and better adherence was significantly predicted by greater family support. Older patients perceived themselves as getting more support than younger patients. Patients on dialysis for a shorter time reported higher levels of family support.	81
16	Oka & Chaboyer (2001)	Japan	325	CS	Diet	<i>Subjective</i> DBS	Sources of social support and satisfaction.	SFS	Self-Efficacy Repression Acceptance Mental Health	Self-reported dietary adherence and dietary self-efficacy were both significantly correlated with family support. Mental health was not correlated with adherence behaviours but negatively influenced dietary self-efficacy. Dietary self-efficacy, perceived support from family, and self-repression explained the most significant proportion of variance in dietary adherence. It was concluded that social support from family indirectly influenced dietary adherence through its direct effects on self-efficacy.	88
17	Pang, Ip, & Chang (2001)	China	92	CS	Fluid	<i>Objective</i> IDWG	Social Support and Satisfaction.	SSQ-SF	Depression LoC	Social support came mainly from immediate family. There were significant negative correlations between high satisfaction with social support and low IDWG, indicating poorer adherence. In regression analysis, satisfaction with social support was a significant predictor of IDWG. Satisfaction with support – and not absolute numbers in the social network – was the most significant predictor of low IDWG, indicating better adherence.	88
18	Sensky, Leger & Gilmour (1996)	UK	45	CS	Diet Fluid	<i>Objective</i> K, IDWG	Perceived Social Support	Novel Scale	Anxiety Depression LoC Adjustment	There were no significant relationships between social support and dietary/fluid adherence. Patients with psychiatric history (e.g. depression) and good social support had lower IDWG, indicating better adherence – an effect not seen in patients' explicitly acknowledging the negative impact of dialysis on life.	75

No.	Study	Country	N	Design	Adherence	Social Support	Variables	Summary Findings	Quality (%)		
					<i>Domain</i>	<i>Measure</i>	<i>Subtype</i>	<i>Measures</i>			
19	Untas, Thumma, Rascle, Rayner, Mapes, Lopes & Combe (2011)	France, UK, US, Germany, Italy, Spain, Japan, NZ, Belgium, Australia	32,332	CS	Diet Fluid Medication Regimen	<i>Objective</i> IDWG, P, K SA	Perceived Social Support and Satisfaction	KDQoL	Lower levels of social support were significantly related to higher IDWG, indicating poorer fluid adherence. In Europe, Australia, and New Zealand, feeling like a burden was associated with higher K, indicative of poorer dietary adherence. In Japan, isolation and dissatisfaction with family time and support was associated with excessive IDWG, indicating poorer fluid adherence. In all countries, feeling like a burden to family was associated with low SA indicating poorer adherence.	86	
20	Untas, Rascle, Idier, Lasseur, & Combe (2012)	France	120	P/L	Diet	<i>Subjective</i> VAS	Family Relations	FES-RI	Anxiety Depression	Cluster analysis generated three family profiles: conflicting, communicative, and supportive. Family-type interacted with mental health: anxiety/depression remained stable for communicative and supportive families, yet increased for conflict families. More patients in conflict families demonstrated poor adherence in all domains.	86
21	Vardanjani, Khalili, Dehkordi, Vardanjani, & Vardanjani, (2013).	Iran	160	CS	Diet Fluid Medication Regimen	<i>Subjective</i> ESRD-A	Perceived Social Support	MSPSS	Depression	Females demonstrated better diet/fluid adherence. Adherence was significantly better in married patients. Social support significantly positively correlated with dietary but not fluid adherence. Social support was significantly associated with perceived importance of adherence behaviours, with patients perceiving themselves as having greater social support also rating adherence as more important. Negative correlations existed between social support and depression.	94
22	Yu, Yeoh, Seow, Luo, & Griva. (2012)	Singapore	20	CS	Diet Medication Regimen	<i>Objective</i> P, K Skipping Shortening	Carer Presence Self-Care Status	Novel Scale	Anxiety Depression Self-Efficacy Treatment Beliefs	14/20 patients were highly dependent on family members to perform dialysis-related tasks (i.e. diet preparation). Patients cared for by others showed significantly better adherence to dietary restrictions. This relationship was not significant for other types of adherence.	88
23	Zrinyi, Juhasz, Balla, Katona, Ben, Kakuk & Pall (2003)	Hungary	107	CS	Diet	<i>Subjective</i> Novel Scale <i>Objective</i> P, K, IDWG, SA <i>Subjective</i> RAAQ RABQ	Social Network (Family)		Self-Efficacy	Living with a spouse was not related to adherence outcomes. Female patients were more likely to adhere. The number of family members living with patients was inversely related to dietary self-efficacy, which in turn predicted adherence. Increasing numbers of family members resulted in lower dietary efficacy beliefs and expectations. Patients with more family members had higher K and IDWG, indicating poorer adherence.	94

Note. CS= cross-sectional; P/L = prospective/longitudinal; P = serum phosphate; K = serum potassium; IDWG = interdialytic weight gain; BUN = blood urea nitrogen; SA = serum albumin; LoC= Locus of Control; FES-RI = Family Environment Scale – Relationship Index; MSPSS = Multidimensional Scale of Perceived Social Support; KDQoL = Kidney Disease Quality of Life Scale; SSQ-SF = Social Support Questionnaire – Short Form ; SFS = Support from Family Scale; DAS = Dyadic Adjustment Scale; RAAQ = Renal Adherence Attitudes Questionnaire; RABQ = Renal Adherence Behaviours Questionnaire; DDFQ = Dialysis Diet and Fluid Non-adherence Questionnaire; DBS = Dietary Behaviours Scale; TCSHP = Treatment Compliance Scale for Haemodialysis Patients; ESRD-A = End-Stage Renal Disease Adherence Scale.

Table 3. Summary of the clinical and demographic characteristics of individual samples, including an indication of where studies included demographic and clinical variables in preliminary and main analysis.

Study	N	Patient Age (Years)			Sex	Time Established on Dialysis				Analysis
		Mean	Standard Deviation	Range		Male : Female %	Mean	Standard Deviation	Range	
1 Boyer et al. (1990)	61			20-81	71:29			<1-20	Years	○●
2 Christensen et al. (1992)	81	51.9			51:49	75.3			Months	
3 Cicolini et al. (2011)	36	70.4	15.8		61:39	81.5	60.8		Months	
		64.6	13.0		42:58	71.6	54.8		Months	
4 Fincham et al. (2009)	62	40.3	9.4	21-60		91.1	87.1	0.5-340	Months	
5 Hitchcock et al. (1992)	55	57.6	13.7	26-81	49:51	3.3	3.0	0-13	Years	○
6 Kara et al. (2007)	180	57.0	14.5	20-84	58:42	47.3	39.2	3-243	Months	○
7 Khalil et al. (2011)	100	61.6	14.9		44:66	4.5	1.9		Years	○
8 Khalil et al. (2013)	190	48.2	14.9	18-84	54:46	5.6	5.2	0.3-25	Years	○
9 Kimmel et al. (1996)	99	54.5	14.5	19-83	81:19					
		54.4	14.3	23-83						
10 Kimmel et al. (1998)	295	54.6	14.13	19-84	71:29	56.6	51.9		Months	○●
11 Kimmel et al. (2000)	174	54.0	13.8	21-80	77:23	2.38	3.86		Years	○●
12 Kutner et al. (2002)	119	75.6	14.5		51:49	433	22.0	377-525	Days	○●
		49.2	15.8		49:51	433	29.7			
13 Moran et al. (1997)	56	57.20	15.1	21-82	64:36	45.75	57.6	1.2-246	Months	○●
14 Oh et al. (2012)	150	55.65	11.46	26-83	52:47	61.48	57.62		Months	
15 Oka & Chaboyer (1999)	325	57.2	12.6		57:43	89	67		Months	
16 Oka & Chayboyer (2001)	325	57.2	12.6		57:43	7.4	5.6		Years	
17 Pang et al. (2001)	92	51.36	10.86	22-79	42:58	79.08	5.55	3-252	Months	○
18 Sensky et al. (1996)	45	41		25-65	62:38	5.5		0-22	Months	○●
19 Untas et al. (2011)	32,332	61.5	14.5		57:42	5.1	5.7		Years	
20 Untas et al. (2012)	120	62.8	16		68:32					
21 Vardanjani et al. (2013)	160	59.95	15.04		61:39	45	50.34		Months	○
22 Yu et al. (2012)	20	64.4	11.6		60:40					○
23 Zrinyi et al. (2003)	107	57.6	14.03		51:49	50.4	25.66		Months	○●

Note. Analysis: ○ = study that considered correlations between demographic/clinical variables and adherence outcomes in preliminary analysis; ● = study that additionally controlled for or corrected for significant relationships between demographic/clinical variables and adherence outcomes when exploring the effects of social support on adherence outcomes in the main analysis.

Table 4. Correction and/or controls made in data analysis for dry weight, adequacy of dialysis, and residual renal function in studies using physiological measures of adherence and - for studies dichotomizing physiological data only - cut-off values and descriptors used to define adherence and non-adherence.

Study	Corrections and Controls			Adherence Cut-Offs						
	<i>Dry weight (Body Mass)</i>	<i>Adequacy of dialysis</i>	<i>Residual renal function</i>	<i>Descriptor</i>	<i>IDWG</i> <i>kg</i>	<i>%</i>	<i>K</i> <i>(mmol/l)</i>	<i>P</i> <i>(mg/dl)</i>	<i>BUN</i> <i>(mg/dl)</i>	
1 Boyer et al. 1990				Excellent	1.00-1.59		3.5-5.59	3.5-5.59		
2 Christensen et al. 1992										
3 Cicolini et al. 2011				Problematic	>2.04kg					
4 Fincham et al. 2004	•									
5 Hitchcock et al. 1992								5.0-6.0		40-100
6 Kara et al. 2007		•		Non-Compliant						
7 Khalil et al. 2011		•	•			>5%	5.5	>5.5	>100	
8 Kimmel et al. 1996	•			Problematic						
11 Kimmel et al. 2000								>7.5		
12 Kutner et al. 2002		•		Non-Adherence						
13 Moran et al. 1997								>5.5		
17 Pang et al. 2001										
18 Sensky et al. 1996	•									
19 Untas et al. 2011	•					>5.7%	>6.0	>7.5		
23 Zrinyi et al. 2003										

Note. • = Correction/control was considered and applied in this study. IDWG = Interdialytic Weight Gain; P = Serum phosphorus; Serum K = Serum potassium; BUN = blood urea nitrogen. Kg = kilograms; mmol/l = millimoles per litre; mg/dl = milligrams per decilitre.

Table 5. Prevalence rates for non-adherence in samples.

	Study		Prevalence
	Subtype	Measure	
3	Cicolini et al. (2011)	Fluid Diet	<i>Objective</i> P, K IDWG Described the number of patients attaining clinically “excellent” levels of adherence. For patients with a named carer, 41.7-53% achieved excellent phosphorus levels, 50-61.1% achieved excellent serum potassium levels, and 8.3-22.2% demonstrated excellent IDWG. For patients with a named carer (i.e. controls), 38.9-50% achieved excellent phosphorus levels, 33.3-55.6% achieved excellent serum potassium levels, and 12.9-22.2% demonstrated excellent IDWG. There were no rates estimated for non-adherence.
6	Kara et al. (2007)	Fluid Diet	<i>Objective</i> IDWG K, P, SA <i>Subjective</i> DDFQ Described prevalence rates for subjective measures only, using DDFQ scores to assign categorical labels defined through standardization of the measure. In relation to <i>dietary</i> adherence, 41.9% reported perfect adherence, 30% reported mild levels of non-adherence, 20% moderate, 3.8% severe, 4.3% very severe; for <i>fluid</i> adherence, 31.9% perfect adherence, 26.9% reported mild levels of non-adherence, 14.4% moderate, 10.6% severe, 16.2% very severe. No information was offered as to how these categorical labels mapped onto actual practices or to physiological outcomes. Did not provide prevalence rates according to objective measures.
7	Khalil et al. (2011)	Diet Fluid	<i>Objective</i> IDWG P, K BUN <i>Subjective</i> DDFQ Described prevalence rates for subjective and objective measures. In the DDFQ, 50% of patients were described as non-adhering to some degree with fluid restriction and 44% non-adhering to dietary restriction. Using physiological indices, 56% of patients were considered non-adherent to dietary restrictions; 52% demonstrated elevated P levels, 10% had raised K, and 1% had increased BUN.
8	Khalil et al. (2013)	Diet Fluid	<i>Subjective</i> DDFQ Described prevalence rates using DDFQ scores to assign categorical labels defined through standardization of the measure. In relation to <i>dietary</i> adherence, 27.9% reported no non-adherent behaviours at all, 20.5% reported mild levels of non-adherence, 29.5% moderate, 6.3% severe, 15.8% very severe; for <i>fluid</i> adherence, 23.2% no non-adherent behaviours at all, 20% reported mild levels of non-adherence, 31.6% moderate, 9.5% severe, 15.8% very severe.
10	Kimmel et al. (1998)	Prescription	<i>Objective</i> P, K IDWG Shortening Skipping Described prescription compliance in terms of attendance per month and time using dialysis as a percentage of time prescribed: patient attendance ranged from 38.8-100% and time compliance ranged from 83.3-100%.
12	Kutner et al. (2002)	Prescription	<i>Objective</i> Skipping P Described the number of patients qualifying as non-compliant according to skipping and shortening sessions and also as indicated by P values. Almost 1/3 of HD and PD patients were non-compliant in one domain. Amongst HD patients, 19% had skipped at least one session and 31% had prematurely shortened in the past month – 19% had P levels considered indicative of non-adherence. Amongst PD patients, 30% had skipped at least one session and 10% had P indicative of non-compliance.
17	Pang et al. (2001)	Fluid	<i>Objective</i> IDWG Described prevalence according to patients displaying problematic IDWG values; 32% of the sample were considered to demonstrate poor compliance.
19	Untas et al. (2011)	Diet Fluid Medication Regimen	<i>Objective</i> IDWG P, K Albumin Described number of patients showing ‘excessive’ levels in physiological measures: 10% of patients were considered non-adherent according to IDWG, 11.9% using serum phosphorous, and 10.9% using K values.
22	Yu et al. (2012)	Diet Medication Regimen	<i>Objective</i> P, K Skipping Shortening <i>Subjective</i> Novel Scale Described prevalence in terms of both subjective and objective assessments of adherence: 20% of patients reported unintentional non-adherence (e.g. due to forgetfulness) and 15% reported intentional adherence; 5% skipped at least one session and 10% shortened at least one session within the past month; 16% appeared non-adherent for diet and/or medication on P levels and 16% according to K levels.

Note. IDWG = Interdialytic Weight Gain; K = Serum Potassium; P = Serum Phosphorus; SA = Serum Albumin; DDFQ = Dialysis Diet and Fluid Non-adherence Questionnaire; HD = Haemodialysis; PD = Peritoneal Dialysis.

Table 6. Summary of studies reporting significant and non-significant results (i.e. whether social support did or did not have a statistically significant direct effect on adherence outcomes) within each adherence domain (i.e. prescription, medication, diet, and fluid), including aspects of social support considered and whether objective, subjective, or a combination of objective/subjective measures of adherence were used.

		Prescription			Medication			Diet						Fluid				
		PSS	QDR	PC	PSS	QDR	PC	PSS	QDR	FRD	IC	SN	PC	PSS	FRD	IC	SN	PC
Significant Results	Frequency	2	1	1	0	0	0	4	0	1	2	0	1	4	1	1	1	0
	Adherence Measures																	
	Studies																	
	<i>Objective</i>	9, 19	11	19								3	19	13, 17, 19	2	3	17	
<i>Subjective</i>							15, 16, 21		20	22								
<i>Combined</i>							6						6					
Non-Significant Results	Frequency	3	1	0	2	1	1	9	1	1	0	1	0	6	0	0	0	1
	Adherence Measures																	
	Studies																	
	<i>Objective</i>	10, 12	9		1, 9	9	19	1, 2, 5, 9, 13, 18		2								19
<i>Subjective</i>	22							9					9, 18, 21,					
<i>Combined</i>							4, 7, 8,				23		8, 4, 7					

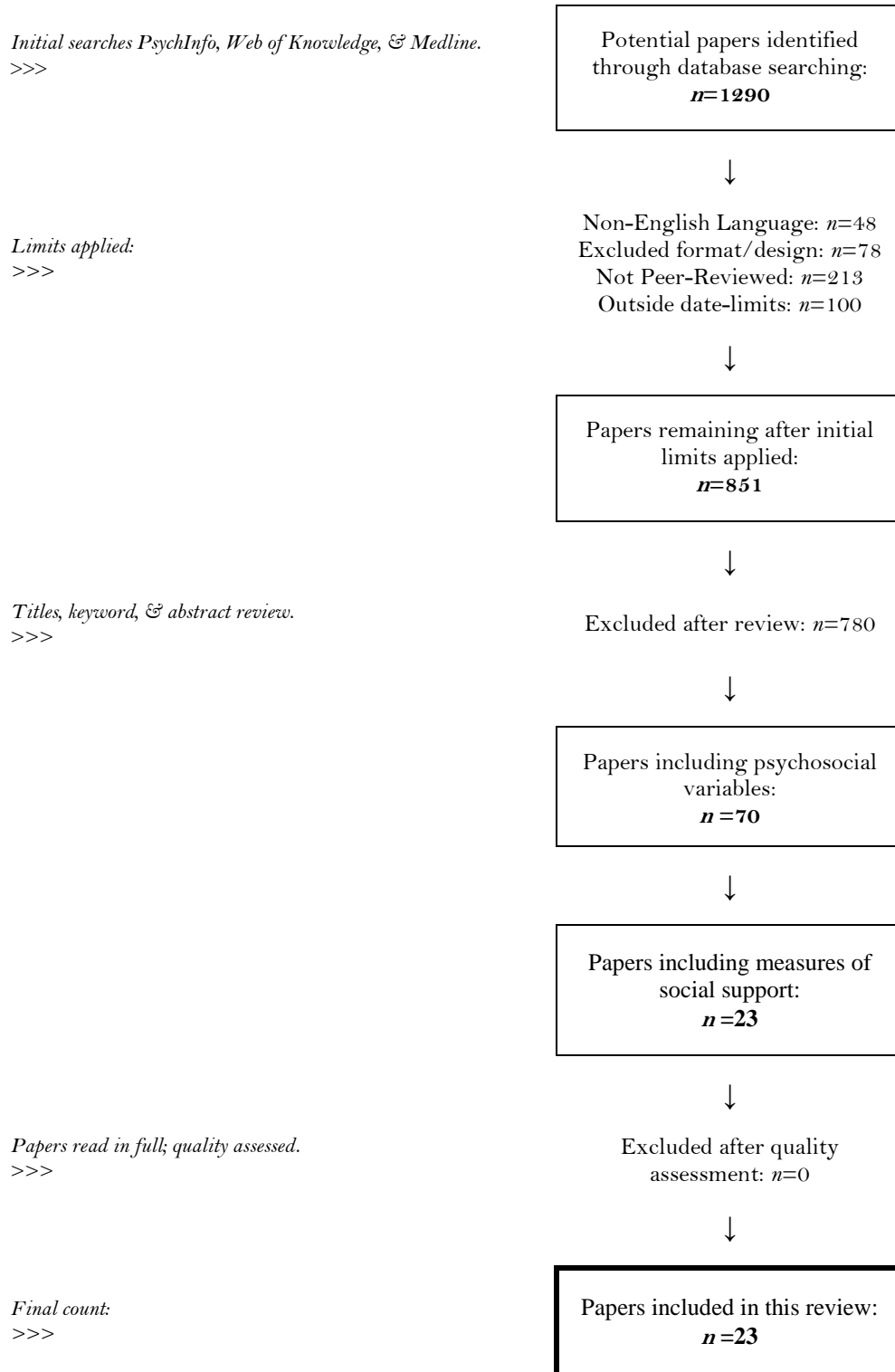
Note. PSS = Perceived Social Support; QDR = Quality of Dyadic Relationship; PC = Psychological Consequences; FRD = Family Relationship Dynamics; IC = Instrumental Care; SN = Social Network. Numbers correspond to study numbers assigned in Table 2.

Table 7. Summary outcomes for the direct effects of social support on physiological indices of adherence, indicating significant and insignificant results (i.e. whether social support did or did not have a statistically significant direct effect on adherence outcomes).

		K	P	IDWG	BUN	SA
Significant	<i>Frequency</i>	2	3	5	0	2
	<i>Studies</i>	3, 19	3, 6	2, 6, (13), 16, 19		6, 19
Non-Significant	<i>Frequency</i>	11	8	7	2	1
	<i>Studies</i>	1, 2, 4, 5, 7, 8, 9, 10, 11, 12, 18, 23	1, 4, 7, 9, 19, 13, 19, 23	3, 4, 7, 9, 10, 18, 23	5, 7	23

Note. In all but one case significant results indicate that social support was *positively* associated with adherence (i.e. that adherence was better where social support was greater); the single case where a negative relationship was observed is noted in parenthesis. K= serum potassium; P = serum phosphorous; IDWG: interdialytic weight gain; BUN= blood urea nitrogen; SA = serum albumin. Numbers correspond to study numbers assigned in Table 2.

Figure 1. Flow-diagram showing the search procedures employed, including outcomes from the inclusion/exclusion and screening processes.



Author(s)		Year:
Title		
Sample Size:		Country of Origin:
Mean Age: SD: Range:	Sex (M:F)	Mean Vintage: SD: Range
Study Design:		
Adherence Domains	<input type="checkbox"/> Prescription <input type="checkbox"/> Medication <input type="checkbox"/> Diet <input type="checkbox"/> Fluid Notes:	
Adherence Outcomes	<input type="checkbox"/> Subjective Measures:	<input type="checkbox"/> Objective Measures: <input type="checkbox"/> P <input type="checkbox"/> K <input type="checkbox"/> Shortening <input type="checkbox"/> IDWG <input type="checkbox"/> BUN <input type="checkbox"/> Other: <input type="checkbox"/> SA <input type="checkbox"/> Skipping
Social Support (subtype):		
Measures :		
Other Variables Included:		
Statistical Analysis		
Key Findings:		
Strengths:		
Weaknesses:		

Appendix 1b: Modified Version of the Downs and Black Quality Assessment Checklist (Downs & Black, 1998)

Studies were awarded (1) where there was satisfactory evidence that the item had been fulfilled, (0) where there was no evidence, and (N/A) where the item was not considered applicable to the study (i.e. related to only cohort studies or case-control studies). As the number of items relevant to each study differed, scores were transformed into a percentage for ease of comparison. Items are organised according to subscales that assess: reporting, external validity, internal validity (bias), and internal validity (selection bias and power).

Reporting

1. Is the hypothesis/aim/objective of the study clearly described?
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?
3. Are the characteristics of the patients included in the study clearly described?
4. Are the distributions of principal confounders in each group of subjects to be compared clearly described?
5. Are the main findings of the study clearly described?
6. Does the study provide estimates of the random variability in the data for the main outcomes?
7. Have the characteristics of patients lost to follow-up been described?
8. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?

External validity

9. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
10. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?
11. Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?

Internal validity – bias

12. If any of the results of the study were based on “data dredging”, was this made clear?
13. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?
14. Were the statistical tests used to assess the main outcomes appropriate?
15. Were the main outcome measures used accurate (valid and reliable)?

Internal validity – confounding (selection bias)

16. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?
17. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?
18. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
19. Were losses of patients to follow-up taken into account?
20. Did the study have sufficient power to detect a clinically important effect where the

Paper 2: Empirical Study

The Lived Experience of Dialysis in Young Adulthood: Exploring the Impact of Treatment in Young Adults Aged 18-35 Years

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Declaration of Conflicting Interests:

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding:

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Document file type Submit *only* documents created in **Microsoft Word**, and only with the regular file extension of **.doc** or **.docx** (do not submit documents with *.docm, .rtf, .pdf* or other extensions).

Paper size Letter, 8.5 x 11 inches, with portrait orientation

Margins 1 inch (1"; approximately 2.5 cmF.) on all sides

Line numbers: None; Line spacing: Exactly "double," with 0" before and 0" after.

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Compile the elements of your manuscript in the following order:

Document 1:

Title page (required)

Document 2:

Abstract and keywords (required)

Main manuscript text (required)

Notes (if any)

References (required)

Appendices (if any)

Tables (if any)

Document 3:

Figure 1 (if any)

Document 4:

Figure 2 (if any; and so forth, with each subsequent figure in a separate document)

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Note: For ease in locating needed information, the various elements are listed below in alphabetical order, and not in the order of anticipated use.

Dialogue

Presentation of participant dialogue (i.e., two or more "speakers") should be set as block quotes/excerpts, indented by ½ inch (approximately 1.3 cm.) from the left margin. Do not use bullets or hanging paragraphs. Begin the narrative of each speaker on a new line. The first time a speaker name is used, type it in full, followed by an appropriate abbreviation in parentheses prior to the colon; thereafter, use only the abbreviation for the speaker name. Refer to the sample manuscripts for an example of dialogue presentation.

Ellipses / ellipsis points

Almost every manuscript contains ellipses. They are used to indicate words missing from quotations, and are to be created in a very specific manner. The proper way to create ellipsis points is as follows: Three (3) dots, preceded, divided, and followed by spaces (i.e., SPACE.SPACE.SPACE.SPACE), like . . . this. If it is necessary to indicate missing words between sentences (instead of in midsentence): Place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space (i.e., .SPACE.SPACE.SPACE.SPACE). . . .

Font size text:

Use 12-point font for *everything* except text in tables, figures, and (if applicable) conversation analysis.

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Use only 8-point font in tables and figures.

Italics should be used only:

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- as appropriate in level-2, -3, and -4 headings; and
- to introduce non-English words, or *unusual* new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular font.

Headings

All headings, without exception, are to be set in 12-point font. *QHR* uses 4 distinct levels of headings (H = Heading). *QHR* uses 4 distinct levels of headings (H = Heading), including: (Note: All headings should be double-spaced, just like the regular text).

H Level	Formatting
H1	Flush Left, Bold Text, in Title Case
H2	<i>Flush Left, Italicized Text, in Title Case</i>
H3	<i>Flush left, italicized text, in sentence case, ending with a period.</i> At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph. Use this heading only if you have a total of four (4) heading levels. Note: Try to avoid the use of H3 if possible, and use only H1, H2, and H4 (see below).
H4	<i>Indented (.5" or 1.3 cm.), italicized text, in sentence case, and ending with a period.</i> At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph.

Use *at least two* heading levels:

For manuscripts with 2 heading levels, use H1 and H2

For manuscripts with 3 heading levels, use H1, H2, and **H4** [*not* H3]

For manuscripts with 4 heading levels, use H1, H2, H3, and H4

Be aware of limitations on the use of heading levels H2, H3, and H4: You are not required to use an H2 heading below any given H1 heading, but if you do, you must use two or more H2 headings; you cannot use just one. The same is true for H3 headings below any given H2 heading, and for H4 headings below any H2 or H3 heading. Justification of margins: All text should be *left justified*.

Length of manuscript

There is no predetermined word or page limit. Provided they are “tight” and concise, *without unnecessary repetition* and/or irrelevant data, manuscripts should be as long as they need to be.

The editor might require a reduction in length if the manuscript contains material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

Line spacing

Everything, in all elements of the manuscript, from the title page through the references and tables (if any), must be exactly double spaced. The only

Lists

Vertical lists (i.e., listed down the length of the page) should be either simple dot bullets or bullets numbered 1., 2., 3., and so forth. Leave a blank, double-spaced line after all lists.

Paragraphs

Paragraphs are to flow, one after the other, without additional line breaks (with few exceptions; see below), and with no extra space between paragraphs. Leave a blank (double-spaced) line between the abstract and the

keywords. Leave a blank line *after* (not before) each block quote, numbered list, or bulleted list. Leave a blank line between block quotes if you have placed two or more in succession. Indent the first line of every new paragraph by ½ (.5) inch (approximately 1.3 cm.), *except*:

- the first line of the abstract or the keywords.
- the first (opening) paragraph of the manuscript text.
- paragraphs immediately after level-1 and level-2 headings.
- paragraphs beginning with level-3 headings.

Use Word's Format > Paragraph function to set paragraph first-line indentations, *but apply this paragraph by paragraph, and not to the entire document.*

Use Word's Format > Paragraph function to set block quote/excerpt and bulleted/numbered list indentations. Note that block quotes/excerpts and lists are to be *completely* indented (not just the first line) by .5 inches (approximately 1.3 cm.) from the left margin only; *do not indent from the right side.*

Quotation marks

In general, use double quotation marks (e.g., "Xxxx.") to set off quotations appearing within regular paragraphs, and to set off words being used with "special" meaning (or unusual spelling to convey special meanings within the text; e.g., "busy-ness"). Do not use quotation marks around quotations presented as block quotes/excerpts. In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., "Xxx, 'Yyy,' xxxx."). Note that when *closing* quotation marks coincide with a comma or period (full stop), the quotation marks go outside (after) the comma or period: "Quotation. . . last word."

Quotations

Quotations of fewer than 40 words should be surrounded by double quotation marks (") and included within the regular sentences of a paragraph. Internal quotations within quotations of fewer than 40 words should be set apart with single quotation marks ('). Quotations of 40 or more words should be set as separate paragraphs, with the entire quotation indented .5 inches (approximately 1.3 cm.) from the left margin (this is also referred to as a "block quote" or "excerpt"). Do not use quotation marks for block quotes unless there is a separate, internal quotation within the larger quotation; in that case, use double quotation marks (") for the internal quotation only. *Make sure all quotations are properly capitalized and punctuated.* Format the indentation for block quotes with Word's Format > Paragraph feature.

See the special section, below, for instructions on formatting *conversation analysis*.

Seriation

Seriation refers to "numbered" lists appearing in sentences of regular text (in other words, across the page rather than in a vertical list). The proper seriation style for manuscripts submitted to *QHR* is (a), (b), (c), and so forth (lowercase letters, enclosed in parentheses).

Keywords

Your keywords are words related to the article topics that readers or researchers could search on to find your published article. They are also used to assist *QHR* in selecting appropriate reviewers for your manuscript during the review process. Keywords should follow on the same page as the abstract. Leave a blank, double-spaced line between the abstract and the keywords (see the sample manuscripts beginning on page 35).

Include keywords *selected only from the QHR Keyword List*. List them exactly as they are shown in the keyword list, in lowercase letters (except for proper names), horizontally across the page, *in the order in which they appear on the keyword list*. Try to select at least five keywords. Use the most specific keywords possible from the list provided.

Individual keywords should be separated by semicolons; note that some keywords are actually two or more words, and might include commas. Do not capitalize the first keyword unless it is a proper name

(i.e., Africa), and do not add a period (full stop) at the end of the keywords. You may request that new keywords be added to the list, but the words should be *general* in nature, and not specific to a narrow topic. New keywords will be added at the editor's discretion.

ELEMENTS OF A MANUSCRIPT

*Note: Some instructions differ for **accepted** manuscripts; please refer to page 28.*

The following elements are **required** for each manuscript, and should be compiled in the following order:

Title page	Submit the title page as a <i>separate document</i> .
Abstract	The abstract is placed on page 1 of the main document.
Keywords	Place the keywords below the abstract, on the same page. Leave a (double-spaced) blank line between the abstract and the keywords.
Main manuscript	The main text of the manuscript begins on page 2 of the main document.
References	References begin on a new page, after the end of the manuscript text, or after the notes, if any (<i>do not</i> submit references in a separate document).

The following elements are **optional**, and may be included in your submission:

Notes	Place notes (also known as endnotes) after the main text, before the first page of references.
Tables	Place tables, <i>one per page</i> , at the end of the main manuscript document, after the references (do not submit tables as separate documents).
Figures	Submit each figure in a <i>separate document</i> , in order, by number.
Appendices	Appendices are published <i>only at the editor's discretion</i> . Place any appendices after the reference list, and before any tables (place them before the bios in accepted manuscripts).

PREPARATION OF MANUSCRIPT ELEMENTS

A maximum of four (4) *types* of documents should be submitted: (a) title page; (b) main manuscript; (c) figures (if any); and (d) permissions (if needed). Despite what the online submission system (ScholarOne Manuscripts / SageTrack) might allow, *do not submit such elements as abstracts, references, and tables in separate documents*. Be sure to refer to the sample manuscripts, beginning on page 35.

TITLE PAGE

The title "page" may be longer than one page. To maintain author anonymity during peer review, it is submitted as a *separate document*. Title page information *should not be included* in the main manuscript document. *Do not format a running header*. The title page should include the following, *in this order*:

Article title	A title should convey, as clearly and <i>succinctly</i> as possible, the main idea, focus, or content of a manuscript. It should be clear in meaning even when standing alone.
---------------	--

Make your title 10 to 12 words (or fewer) in length; avoid long, "wordy" titles. Avoid titles with colons or quotations unless they are *necessary* to convey an important concept or idea in the article. Type your title in *Title Case*; this means you should:

- capitalize the (first letter of) the first word
- capitalize all important words
- capitalize *all words that have four (4) or more letters*
- capitalize the first word after a colon (:), period (.), or em dash (—)

Author names

List the name (not just initials) of each author, *without credentials*, in order, horizontally across the page. If there are two authors, list them as follows: Janice M. Morse and Author Two

If there are three or more authors, list them as follows: Janice M. Morse, Author N. Two, Writer Three, and Fourth Author (and so forth). After each name (or *after* the comma following a name, if applicable), use a superscript number to link that particular author with his or her *primary* affiliation (see the section on author affiliations, below).

Author affiliations

Using the same superscript numbers as used with the authors' names (see above), list ***only the primary affiliation*** of each author, not multiple affiliations (see the sample manuscripts). Spell out all city, state, and country names (exception: use USA instead of United States). Spell out any organization or institution names (for example, *University of Utah* instead of *U of UT*, or *World Health Organization* instead of *WHO*).

Corresponding author information:

Use *only* the following format for the corresponding author information, and *do not* include any information that is not listed below. List information only for the individual who should be contacted by readers after (if) the article is published. Note that this should be a *complete mailing/postal* address. Example:

Janice M. Morse, University of Utah College of Nursing, 10 S. 2000 E., Salt Lake City, UT 84112-5880, USA
Email: QHR-Editor@nurs.utah.edu

Authors' Note:

This is optional. This is the place to mention, perhaps, that portions of the article were presented at a professional meeting, or other information of that sort.

Acknowledgments

This is optional. The section is limited to two (2) or three (3) *brief* sentences. Overlong acknowledgments will be reduced at the copyeditor's discretion. Do not include long descriptions of persons being acknowledged, and do not include roles, titles, or credentials.

Declaration of conflicting interests

You must use one of the following statements, *in the exact words* shown below. *If you have no conflicts of interest (or potential conflicts of interest):* The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

If you have conflicts of interest:

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: [Then, ***in sentence form***, list all specific author relationships with organizations and/or products that were declared].

Funding

You must use one of the following statements, *in the exact words* shown below. *If you did not have financial support:* The author(s) received no financial support for the research, authorship, and/or publication of this article. *If you did have financial support:* The author(s) disclosed receipt of the following financial support for the research, authorship, and or publication of this article: [Then list, ***in sentence form***, all entities/organizations that funded the research and/or authorship].

ABSTRACT AND KEYWORDS

The abstract should be placed at the top of page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and briefly describe your article. It should not contain headings

or citations, and should not be divided into sections. Place your keywords below the abstract, on the same page (see “Keywords,” above).

Double space the entire abstract page (including the keywords). Briefly state the purpose of your research, the main findings, and your primary conclusions. Make sure the abstract is written in the first-person, active voice.

MAIN MANUSCRIPT

The main text of the manuscript begins at the top of page 2 of the document, immediately after the abstract page. *Write your article in the first-person, active voice.* The main text of the manuscript should be broken into appropriate sections by the use of section headings. Sections should flow in a logical sequence, and include, at a minimum, *Methods*, *Results*, and *Discussion* (these are all level-1 headings); other level-1 headings and subheadings may be used at the author’s discretion. The author may choose to use different names for the three main sections, but the basic content should be that which would appropriately fall under the headings of *Methods*, *Results*, and *Discussion*. There are very specific requirements for the preparation of in-text citations; refer to the *APA Publication Manual*, 6th edition, for details. Every in-text citation should have a corresponding reference in the reference list—*no exceptions*.

During the review process, author citations should include only the word *Author* and the year: (*Author, 2008*). If and when the manuscript is accepted for publication, the missing information can be restored. Double space the entire manuscript document, *except for text contained in figures*. Use only U.S.- English spelling (except in the references, as appropriate, and for direct quotations from published written sources). Use U.S.-English translations of non-English quotations or excerpts. Use a minimum of two (2) heading levels. Attend to copyright regulations and permission requirements (*required*). Submit, at the time of manuscript submission, written permission for the use of any names, photographs, or copyrighted tables, figures, and/or text; written permission must come from the person(s) depicted in the photographs, or in the case of copyrighted work, from the copyright holder (which is not necessarily the author or the journal in which it is published; see page 7).

REFERENCES

Note: Proper formatting of the reference list is the responsibility of the *author*, NOT journal personnel. The reference list (also known as a bibliography) should include complete references for the sources used in the preparation of your manuscript. *Every reference* must be cited in the text.

The reference list should begin on a separate page (not in a separate document) following the last page of manuscript text (or after the notes, if any). Each type of reference (journal article, book, chapter in edited book, newspaper, online reference, and so forth) must be formatted in accordance with the precise guidelines contained in *APA*, 6th edition.

Elements such as listing order, spelling, punctuation, spacing, capitalization, and the use of italics or Roman (regular) font are as important as the content of the reference. Note that if an author has two or more initials, there should be spaces between the initials; incorrect = X.Y.Z.; correct = X. Y. Z. References should be listed in hanging paragraph format (with indentations at ½ inch or 1.3 cm.), in alphabetical order by the last name of the first author; additional considerations might apply (see

APA). The hanging paragraphs should be created by using Word’s Format > Paragraph feature.

During the review process, author references in the reference list should include only the word “Author” and the year: *Author. (2008)*. To prevent author identification during the review process, do not include the article title, journal name, or any other part of the reference. Do not place these references in alphabetical order in the reference list; place them at the very beginning or very end of the list. If and when the manuscript is accepted for publication, the missing information can be restored and properly placed.

Avoid the use of unnecessary references and lengthy reference lists. Extensive bibliographies will not be published; articles should include only the “essential” or key references. If the author wishes to offer a secondary reference list (for example, references used in meta-analysis), it should be so stated in a note, and made

available to readers by contacting the author directly. Do not include such a list in the manuscript document, but it may be submitted separately for purposes of review.

Use *only* the 6th edition of the *Publication Manual of the American Psychological Association (APA)* as your source of instruction for references (this is critically important). Translate non-English titles into English (see *APA* for instruction on how to do this). Reference and cite all other studies mentioned in the article. Test all Internet URLs (Web addresses) immediately before submission to ensure that they are accurate, and that the sites are still accessible; do this prior to submission of all revisions and accepted manuscripts, as well.

APPENDICES

Appendices are not encouraged, and are published only at the editor's discretion. If included, appendices should be placed in the main manuscript document following the reference list, and before any tables (place them before the bios in an accepted manuscript). *Appendices must be referred to in the text.*

WHAT YOU SHOULD NOT DO

Title page

- Do not type your title in ALL CAPITAL letters (this is especially important when entering the article title in the ScholarOne Manuscripts / SageTrack system).
- Do not place a period (full stop) at the end of your title.
- Do not include unnecessary words, such as *A Qualitative Study*, *A Doctoral Student's Investigation of*, *An Ethnographic Study*, and so forth.
- Do not list secondary or additional author affiliations (departments, divisions, hospital units, and so forth).
- Do not use abbreviations (except USA).
- Do not include department or division names, or secondary unit names.

Abstract

- Do not include the manuscript title on the abstract page.
- Do not indent the first line of the abstract.
- Do not include citations.
- Do not show the word count.
- Do not repeat text from the manuscript in the abstract.

Main document

- Do not include the manuscript title.
- Do not include any author-identifying information.
- Do not include participant identifiers (name, pseudonym, age, and so forth) except to identify a particular category of respondent (e.g., men aged 18 to 24; community professional; psychologist; and so forth), and even then, include identifiers only when *necessary* for reader understanding.
- Do not include names of specific study sites (hospitals, organizations, small towns or villages).
- Do not use *any* headings (such as "Introduction" or "Background") at the beginning of the manuscript.

References

- Do not format the hanging paragraphs with hard returns ("enter") and tabs.
- Do not submit the reference list as a separate document (except for lists such as meta-analysis references, as noted above).

FINAL CHECKLIST FOR SUBMISSION

GOAL: To submit the perfect manuscript. This checklist is intended to facilitate the swift internal review of your manuscript prior to submission.

GENERAL MANUSCRIPT PREPARATION

AVOID COMMON PROBLEMS:

- Refer to your article as an *article*, not as a paper or a study.
- Avoid anthropomorphism. Neither your study nor your article conducted the research: you did. Neither your study nor your article considered, chose, utilized, explored, selected, or took any other type of action: you did.

CHECKLIST:

- Consistently use the first-person, active voice in your writing.
- Be accurate and consistent with verb tense: things that happened, were written, or were said in the past should be written about in the past tense.
- Submit the title page as a separate document.
- Obtain (and submit) any needed permissions for use of copyrighted work and/or for the use of photographs/images.
- Obtain an informal peer review of your manuscript prior to submission (see the review criteria on page 55).
- Have your manuscript professionally edited prior to submission. If English is not your first language, make certain your editor is an expert in the English language.

QUOTATIONS

AVOID COMMON PROBLEMS:

- Participant identifiers and/or codes included with quotations pose a potential threat to participant confidentiality; do not use them. Even pseudonyms should be used with caution, especially if it is possible for the reader to “track” multiple comments presented from a particular participant.
- Ellipses/ellipsis points (. . .) are to be used only to represent deleted words or phrases, and not pauses in speech.

CHECKLIST:

- Set quotations of fewer than 40 words within regular sentences. Set quotations of 40 or more words as block quotes. (Use Word’s “Word Count” feature.)
- Indent block quotes by ½ inch (approximately 1.3 cm.) from the left margin only. (Use Word’s “Format > Paragraph” feature to create the indentation.)
- Type your quotations in 12-point font, double spaced. Do not use italics.
- Cite and reference all quotations taken from sources other than research participants, and include page numbers in the citations.
- If you add words of explanation or comment within quotations, place those words in [brackets] rather than (parentheses).
- Properly capitalize and punctuate all participant quotations.

REFERENCES & CITATIONS

Follow the sixth edition of the *APA Publication Manual*.

AVOID COMMON PROBLEMS:

- *APA* has stipulated a particular format for each specific reference type; be sure to use the correct format. Note that not all types of periodicals are referenced in the same manner as journal articles.
- References and citations should be prepared with exactness and attention to detail. The order of listing, spelling, punctuation, spacing, capitalization, and use of italic or Roman font are all important.

CHECKLIST:

- Spell out all journal names, and provide complete page numbers (e.g., 172-185 rather than 172-85).
- “Blind” your personal (author) references and citations as noted in the *Guidelines*.
- Double check the spelling of all reference author names, and ensure that both spelling and years of publication are consistent between the reference list and the in-text citations.
- Provide English translations for all non-English titles (retain the original titles).
- “hanging” text by ½ inch (approximately 1.3 cm.), using Word’s “Format > Paragraph” feature.

TABLES

GOAL: To organize and present relevant data that would be too cumbersome or complex to write into the text. Our standard is space. If your material can be more efficiently presented as text, do not make a table. A table must not duplicate material already appearing in the text. Place each table on a separate page at the end of your manuscript document.

AVOID COMMON PROBLEMS:

- The typesetting process removes all bullets from tables (whether numerals, letters, or dingbats); do not use them.
- The use of underlining, all uppercase (capital) letters, and italics can make a table look busy and cluttered, and can obscure important data. Use these features sparingly or not at all. Use bold font sparingly.

CHECKLIST:

- To maintain anonymity, present participant characteristics in aggregate (group) form, and refrain from listing individual participant characteristics.
- Make sure your table has a minimum of two (2) columns, a minimum of two (2) rows, and a clear and concise heading for *every* column.
- Create your table in “portrait” orientation on the page, within the regular 1-(approximately 2.5 cm.) margins of the document.
- Give your table a clear, descriptive, and concise title.
- Place individual data items or grouped data in separate rows of the table, rather than placing multiple items in a single row.

FIGURES

GOAL: To create useful and coherent figures that clarify complex concepts or accurately illustrate models and/or processes. Make your figure simple, clear, and easy to read and understand.

AVOID COMMON PROBLEMS:

- Put your efforts into presenting clear, meaningful data rather than “fancy” or artistic creations. Achieving simplicity, accuracy, and clarity should be your goals.

- Do not use shading, color, or bolded font.
- Too many lines and arrows, and especially lines and arrows that cross each other or cross text boxes, can lead to confusion and make a “muddle” of a figure, obscuring rather than revealing intended meaning. Do not use “heavy” or “bolded” lines and arrows.

CHECKLIST:

- Prepare and submit each figure in a separate document.
- Create your figure to be read from left to right and from top to bottom.
- Arrange text boxes in an orderly fashion, making them no larger than necessary to contain your text.
- Make your lines and arrows the proper length, so their beginnings and endings join the cells and clearly indicate direction.
- Use single line spacing for the text, and place the text in a horizontal orientation so it is not necessary to turn the document to read the figure.
- Give your figure a clear and concise title or legend. Include any notes after the title or legend rather than placing them below the figure.
- If using a participant’s artwork, be sure the lines are sufficiently distinct and dark enough to reproduce well if printed in the journal.

TABLES

Note: QHR personnel neither create nor make significant revisions to tables; this is the responsibility of the author. Tables organize *relevant, essential data* that would be too awkward or too lengthy to include in the text, and should be used *only* to provide data not already included in the text. For example, grouped participant demographics take less space presented in a descriptive paragraph than they do as a table. Tables are to be accompanied by both their number (Table 1, Table 2, and so forth) and their title (*required*). Tables and table placement are mentioned in the text, but the tables themselves are placed at the very

- Ensure that all abbreviations are explained in the notes.
- Ensure that the table is clear and comprehensible even without the surrounding article text (it should be able to “stand alone”).
- Make your table titles *concise* and *descriptive*.
- Keep your table as small as possible; use only the space necessary to contain your data. To fit within a single column of the journal, the table should be no wider than 3¼ inches (approximately 8 cm.); to fit across both columns it should be no wider than 6 inches (approximately 15.25 cm.). Narrow the table columns to eliminate unused “white” space.
- Place explanations, clarifications, citations and source notes, symbol and abbreviation identification, and other “nondata” information in notes below the table.

WHAT YOU SHOULD NOT DO:

- Do not use shading or color, or overuse bolding and/or italics (which can detract from a table, making it look “busy” without enhancing it in any way); do not use “heavy” or bolded lines.
- Do not list participants individually; instead, present group characteristics.
- Do not set tables in landscape orientation.
- Do not use bullets or numbered lists in tables.
- Do not make simple lists into tables; instead, place the lists in the manuscript text. end of the main manuscript document. The author should designate placement of each table within the manuscript by entering (flush left, on a separate line between paragraphs), INSERT TABLE 1 ABOUT HERE. *Table callouts should be placed following the paragraph in which they are first mentioned.*

Create the table the way it should appear when published, then double space all text, including column headers and notes. Use 12-point font for the table number and name, and use 8-point font for table content and explanatory notes. “Hide” all vertical lines and all horizontal lines except the following: top line of table, bottom line of table, and line below the main column headers. Multiple tables within the same manuscript should be similar in appearance and design. (See the sample table, below.)

Considerations:

- Make sure that what you are trying to create actually *is* a table; all tables must have column headings, at least two (2) columns, and at least two (2) rows. Most simple lists do not qualify as tables.
- You must *actually create a table*, even though most lines will be hidden.
- Put each table on a separate page (*not* in a separate document).
- Use only *portrait* orientation for your tables.
- Include only necessary data.

FIGURES

Like tables, figures should be used *sparingly*, and only when it is *necessary* to clarify complex relationships or concepts. Single space all text contained *within* a figure (but not the figure number, figure title/caption, and notes, which should be double spaced). Figure placement should be mentioned in the manuscript text, but *each figure is to be submitted in a separate document*, with the figure number and figure title on the first page, followed by the figure itself on the second page. Figure titles/legends should be *concise* and *descriptive*.

The author should designate placement of each figure within the manuscript by entering (on a separate line between paragraphs) INSERT FIGURE 1 ABOUT HERE. Figure callouts should be placed following the paragraph in which they are *first* mentioned. *Note:* Regular Word.doc documents are *strongly preferred* over .jpg or other document types, and are easier to revise, if necessary. See *APA* for requirements regarding the use or adaptation of copyrighted (previously published) material.

CONSIDERATIONS:

- In the published journal, photographs and other images are referred to as “figures.”
- Put each figure in a separate document.
- Use only 8-point font for figure text and notes.
- Make sure your figure is created to be read from *left to right*, from *top to bottom*.
- Use sufficient space between figure elements to ensure clarity, but eliminate unnecessary space.
- Make sure that hand-drawn figures (such as participant artwork) are dark enough to reproduce clearly when published.
- Use bolding and italics *sparingly*, and underlining only if absolutely necessary.
- Place your figure number and title/legend on the first page of the figure document.
- Place the figure itself on the second page of the figure document.
- Make sure your figures have “crisp,” clean lines and text. “Fuzzy” figures are not acceptable, and scanned figures are generally fuzzy.
- *Keep figures simple*, with as few lines, boxes, and arrows as possible; use plain arrows and solid, nonbolded lines. The style of the various elements of your figure must be consistent. Be careful about spacing and alignment of elements, including beginnings and endings of lines and arrows.
- Be aware that *QHR* does not publish in color; hand-drawn artwork and all photographs will be published in black and white only.

WHAT YOU SHOULD NOT DO

- Do not double space text within figures.
- Do not use shading or color.
- Do not place your figure inside an invisible “box” or “frame”; in other words, do not save the figure as a single item; save it as a collection of discrete elements, each of which can be corrected if necessary.
- Do not include your figures in the main manuscript document.

Abstract

This study explored the lived experience of dialysis in young adulthood. Semi-Structured interviews were conducted with four male patients – aged 24-31 years – all successfully established on maintenance haemodialysis. Data were collected and analysed according to the principals of interpretative phenomenological analysis (IPA). Two interconnected aspects of experience were identified, forming two broad categories of themes: biographical disruption and biographical repair. Biographical disruption described the immediate and ongoing negative impact that dialysis had on patients' lives, including failure to complete developmental tasks and difficulty maintaining a place within social networks. Patients also perceived multiple barriers to initiating and sustaining intimate relationships (e.g. sexual dysfunction and body-image disturbance). Biographical repair revealed a process of adjustment and adaptation, with patients finding new meaning in life on dialysis through efforts to reconnect with lost peers and seek alternative interests. Results are discussed in relation to the important of development perspectives in clinical health psychology.

Keywords: young adults, interpretative phenomenological analysis (IPA), health and well-being, relationships, social development

Established renal failure (ERF) is an irreversible state in which the kidneys no longer function at levels sufficient to sustain life; it is estimated that there are currently over 50,000 adults in the United Kingdom (UK) with ERF, most of whom rely on dialysis to ensure survival (Gilg, Rao, & Fogarty, 2013; Shaw, Pruthi, Pitcher, & Fogarty, 2013). These patients must make a long-term commitment to treatment, attending regular dialysis sessions and adhering to strict lifestyle modifications, often whilst experiencing challenging side-effects (e.g. fatigue, muscle cramps, insomnia, bone/joint pain, and sexual-dysfunction; Caplin, Kumar, & Davenport, 2011). It is recognised, therefore, that whilst dialysis saves lives, it may also be considered life-limiting: it is a complex, demanding, and time-consuming intervention and many patients report understandable difficulty adapting to its exigent regimen (Harries, 1996).

The Impact of Dialysis

Many dialysis patients report that they lack space for 'normal' life alongside busy treatment schedules (Hagren, Petersen, Severinsson, Lozen, & Clyne, 2001), conveying a strong sense of restriction and personal sacrifice (Smith, 1996; King, Carroll, Newton, & Dornan, 2002; Al-Arabi, 2006). Patients frequently cite a desire for 'normality' whilst struggling to integrate dialysis into pre-existing routines (Martin-Macdonald, 2003), perceiving significant social upheaval and reacting negatively to the relentless 'ongoingness and uncertainty' that treatment brings (Polaschek, 2007). Dialysis patients are rarely able to sustain gainful employment and regularly express dissatisfaction with time available for family and friends; indeed, many report an enforced abandonment of personal and professional goals early in treatment (Untas et al., 2011; Theofilou & Panagiotaki, 2010).

Patients may also struggle with the types of physical changes that patients on dialysis can experience (Martin-McDonald, 2003): beyond the presence of fistulas and catheters, patients often experience significant changes in weight, skin-discolouration, and severe oedema of the limbs – highly visible indicators of the toll that treatment takes on the body (Galpin, 1991). These changes are associated with elevated levels of body-image disturbance, higher rates of anxiety/depression (Partridge & Robertson, 2011), and increased feelings of sexual unattractiveness (Tanyi, 2002). Dialysis is observed to significantly reduce frequency of sexual contact and levels of intimacy, generating additional strain within established relationships (Yilmaz & Özalin, 2011; Doss & Polaschek, 2012).

Studies exploring the impact of dialysis on couples and families have noted that long-term partners do tend to share lifestyle changes with patients (Brunier & McKeever, 1993), often resulting in a 'mirroring' of negative affect within dyads (White & Grenyer, 1999). Partners can, however, facilitate successful adaptation, with positive responses to dialysis in a spouse predictive of superior adjustment in patients (Horsburgh, Rice & Matuk, 1998). Consistent emotional support from a partner can protect patients from psychological distress (Gee, Howe, & Kimmel, 2005); whilst

patients without partners demonstrate higher levels of anxiety, poorer self-esteem, and a far greater need for intervention from healthcare professionals (Ekelund & Anderson, 2010).

Young Adults on Dialysis

Dialysis is usually a later-life intervention: in the UK the mean age at initiation is 66.5 years, with 50% of patients aged 40-64 years, 19.8% aged 65-74 years, and 15.6% ≥ 75 years of age (Shaw et al., 2013). Renal failure, however, may occur at *any* age and 14.7% of dialysis patients are aged 18-39 years. These younger patients make up a significant proportion of the dialysis population, yet their experiences are not well-represented within the literature. Most research tends not to differentiate patient experiences by age or else focuses on the experiences of much older adults (Brown & Johansson, 2011; Murtagh, Addington-Hall, & Higginson, 2011). The paucity of empirical research exploring the experiences of young adults has already been highlighted in other medical fields (Zebrack, 2011), where it is noted that patients aged 18-35 years tend to be grouped with either paediatric or older adult populations, resulting in the unique psychosocial and service needs of this cohort being overlooked (Haase & Peters, 2004).

It is recognised that whilst all patients might experience a common set of life disruptions in response to serious illness, they are likely to experience them differently at different life stages (Zebrack, 2011). Younger dialysis patients may face additional hardships because of the intersection of illness experience with age-appropriate developmental tasks: early adulthood is a formative age that often involves transitioning from parental care, pursuing education/careers goals, establishing identity, developing relationships, exploring sexuality, and starting families (Diaz-Gonzalez de Ferris, 2011). Arnett (2000) refers to this time as 'emerging adulthood', conceptually distinct from adulthood-proper: a time of physical, social, emotional, and psychological flux. It is possible that young adults will experience different responses to dialysis as a result of treatment being initiated during this developmentally sensitive period - this has yet to be explored.

Study Aims

In the absence of qualitative research addressing the subjective experiences of young dialysis patients, it remains unclear what impact the intervention has on their lives and what personal meaning they attach to treatment experiences. This study aims to correct this oversight by exploring the lived experience of dialysis for young adults.

Methods

Design

A cross-sectional qualitative design was employed. This was informed by the principals of interpretative phenomenological analysis (IPA), an approach designed to explore how individuals' interpret and make sense of their experiences. These choices reflect both the exploratory nature of the study and its commitment to understanding the personal meaning attached to the experience of dialysis: it is the subjective rather than objective elements of experience that are prioritised in IPA and that define its 'phenomenological' nature (Flowers, Hart, & Marriott, 1999).

IPA adopts an idiographic approach that encourages greater depth of analysis at the level of the individual, enabled through purposive sampling of smaller numbers of participants. It employs qualitative modes of data collection that afford participants a far greater role in guiding the research process and outcomes. IPA was also favoured for its conceptualisation of research as an inductive process, aiming to explore and illuminate rather than to establish generalisable rules and theories. It was not intended that this study would produce a definitive description of 'the experience' of all young dialysis patients; it sought to highlight the nature and context of possible responses to dialysis by exploring representative cases.

Recruitment

Patients were recruited from three sites within Betsi Cadwaladr University Health Board (BCUHB) in North Wales, all specialist dialysis units attached to large regional hospitals. Access to patients was arranged through consultant nephrologists, with potential participants identified by renal nurses using established patient databases. In accordance with the principals of IPA recruitment was constrained by explicit inclusion/exclusion criteria.

Inclusion:

- Receiving regular (maintenance) dialysis either at home or in a hospital unit.
- Established on dialysis for a minimum of three months.
- Aged between 18-35 years of age.

Exclusion:

- Experience of dialysis before the age of 18 years.
- English not spoken to a standard sufficient to participate in interviews.
- Cognitive impairment restricting ability to give informed consent and/or participate in interviews.

Seventeen eligible patients were identified and approached by renal nurses. Patients were first asked whether they were interested in participating in research, with those responding affirmatively given further information. A verbal overview detailing research aims/procedures was provided by nurses, supplemented by a research pack containing a comprehensive written information-sheet and opt-in slip. Patients returning opt-in slips were contacted by the researcher to arrange meetings. All signed written consent forms.

Four participants were recruited. Although small, this size was considered sufficient for IPA, which places greater emphasis on the procurement of *quality* data than on a given *quantity* (i.e. number of participants/interviews). In IPA the 'right' sample size does not exist in a nominal sense (Smith & Osborn, 2003) and although consideration was given to widening inclusion/exclusion criteria, the data collected from this sample were considered sufficiently rich in quality.

Participants

All participants were male with ages ranging from 24-34 years; time on dialysis ranged from 5-14 years. All used haemodialysis: two at home and two in hospital-units. Two patients lived with immediate family and two lived alone. Two patients had previously received kidney transplants that had subsequently failed. All were single, unemployed, and had no children. All were assigned pseudonyms to ensure anonymity.

Data Collection

Single semi-structured interviews were conducted with each patient. Interviews were guided by a broad interview schedule (Appendix 2a); however, the general tone of interviews remained non-directive. Participants were encouraged to freely explore different subjects within designated topic areas. The interview schedule was developed after reviewing existing qualitative literature, with more focused questions/prompts intended to elicit where age could be considered pertinent to the meaning/interpretation of experiences. All patients were interviewed at home. Interviews were audio-recorded and transcribed verbatim. In accordance with IPA convention, all spoken words, false starts, pauses, laughs, and other notable features of speech were recorded in transcription to aid analysis (Smith, 2003). As suggested by Fade (2004), field notes were made to record observations,

including non-verbal communication, eye-contact, tone, fluidity of speech, and general impressions of participants/interviews. Interview durations ranged from 98 to 121 minutes.

Data Analysis

In IPA, data are not collected or analysed in a contextual vacuum and researchers are not required to abandon or suppress their own thoughts, feelings, and ideas; indeed, where the 'phenomenological' aspect of analysis refers to the goal of understanding the subjective nature of experience, the 'interpretative' component refers to researchers' own dynamic contribution to this process (Smith, 1996). It is recognised that a researcher's own preconceptions influence their understanding of the data; access to the lived experience of a participant is dependent upon - and complicated by - a researcher's preconceived values and ideas: the 'personal world' of the participant is interpreted through the 'personal world' of the researcher. This relationship encompasses a 'double hermeneutic', in which "the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003; pg 51). Considerable time was allotted before, during, and after analysis to consider the researcher's own thoughts/feelings towards the subject matter and the research process.

Following guidelines provided by Smith, Flowers, and Larkin (2009), transcripts were read and re-read multiple times to enable an holistic understanding to be established, this was followed by a process of note-making, theme identification, abstraction, theme organisation, and super-ordinate/sub-ordinate theme allocation – a detailed description of this process appears in Appendix 2b. A sample of analysis is presented in Appendix 2c. Core themes were identified and are presented in a narrative form to communicate participants' subjective understanding of events.

Quality

As standards of 'quality' applied to qualitative research differ markedly from criteria used to discern reliability/validity in quantitative studies, this study applied the four principals of quality for qualitative research outlined by Yardley (2000): sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (Appendix 2d).

Ethical Considerations

Ethical approval was granted by North Wales (East & Central) NHS Research Ethics Committee (Ref:13/WA/0364) and the study was subject to site-specific NHS R&D approval after full review.

Results

Two interconnected aspects of experience were identified, forming two broad categories of themes: *biographical disruption* and *biographical repair*. The former described the immediate and ongoing negative impact that dialysis had on patients' lives, strongly associated with intrusion and loss, whilst the latter revealed a process of acceptance, adjustment, and adaptation, with patients describing reconstruction and regeneration that allowed them to find new meaning in life on dialysis. This reflected a transition of moving from a life lived *for* dialysis to a life lived *with* dialysis. These themes were not mutually exclusive; indeed, they are dynamically interconnected - biographical repair necessarily emerged from the biographical disruption that dialysis caused. There were clear divisions within the sample: all patients were represented within themes expressing biographical disruption; however, there were varying degrees of representation within themes describing biographical repair - patients established on dialysis at home appeared to have undertaken the process of reconstruction and repair with far greater success than those receiving dialysis in hospital units. Themes are outlined – along with descriptive summaries – in Table 1.

1. Biographical Disruption

Missing Out

Would Have, Could Have, Should Have...

All patients retained a strong sense of the lives they could have been living without dialysis: treatment was felt to have disrupted and delayed this life. Patients described feeling deprived of experiences they believed young people should be having and were acutely aware that important developmental tasks (e.g. leaving the parental home) had not been completed. All spoke of being abruptly diverted from a 'normal' path. Matthew explained:

I should be living a normal life. I should have a job. I should have moved out of this house ages ago; I mean it's my parent's house. When I was nineteen, I had a job lined-up, a flat lined-up, I had a girlfriend - everything was going great and then suddenly, bang! Everything went - it was horrible.

Matthew listed important milestones that he felt he ought to have achieved "ages ago", with his repetition of "should" reinforcing the sense of unmet expectation. The sudden and traumatic "bang" that marked the start of treatment seemed to divide the life in which he "had" – on course and full of potential – from his new life with its "horrible" losses. Not achieving goals appeared especially frustrating because patients were so close to achieving them – acknowledged in Matthew's recollection that these things had been "lined-up". These missed experiences were framed as rites of

passage (i.e. important parts of the process of growing up and becoming an adult). For David, they were closely tied to gaining independence, which he felt he had failed to do due to continued reliance on parents, healthcare professionals, and dialysis itself. He explained:

...life's only just beginning at eighteen, that's the way I see it, and, do you know what I mean, everything builds up to like you wanna go out drinking, you wanna do this, you get your own independence, you get your driving license, you, you know, everything starts at eighteen – the whole build-up of childhood is so that you can go out and explore the world how you want. [...] But for me it was like as soon as I hit eighteen, I felt like I could never grow up, because I always relied on someone or something.

David felt that he had missed out on the final stages of transition: the “build-up” from childhood failed to reach its culmination, leaving him stuck as a child. Indeed, David felt that life had been “on hold” for the first five years of treatment. This sense of having missed out differentiated the experiences of younger patients, as Matthew noted:

If I was eighty, you know, like some of the other guys, they're like “Oh it doesn't matter, I've done what I've wanted to do with my life, I've got married, I've had kids, I've done!” but I'm twenty-four, I've done fuck all. ...I haven't done anything. ...I've missed out.

This felt deeply unfair: where older patients had “done”, younger patients were deprived of the opportunity to do. This was, therefore, a different kind of loss, defined by unfulfilled potential.

Left Out

Dialysis impacted negatively on peer relationships, with strong feelings of loss and isolation expressed. Patients again reported missing out: whilst friends were out having fun, they had to attend dialysis sessions, adhere to demanding lifestyle changes, and cope with treatment side-effects. David recalled “I was going up to the hospital whilst they [friends] went up for a day in [city], they'd come back and I'd be like “Oh aye, yeah?” and they'd talk about what they'd done...” When asked how he felt about this, his immediate reply: “Well, left out, innit?” Peers were getting on with life and had left patients behind. Steven explained: “I don't really have anyone to hang out with, 'cause they've all got jobs and they're living their lives and I'm sort of stuck in this little time-bubble not going anywhere.” Friends were out “living their lives” and Steven clearly felt that he was not living his: where he spoke of being “stuck”, he implied that he was not progressing in the way that his friends were. He was alone in a time-bubble, separated from the rest of the world but also temporally suspended, not moving forward.

Matthew described his social life as “terrible” explaining: “...everyone says “Oh, why don’t you go out and hang out with your friends?” Well, they’re at work, I can’t just turn up at their work and say “Hang out with me! I’m lonely and disabled!” This was a powerful description; although delivered with humour, it seemed to reveal how Matthew truly saw himself: isolated, restricted, and potentially a figure of pity. Indeed, Matthew commented that “people pity me all the time” which “feels like they’re putting you down”. Matthew was not part of the world of work occupied by his friends; he was alone in the world of his illness. Patients did sustain social contact with peers; although often limited and sporadic. Both practical difficulties and the widening gulf between lifestyles made it difficult to maintain a place within social networks.

Alone and Lonely: Intimate Relationships

I would really like one but...

Patients – all single – compared their lives unfavourably to peers and family members who had partners and also lamented lost relationships. Matthew explained:

I’ve been very, very single for four years and very, very alone. ... It’s like having your heart trapped in a glass cage. You’ve got a lot of feelings that you want to get out there but just nowhere for them to go. ...you’re often left just sat on your own, just like “Now what...?”

Matthew described his heart as trapped: he did not lack feelings or desires, he simply had nowhere to express them. Patients wanted relationships; however, these ambitions were curtailed by the physical constraints of treatment (e.g. fatigue). This generated conflict and contrast within narratives; as Steven revealed: “I would really like one [relationship] *but* the way things are going at the moment, I just prefer my own company...” Relationships took effort and energy, which dialysis depleted. Steven continued:

I find it difficult to keep relationships now... I just can’t be bothered. ...I just go on dialysis and then I just want to be left alone. ...since I’ve been on dialysis I don’t have the energy to fight for anything and I prefer just to let it dwindle out and just leave it be.

There was appreciable contrast between patients’ seeking partners and feeling so drained that they just wanted to be left alone.

An Unfair Burden

Patients feared being a burden to prospective partners. Matthew described his health as precarious, explaining: “It’s just the pressure of being this ill all the time. I could die at any point...” He then needed to consider sharing this existence with somebody, continuing:

I don’t think I could put someone else through that... ..everyone will go “Oh but it’s their choice if they want to do that and then they can be with you.” ...I respect that but at the end of the day, if you’re ill and you’re disabled and you’re constantly ill, it puts a lot of strain on the other person, a lot of pressure. I don’t think I know or have anybody that I could, you know, that I want to do that to.

Matthew implied that he would be imposing something terrible on a partner – as if being with them would be something awful he would *do* to them. Acknowledging the pressures of dialysis, he felt selfish for wanting to share that life with someone else. This conflict was of wanting to be in a relationship because you care for someone and not wanting to be in it for the same reason.

Dialysis had placed a strain on David’s marriage, changing his approach to relationships, explaining: “I wouldn’t want to feel a burden, putting someone through that again. ...I don’t think she realised how hard it was actually going to be...” Motivated by painful past experiences, patients felt that they had to carefully consider whether prospective partners could really “handle” dialysis. Matthew reported: “...anytime I get close to anybody, it’s the same thing ‘Oh, I don’t think I can handle you being ill.’” David had also wrestled with these issues: he had not wanted his wife to feel pressured into a caring role, yet found she was unable to cope with treatment demands. He explained:

She felt that I *needed* her and I didn’t, I *wanted* her. ...But, I mean, obviously she wasn’t strong enough... some people just can’t handle stuff...I need to look for someone that can handle it, because it’s a hell of a lot to take in for someone.

Handling dialysis entailed knowledge of the treatment *and* psychological/emotional resilience.

Disclosure

Patients described significant apprehension about disclosing that they were on dialysis. Fearing rejection, David was deliberately ambiguous: “...I don’t tell them anything about dialysis. ...I just say I have a health problem, do you know what I mean, and they take that how they want...” Steven even abandoned his diet to conceal his illness from a female friend, explaining:

It's awkward because I don't, like, stick to my diet or anything, I just act as if I'm normal, so like the fact that I'm ill just gets pushed to one side for the time being and, er, I know it's not good for me in the long run but it's just easier in one way, than telling someone that you're ill...

Steven tellingly referred to acting *as if* he were normal, indicating that he did not feel he was. He jeopardised his health to have the 'normal' experience of starting a relationship. It seemed easier, perhaps necessary, to push his illness aside for this to happen. Disclosure shattered illusions of normality, potentially provoking pity. Steven recalled "...slighting fearing the fact that they'd feel sorry for me but also... ...they don't really like to go out with people who are ill." Patients were aware of the significance of the news; Matthew explained:

...I'd like to get to know somebody first, you know, have decent conversation, try and get something in common, so then it, you know, it softens the blow [laughs]. 'Cause, you know, the kidney failure thing – or cancer or, you know, any kind of disease – is basically like hitting someone in the face with a hammer. It's sudden, blunt, heavy, and it's a lot to put on somebody.

This description may provide insight into Matthew's own experience of being told of his kidney failure – a sudden, blunt, and heavy blow. Not disclosing protected potential partners; attachments were formed to limit the damage. Patients had to judge carefully when the time was right to disclose, although uncertainty often remained: Steven had recently disclosed to a friend, explaining "...it was a weight off my shoulders for that part of it but then there's still in the back of my mind 'Yeah, I'm ill, she's going to go and look for somebody else'."

Not in the Mood

Dialysis was also associated with sexual dysfunction and reduced interest in sex. Patients appeared embarrassed discussing this subject, yet its importance is communicated by the fact that they did so even with a female researcher. Reflecting on his sex-drive, Steven reported: "It kind of dwindles when you start dialysis; I think that's the only thing that would concern the male." Steven distanced himself from this statement by referring to something that might concern "the male" when it really seemed to be a significant concern for *him*. A reduced sex-drive may have challenged notions of masculinity – presented as something important to *all* males. Matthew recalled:

I couldn't perform because I just couldn't bring myself to do it. I felt horrible and as much as I wanted to, it was one of those apathetic moments where you just can't bring yourself to do something. ...you just keep putting it off and putting it off and putting it off.

Describing an inability to ‘perform’ implied expectation and pressure. Matthew wanted to engage but physically could not and his frustration was clear. For Steven, the impact was even greater as he and his partner had been trying to start a family. He explained:

I was annoyed with myself ...I just wasn’t in the mood, I just, well, looking back at it now I’m getting angry [laughs], it’s, er, yeah, I just couldn’t be bothered... I just wanted to be like one of those stereotypical things that you see on telly really, just turn over and go to sleep [laughs]. ...the lack of sex-drive when we wanted to start a family just led to the breakdown of the relationship.

Recalling this experience evoked anger; the laughter that punctuated Steven’s speech may have reflected embarrassment but seemed more likely an attempt to defuse difficult emotions. Sexual dysfunction perhaps made it necessary for patients to minimise the importance of sex; Matthew explained: “...sex can go and hang its hat somewhere else – I’d like just to be with somebody, just to hold them and, you know, having a decent conversation with somebody – a meaningful conversation.” It is unclear whether Matthew would have been quite so dismissive of sex had his sex-drive not been reduced by dialysis; this may reflect substitution or attempts to project greater importance onto elements of relationships that he could still enjoy.

The skin you’re in...

Physical changes resulting from treatment also impacted negatively on self-esteem. Matthew explained: “I’m covered in scars. I feel disgusting. So, it’s quite difficult for me to open up to somebody. ...stretch marks and all sorts. I mean, it’s just... you take your clothes off and you don’t like the skin you’re in.” Matthew felt vulnerable, trapped in a body that he did not like. He questioned how somebody could ‘like’ him physically, when he did not like himself: “I have no control, my body type changes constantly... It’s demoralising. ...I can’t go out there and have the confidence to talk to people – or women – at all. It’s soul destroying...” Physical changes had a psychological and emotional impact; lacking control, Matthew felt powerless and exposed.

All patients had fistulas and wore long-sleeved tops to cover them in public. Feeling self-conscious, Steven explained: “I don’t like other people seeing my arm, because they tend to stare. ...I just don’t like it, I feel awkward and I feel like I shouldn’t be there.” Steven felt that he did not belong. He continued: “...I don’t feel comfortable around anyone else, I don’t like the way my body looks anymore, since I had that [fistula] done. So, I always tend to put large jackets on, hoodies, just to hide everything.” Fistulas were overt signs of dialysis that differentiated patients from peers - the feeling of not being ‘normal’ was again strongly expressed.

That's All My Life Is Now

Restriction

The demands of treatment prescription restricted patients. Steven described spending life “tethered to a machine”, unable to get away from dialysis: perhaps both physically *and* mentally. Between sessions patients were also restricted by fatigue; Steven continued: “I never have energy to do anything. I’m always tired. ...I hate it to be honest. I can’t do anything.” Matthew concurred: “I can’t just go out and do something because if I walk round for longer than ten minutes I get physically sick... ...it’s just meh.” Life was defined by the things that these patients could *not* do. Describing this situation as “meh” indicated passive resignation, yet there was also clear frustration. Restriction encroached on patients’ wider sense of personal freedom, with the lack of spontaneity lamented by all. Peter explained:

I can’t just think, you know, “To hell with this! I’m going to Scotland to see the sights!” I can’t just go, because if I do I could just die, because I need to, you know, arrange a lot of stuff, hospitals and things, gotta take all my tablets, make sure I’ve got enough, and it’s just hassle really...

Non-routine events quickly became a “hassle”, requiring significant planning. Peter somewhat blithely noted the risk that he “could just die”, yet this was a genuine threat. Matthew explained: “I’ve still got the get up and go attitude to want to do something, it’s just now I’ve got to plan ahead if I want to spontaneously do something [laughs]. ...which is terrible really.” Matthew laughed at the absurdity of having to plan spontaneous experiences: spontaneity was, perhaps, an important part of his identity as a young person – he *wanted* to call experiences spontaneous even whilst knowing they were not.

Patients receiving dialysis in units reported greater restriction: units enforced strict timetables. These patients had to wait for transport and were severely fatigued after sessions. Limitations, however, were present for all, only overcome where patients invested significant time and effort.

Day In, Day Out

The dialysis routine was unavoidable and inescapable and patients reported feeling worn down by its ongoing nature. David used humour to mask a serious point when he explained:

...the nurses are like “Oh I’ve got a two week holiday coming up.” but *you* can’t even have two weeks holiday; people on dialysis can’t. They have to sit there and, well, yeah, it would be nice to have a week off! ...I mean obviously you say it as a joke but really you do think it.

Holidays are an opportunity to get away from everyday routine and be temporarily relieved of the stresses of life – a deserved reward for working hard. David was extremely frustrated: it did not seem fair that nurses could escape from dialysis routines, whilst he was stuck. Steven reported that dialysis patients “...basically live in the hospital...”, while Matthew explained:

I'm in the hospital every other day. ... Life is me just sitting on my bed waiting for the day to end, to go to sleep, to go to dialysis – that's all my life is. ...I come home, I go straight to sleep, and I wake up about one, two o'clock in the morning, make myself something to eat and then go back to sleep.

The dialysis routine was psychologically as well as physically tiring; Peter reflected “...it just gets monotonous, you do the same thing all the time.” and Matthew tellingly referred to treatment as “a drudge”, explaining “It's just day in, day out; you walk in, you sit down, you just get it over with and then you leave. That's how it is.” The passive, detached way that patients spoke about treatment presented them as merely acquiescent.

2. Biographical Repair

Home Dialysis: From Living for to Living with

More of a Life...

David and Peter suggested that home-dialysis transformed life by affording them far greater freedom. This was in sharp contrast to the continued restriction and rather more severe side-effects (e.g. fatigue) that Matthew and Steven described. By using dialysis overnight, treatment no longer obstructed Peter's daytime plans: this meant: “. . . you weren't having to fit things *round* dialysis, you were doing the dialysis after or before you done the things...” As dialysis was no longer the focus of life, the “things” Peter wanted to do could take priority – a change described in revelatory tones. David's experience was similarly positive: dialysing for two hours every day offered “much more of a life”. There was still a routine; however, it was flexible and offered patients' greater control. David explained:

...you can change it, that's the best thing about dialysis at home, at hospital you can't, you have to make plans around it. At home, if I wanna go to the gym or the snooker or do anything, I can do that first *then* do that [dialysis]. ...But in the hospital, you're set hours are: Monday, Wednesday, Friday, Tuesday, Thursday, Saturday, morning, afternoon, night and you *have* to turn up...

David prioritised the kinds of experiences one might expect a young adult to pursue: going to the gym and seeing friends, potentially repairing much of the disruption that dialysis initially caused. David had previously struggled to ‘place’ dialysis in his life, explaining:

When I first went on dialysis it was like two lives: I would go to the hospital, that was one life on dialysis, and then I’d come back and live my normal life... ..I split it. I’ve always had a barrier between it... Dialysis is only coming into my life now because I’m at home and I’m doing two hours daily. ...it’s shown me that you can live on dialysis, you don’t have to just exist on dialysis; you can live. You have to get it to fit around you and it has to work for you ...

Having either a “life” *or* “dialysis” was how David previously coped with restriction. Home-dialysis created experiential change, yet also transformed his attitude: he could finally see dialysis being integrated into his life. Dialysis was working *for* these patients, offering more than a simple existence.

A New Way

Dialysis deprived patients of opportunities; however, David and Peter felt that it relieved them of pressures too. David reported that when it came to education, work, and money “that ship has sailed” allowing him to circumvent “a load of hard work and a load of stress”. Patients were on a different path but not necessarily a worse path. Peter explained:

I think I’m more relaxed then I was before, ‘cause I was thinking that I had to get a job and like, I’ve got to have a job to get money... ..it’s more relaxed now ‘cause I don’t have to worry about things like that...

Although Peter repeatedly noted that he was “gutted” to lose his job, he used his free time to his advantage: Peter developed an interest in art and local history and David completed a college course. Both were proud of their achievements and found real meaning in these new pursuits: where one door closed, another opened.

Freedom associated with home-dialysis also encouraged these patients to reconnect with peers, which seemed to change how they saw themselves. David explained:

...[home-dialysis] sort of opened your eyes that it’s not all that bad... ..after time on dialysis and not doing nothing, you know what I mean, it was a weird thing finding my mates back again from when I was growing up and doing actual normal things again, it did help...

Re-establishing relationships with peers allowed patients to see that they were still ‘normal’, which had a positive impact on wellbeing. David felt that he was ‘back’ where he had been before dialysis, perhaps where he belonged. It seemed likely that many of the limitations imposed by dialysis were generated by patients’ beliefs about what they could and could not achieve on treatment – it was experience that showed patients how much of their ‘lost’ lives they could recover.

To Live Before I Die

Dialysis forced patients to reflect on their mortality. This prompted considerable distress but also encouraged positive reframing: patients were ultimately grateful to be alive. Matthew and Steven were less inclined to adopt this position, given their extremely negative evaluations of treatment; however, David and Peter expressed optimism – communicating a desire to live whilst they had chance. David recalled “It [dialysis] made you realise that life isn’t going to be there all the time”. After initial disruption, these patients appreciated, and perhaps even anticipated, the potential for further losses and did not want to squander opportunities. David continued:

I just don’t think of it as “Oh, I’ve got five years left; I gotta sit down and sit on the sofa.” I don’t think of it that way, I think of it as “I’ve got five years left; I’m gonna live my so-called bucket list!” I want to do things. It might sound stupid at thirty, but at the end of the day, if I don’t do them, if I don’t experience them, then I’ve lost out on life.

Having been close to death kept David “focused on what I want to do”, motivating him to make the most of life. He explained “...it’s just made me mentally stronger. ...mentally needing to do something”. As David spoke he made frequent gestures towards his dialysis machine, which was perhaps a *momento mori*: this machine kept him alive but could also take life away.

These patients also felt more assertive, as Peter explained:

I won’t do things I don’t want to more, well, basically now I’m here to have fun, for now, sort of thing. What I thought was going to happen has not happened, so just have a laugh now, sort of thing, and things I don’t wanna do – unless they’re things that I have to do – I won’t do, sort of thing.

Life had not turned out as patients hoped, yet this loss was counteracted with a determination to make the most of what was left.

Discussion

The descriptions of life on dialysis offered here by young adults were broadly concordant with those outlined in research with older patients: all had experienced restriction, struggling to adjust to the relentless and ongoing nature of treatment (Polaschek, 2002), and all had grappled with the challenges of living *for* rather than *with* dialysis (Smith, 1996; King et al., 2002). The young adults in this study, however, appeared to experience a more pronounced sense of biographical disruption, challenged by a feeling that their lives had been abruptly diverted from a 'normal' path. Most felt unfairly deprived because they had 'missed out' on important age-related milestones; patients were left divested of experiences that they expected to have as they emerged into adulthood and this heightened the acute sense of loss.

The concept of disruption presupposes a sense of normality from which life can deviate; what is perhaps unique about deviation from a 'normal' life in young adulthood is that normality at this age is heavily defined by choice, opportunity, and exploration – it is usually a dynamic period of continuing change. Arnett (2000) describes this as an age of possibilities, wherein optimism reigns: certainly, patients in this study described pre-dialysis life in terms of potential and forward momentum. Moving from such an excitingly nascent position may have made the sudden restriction and enforced dependence associated with dialysis feel all the more pronounced – a shocking contrast in which opportunity and freedom were forsaken in addition to more tangible losses.

Dialysis impacted on many areas of life; however, its social consequences appeared most striking. This study highlights potential difficulties young patients may face in trying to establish/maintain wider support networks, especially in terms of staying connected with peers – a consequence of treatment that may leave young patients at risk of social isolation. At a time when the young adults in this study wanted to be 'normal' they often felt defined by their illness, which seemed to challenge notions of social identity. They also experienced physical changes that disturbed body-image and lowered self-esteem, significantly impacting on confidence in social interactions. There was a sense that social acceptance required concealment: from the covering up of fistulas to the deliberate non-disclosure of illness. One might question whether these patients had sufficient opportunity to discover and be their authentic selves.

Existing research highlights the importance of supportive partners in facilitating adjustment to dialysis (Horsburgh, Rice & Matuk, 1998); however, these young patients had yet to find partners. Most wanted intimate relationships, yet faced multiple barriers: lacking energy, fearing disclosure, and worrying that it was unfair to burden others. Patients also experienced sexual dysfunction, impacting negatively on physical aspects of relationships. Although this mirrored results of research with older married patients (Yilmaz & Özalın, 2011; Doss & Polaschek, 2012), sexual dysfunction

appeared to be an especially challenging development for these younger males and was certainly a barrier to starting a family.

Not all patients in this study stagnated in the biographical disruption caused by dialysis: there was also evidence of biographical repair, wherein patients accepted losses and created new lives on dialysis. Only the two patients using home-dialysis appeared to have started this process: one might query whether these patients appeared better adjusted because they received home-treatment or were receiving home-treatment because they were better adjusted - it is feasible that home-dialysis was offered because clinicians felt that these patients would make good use of the opportunity and/or were in a better position to handle the responsibility. However, these two patients themselves felt that home-dialysis increased choice and lessened restriction, allowing time/space for life to be restarted, it seems likely that this was an important transition. Increased responsibility may encourage personal growth in this population, especially where these patients feel that they have been trapped in childhood by the restriction and dependence enforced by treatment. Self-management often bolsters self-efficacy and helps patients to accept illness (Coyne, 2013); offering younger adults the option of home-treatment earlier might also help to limit the sense of disruption experienced.

In this study, young adults did appear to adjust to treatment; being young may even provide greater opportunity to create a good life with dialysis – it may prove harder for older patients to change and integrate treatment into established lifestyles. Although these young patients were challenged by dialysis, there was evidence to show that they could, where appropriately supported and empowered, recover stability and meaning.

Limitations & Further Research

Small sample sizes may be considered a limitation in research seeking to define definitive experiences or to generate generalisable theory; however, this research aimed to provide insight into potential responses to dialysis in young adults by exploring representative cases and a smaller sample provided the opportunity to explore cases in greater depth. This respected the idiographic traditions of IPA. A more notable limitation was that the sample contained only male patients. Homogeneity in samples is encouraged in IPA; however, it is recognised that female patients may have presented different perspectives, especially given known difference in male/female views on issues such as body-image in young adulthood (Grossbard, Lee, Neighbors, & Larimer, 2008). Female patients may have expressed different or additional concerns (e.g. issues around starting families) and further research is still needed to explore this. Further investigation is also recommended to explore comparisons between patients on home-dialysis and those attending hospital units. Consideration of clinicians' decision-making as regards home-treatment may also be

useful. This study was cross-sectional and so could not discern whether patient experiences changed over time; indeed, differences in the degrees of acceptance and biographical repair noted in the sample may have reflected a process of adjustment in different stages – longitudinal research should be undertaken to explore this possibility. There are certainly numerous avenues for further research opened up by this study.

Conclusion

Existing research has focused on how dialysis impacts on the established lives of older adults: it is important that clinicians understand interactions between the developmental tasks of young adulthood and the various challenges of living with dialysis. The clinical tasks emerging from this study relate both to helping patients accept losses *and* facilitating the rebuilding of a life with dialysis. The overwhelmingly optimistic message is that young adults represented in this study could adapt and create meaningful lives on dialysis.

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Table 1. Categories, themes, and subthemes: labels and descriptive summaries.

Category	Theme	Subtheme	Descriptive Summary	
Biographical Disruption	Missing Out		Captures the overt sense of biographical disruption reported by patients.	
		Would have, should have, could have...	Describes contrast between the lives patients lived with dialysis and their ideas about the lives they felt they should have been living without it, encapsulating the sense that patients had been diverted from a 'normal' path and documenting the experiences they felt they had missed out on.	
		Left Out, Left Behind	Addresses the sense of missing out socially and in comparison to peers, portrayed in descriptions of peers moving forward with their lives and leaving patients behind.	
	Alone & Lonely: Intimate Relationships			Describes the impact of dialysis on patients' ability to start and sustain intimate relationships.
		I would really like one but...	Captures the conflict and contrast between desires to have an intimate/romantic partner and barriers posed by treatment (e.g. fatigue).	
		An Unfair Burden	Explores conflict over whether it is fair on prospective partners to ask them to share a life with someone on dialysis and communicates the need to identify partners who can cope with the strains of treatment.	
		Disclosure	Describes apprehension about telling prospective partners about dialysis and efforts to avoid disclosure to remain 'normal'.	
		Not in the Mood	Outlines the impact that dialysis had on sexual aspects of relations and how sexual dysfunction depleted self-esteem and placed strain on relationships.	
		The skin you're in...	Explores how the physical changes associated with dialysis impacted on body-image and self-esteem, with particular reference to patients' confidence in relating to prospective partners.	
	All My Life Is Now			Captures the sense that all there was to life was dialysis and explores some of the physical and psychological barriers posed by treatment.
		Restriction	Describes the limits imposed on life by dialysis and its physical side-effects, limiting day-to-day activity and preventing spontaneity.	
		Day In, Day Out	Explores the ongoing nature of treatment and the sense that the dialysis routine was an inescapable force.	
Biographical Repair	From Living for to Living with		Conveys the freedom and control afforded to patients on home-dialysis and the how this transformed treatment positively.	
		More of a Life...	Describes how patients started to reprioritise their own interests, rather than working around dialysis routines.	
	A New Way	Explores how home-dialysis allowed patients to reconnect with friends and define new directions in life.		
	To Live Before I Die	Describes how premature exposure to issues of mortality motivated patients to want to live as fully as possible.		

Appendix 2a: Interview Schedule to guide interviews.

Introductory Questions (Ice-Breakers)

About You

P: Introductions/Background (brief)

P: Reason for Dialysis/Type of Dialysis – why chosen>positive/negative?

Treatment Initiation

P: Timing (life events: education/career, relationships, living situation)

Context: When did you start using dialysis? What other things were happening in your life at that time?

What is life like for you on dialysis – in your own words?

P: Negative Aspects/Challenges

P: Positive Aspects

How has life changed since you started using dialysis?

1) Physical

P: Descriptive

P: Thoughts/Feelings

P: Self-Esteem/confidence

P: Physical

2) Social Life

P: Change in activities

P: Continuity

3) Relationships

P: Family

P: Friends

P: Romantic >>status (single/relationship>feelings towards the future, changes?)

P: Intimate/Sexual>> have there been changes as a result of dialysis?

Probe for potential difference in respect to gender

Check timings – life stages, specific challenges at this time of life?

Has dialysis has changed the way you think about and plan for the future?

P: Plans now – changed?

P: Feelings

P: Attitude: hope > positive/negative?

P: Education/Career

P: Relationships

P: Family/Children

P: Treatment – Transplant

Opportunity to reflect on interview...

Is there anything that has been missed or that you feel it is important for us to know?

Note. P= Prompts to follow and guide broad/open questions.

Appendix 2b. The process of data analysis using interpretative phenomenological analysis, adapted from Smith et al. (2009).

Stage in Analysis	Description of Process
1 <i>Reading, Re-reading & Note-Making</i>	Initially, each transcript was read several times familiarise the researcher with the data and to gain an overall impression of what the participant was trying to say. Smith et al. (2009) describe this as entering “a phase of active engagement with the data” (pg. 82), in which the reader begins to fully appreciate the ebb and flow of the narrative and the nature of the experiences that are being communicated. Interesting and significant passages were highlighted and notes describing the issues raised were made in the margin. Initially these notes reflected immediate reactions to the text; however, these gradually focused on more specific details (e.g. nuances of the language used or specific emotional responses) and also began to incorporate wider contextual details and ideas.
2 <i>Theme Identification & Interpretation</i>	Transcripts and notes were then reviewed to identify interconnected ‘themes’, with observations grouped according to the context and meaning being conveyed. This process reduced the dataset whilst retaining its complexity and meaning. Themes that emerged reflected the participants own words and experiences, but were structured around the interpretations of the researcher. A ‘themes document’ was created to collate extracts of transcripts exemplifying each theme. Once themes had been established within a single transcript, it was necessary to appraise how these themes ‘fit’ together conceptually. The list of themes was printed out, cut-up and attached to a board so that they could be moved around. This was performed to explore, through spatial representation, how themes related to each other. Conceptually similar themes were placed in close proximity to each other and incongruent themes positioned at proportional distances.
3 <i>Abstraction & Organisation</i>	Abstraction involves formally housing similar/related themes within ‘superordinate’ categories. Master themes were assigned conceptually defined titles that summarised how each cluster of themes were interlinked; labels encapsulated the essential message and significance of the observations made. The naming of themes required a higher level of abstraction, incorporating interpretation of the individual, the interview situation, and the overall message being communicated. It was necessary to consider each theme in the context of the entire transcript and to establish how and why significant ‘events’ interconnected within the narrative.
4 <i>Moving to Other Cases</i>	The same process was repeated for each transcript, with care taken, as far as possible, to ‘bracket’ the ideas and themes from previous cases while the next case was being analysed. This was done in an attempt to respect the idiographic nature of IPA. Smith et al. (2009) acknowledge that the influence of previous cases will almost inevitably encroach on aspects of subsequent analysis; however, they state that strict adherence to the systematic approach outlined above should minimise any potential bias. In addition, where new or unique themes were identified in a transcript, already analysed transcripts were <i>re</i> -analysed in an iterative process to check that themes had not been overlooked. This maintained a sense of continuity within the overall process of analysing an interconnected sample of individuals.
5 <i>Modelling</i>	After each case had been analysed there was a list of superordinate/subordinate themes and a ‘theme document’ containing representative quotes for each transcript. All were then reviewed for connections, looking to see which themes recurred, were conceptually aligned, appeared most important, and/or illuminated other cases. A table of themes for the entire sample was then created, depicting and summarising all superordinate/subordinate themes. The final list of superordinate themes contained examples found in all participant interviews (i.e. represented shared themes). Some were excluded in a process of theme ‘pruning’ on the basis that they did not contribute significantly to the emerging narrative. The final list was organised into conceptually-related groups to identify an overarching story - a process of ‘modelling’ the data. The final structure was organised into a visual-model representing the dynamic relationships between emergent themes. This model was judged to be the most accurate reflection of participants’ experiences. To supplement this process and to allow a move from analysis to narrative construction, the relevant aspects of individual ‘themes documents’ for each transcript were merged into one master document

At all stages in analysis memo-writing occurred to record the analytic decision making process and to aid both future decision-making and narrative construction.

Appendix 2c: Example of data analysis using transcript extract.

Emergent Themes	Original Transcript	Initial Thoughts & Exploratory Comments
<p>Biographical Disruption Missed Milestones Lost Momentum/Direction Nostalgia Contrast – Then/Now</p> <p>Contrast – Then/Now Loss of Opportunity Lost Momentum/Direction Sudden/Traumatic Change Restriction Living for Dialysis</p> <p>Side-Effects – Physical Loss of Control of Own Body Restriction Constant</p> <p>Exhaustion/Fatigue Restriction Routine/Pattern Emotional Avoidance Separation of Body/Self Focus on Physical Identity/Self-Esteem</p>	<p>As I said before, I had a job, I was gonna get a flat, I had a girlfriend, she was going to move in with me, it was possibly gonna get serious... I'd have my own place. I'd be going out having drinks with my friends, you know, meeting women and possibly bringing them back to said flat! [Laughs] And, you know, things would progress from there. But now, it's just [pause], it's just not going the way I wanted it to.</p> <p>When you talk about the way you wanted it to be, what would that life have been like?</p> <p>Before I was ill I got A-Levels in science, I did GCSEs and A-Levels, I was going to move onto a degree, maybe something more, maybe, I don't know, a Masters or a Doctorate, something really important. I was going to try, you know, to go through the whole science side of things, maybe, er, become a technician, work in a hospital or a school or something or a university. Just, you know, the world was my oyster and that's all fell, all of a sudden the wall came down and I was restricted on everything I could do. And, er, I saw my life doing something, actually amounting to something; but as you can see, I'm wearing sweatpants and a t-shirt and I was asleep – and probably would have been asleep until one o'clock in the afternoon – that's my life.</p> <p>What is a day in your life like at the moment? I know we've talked before about the sleeping patterns and needing that sleep. What are the effects of dialysis day-to-day?</p> <p>Okay. After haemodialysis, which is what I'm on now, which is the blood dialysis through the arm, er, directly after dialysis: nausea, light-headedness, a disorientated feeling, like your body is not quite your own, also joint pain, which is not severe, but it's there, you can feel it when you move. Have you ever had a cold and it's gone into your joints?</p> <p>Yeah...</p> <p>It's kinda like that when you're trying to move, you just feel lethargic and you hurt and you just don't wanna do anything, but couple that with exhaustion. That's how it feels right after dialysis. And usually that's about, like that til six o'clock in the afternoon. I come home, I go straight to sleep, and I wake up about one, two o'clock in the morning, make myself something to eat and then go back to sleep. I wake up again at about one o'clock in the afternoon and then I just get on with my life because I don't feel it, the feeling goes, it's just your body having to re-orient itself after this major thing, because, you know, having all your blood sucked out and then pumped back into you, you're body's like [whispers] "I don't like this..." but it shows because, you know, you look a mess. You're pale with black rings around your eyes.</p>	<p>Reiteration of what was <i>going to</i> happen (adds emphasis – important?); sense of being on a certain path. Listing milestones, developmental tasks (?): moving out, gaining independence, and career development. Ownership of own space and own life. Spans different areas of life – work, social life, forming intimate relationships (i.e. 'typical' experiences); going out and discovering the world. Sense that things <i>would</i> progress and then change; contrast of then and now. Pause = reflection, disappointment, how to articulate the loss? Feeling of being off-course, not how it was expected to be and not the life he wanted.</p> <p>Pre-dialysis reference points, often used to illustrate contrast and draw attention to the significance of change. Again sense of movement, progress, momentum before dialysis. Could have been important – implies that life now is not or cannot be? Again what was "going to" happen – has he really let go of that past? Loss of potential and opportunity – the "world was my oyster" – possibilities. The falling away of the exciting life that could have been; sudden (traumatic?) change, as a wall coming down = imprisonment, restriction because he is confined to his small walled world. Contrast of everything being possible to nothing being possible. Life could have amounted to something; now amounts to nothing? Clothes for comfort, spending the day asleep, not seen as a worthy life? Apologetic? Self-evident that this is not the life he was supposed to have?</p> <p>Physical effects of treatment: described in terms of losing ownership of own body, like the loss of your own blood during the process, which also becomes not your own as it leaves the body? Combination of different negative physical symptoms.</p> <p>Being held back by his own body; physical restriction imposed by the treatment even after the session has finished. Really negative but also couple it with something else negative – emphasis on the accumulative effects. A lot of time is taken up in sleeping off the treatment side-effects; description of only then being able to 'get on with my life' shows that there is not much life left? Not feeling it – the feeling goes, is this a detachment from it? His body as being very separate from 'him', it is the body that is dealing with dialysis not him? Distancing himself from the 'major thing' by framing it as an experience that just his body goes through? Separates body off to have its own voice – his body telling him that it does not like the process of dialysis; how does <i>he</i> feel about it? This emotional component is missing; it is reduced to a physical exchange. The body does not like it but it is him that ends up looking a mess, so the physical body is a reflection on him (and both is and is not him). Self-esteem and identity – I look like a mess.</p>

Note. This table offers an example of how raw transcripts (middle column) were initially analysed, with initial ideas being noted down as an immediate reaction to the data (right hand column). This then led to ideas being encapsulated in the emerging themes (left hand column).

Appendix 2d: Four principals of ‘quality’ in qualitative research adapted from Yardley (2000) and Smith et al. (2009).

Principal	Definition
1 <i>Sensitivity to Context</i>	Encourages researchers to reflect on the immediate socio-cultural context in which the research is being conducted: knowledge of the people/places under investigation should include “the normative, ideological, linguistic and/or socio-economic influences on the beliefs, objectives, expectations and talk of all participants” (Yardley, 2000; pg. 220). Researchers should also be aware of how <i>they</i> impact on data collection within that context (Potter & Wetherell, 1995); considering factors such as gender, age, and occupation.
2 <i>Commitment & Rigour</i>	<i>Commitment</i> is demonstrated by prolonged engagement with the subject, competence in the methods employed, and immersion in the data. Interviews especially require personal investment, with researchers attending closely to what is being communicated in a receptive and empathic manner. The interpretative nature of analysis also requires commitment to data; researchers submerge themselves in the world of the participant as both seek to make sense of experiences (Brocki & Wearden, 2006). <i>Rigour</i> implies methodological thoroughness, completeness in data collection/analysis, and adequately answered research questions. Rigour is demonstrated in interviews, where researchers are attuned to what the interviewee is saying whilst keeping sight of both the overall direction and data production; in data transcription, where details such as tone and emotionality displayed in speech are recorded (Poland, 1995); through the use of field notes and researcher reflections; and in the completeness of data interpretation.
3 <i>Transparency & Coherence</i>	<i>Transparency</i> is shown where each stage of research is described clearly (e.g. recruitment, interview processes, and analysis) and justified in relation to the overall research aims. <i>Coherence</i> relates to the clarity and cogency of the research as a body of work (Elliott, Fischer, & Rennie, 2010). Themes should be logical and presented in a conceptually coherent way, with a narrative that tells a convincing and relevant story. Results should accurately recreate the experiences of participants in a meaningful way and it should be clear what participants themselves sought to communicate.
4 <i>Impact & Importance</i>	The final test is whether research is “interesting, important, or useful” (Smith et al., 2009; pg. 183). It is not sufficient for research to appear rigorous and plausible if the message communicated does little to influence and/or engage others; Mays and Pope (2000) also stress the importance of <i>relevance</i> , suggesting that the value of a study should be assessed in respect to its original aims and intended application.

Paper 3: Contributions to Theory and Clinical Practice

This final paper integrates findings from the literature review and empirical study to consider their combined impact. It is presented in three sections: 1) contributions to theory and recommendations for future research; 2) clinical implications; and 3) personal reflections on the research process and outcomes.

1) Theoretical Implications and Future Research

Health psychology research typically adopts an illness or treatment-specific approach, wherein all patients receiving a particular diagnosis or intervention are grouped together and their experiences collectively explored, as in the research focusing on adherence and social support presented in the literature review. There is, however, a danger that important elements of experience will be missed if all patients sharing a diagnosis/treatment are always treated as one homogeneous group: the research presented in this thesis found that *age* – though often overlooked – is a variable that can significantly influence illness experiences.

Findings from the empirical paper suggest that young adults on dialysis experience unique responses to treatment; its impact on their lives is best understood in the context of age-specific developmental paths. These young adults appear to share more in common with young adults experiencing other long-term or life-threatening conditions than they do with much older adults on dialysis. Indeed, perusal of the wider health literature confirms that young adults share concerns across illness populations: young cancer patients also report body-image disturbance, sexual dysfunction, and apprehension about initiating intimate relationships (Carpentier & Fortenberry, 2010), young adults with diabetes have described a negative impact on peer-relationships and social identity (Dovey-Pearce, Doherty, & May, 2007), and young epilepsy patients share the challenge of transitioning from parental care (McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004). It is recognised that the transition from childhood to adulthood spans physical, social, psychological, and emotional domains: concerns about establishing identity, developing a positive body-image, exploring sexuality, separating from parents, increasing involvement with peers, dating, making decisions about careers/employment, higher-education, and/or family-planning (Arnett, 2000). More focused longitudinal research may help to more accurately define and measure each of these developmental concepts and how they interact with specific illness experiences: e.g. how the impact of dialysis on peer networks and ability to form new relationships effects adherence in a social context. Indeed, it is likely that a better understanding of this developmental context will facilitate a greater understanding of many of the more generic difficulties faced by patients of all ages (e.g. adherence).

The systematic review explored adherence behaviours with the understanding that poor adherence can have a significantly deleterious impact on treatment outcomes. No consistent relationship was

found between social support and adherence, a result that contrasted with findings from other illness populations (e.g. diabetes; Gallant, 2003). It is possible that the influence of social support depends on a number of additional factors not considered in the studies reviewed – including age. It seems likely that the forms of social support available and the types of support needed will vary significantly according to the stage of life that each patient is in. Patients starting dialysis in young adulthood face a number of additional challenges in respect to maintaining social connections and the support networks in place around them are, consequently, more likely to be those established in childhood. For young adults, social support appears to come predominantly from immediate family (e.g. parents), a fact that may itself generate conflict at a time when these patients might otherwise be transitioning away from parental care. Indeed, the systematic review highlighted the importance of family dynamics: these may be more or less important in a patients' family of *origin* (i.e. parents and siblings) as compared to family of *choice* (i.e. friends or spouse). Older patients are more likely to be living with the latter, having a partner and potentially children; they may even be living with adult children in very older age.

Evidence for a link between social support and adherence appeared most consistent where support was instrumental (i.e. practical) and provided by an individual designated as a carer (e.g. a spouse). However, the empirical paper revealed the challenges that young dialysis patients can face in establishing and sustaining intimate relationships, with a strong reluctance to burden others with a life on dialysis. Indeed, it was strongly suggested that patients would only enter into relationships where there was no expectation placed on the other person to provide this kind of care. Patients feared being a burden to others and wanted 'normal' relationships with partners, not carers. There may be an aspect of age-related expectation that influences how comfortable patients' feel in positioning a partner into a caring role – and how comfortable partners feel in adopting this role. It may be easier for parents to continue in a caring role where patients are younger. How age influences the dynamics of caring relationships is another research topic that has not yet been explored in the context of dialysis; it is recommended that these issues are considered.

Even if, as indicated, social support does not directly influence adherence, its role in facilitating positive health outcomes has been robustly demonstrated, making the challenges faced by young adults on dialysis in accessing support a legitimate concern. There is evidence to suggest that young adults are more likely to adapt successfully to dialysis if they have protective factors that increase their resilience – including support from family and friends (Bell & Hope, 2012). Further research could usefully explore how social support structures vary according to age, what meaning is attached, and what impact this has on the illness experience.

Establishing the *meaning* that these concepts hold for patients is an important goal; the empirical paper has demonstrated the value of qualitative research in this respect. Both quantitative and

qualitative approaches are clearly useful and necessary; however, it is noted that whilst quantitative research can identify potential differences in outcomes by statistically controlling for age, it cannot necessarily reveal the underlying causes. Quantitative research considers age as a number, whilst qualitative approaches are able to explore meaning and context. Certain elements of the illness experience are not easily quantifiable; e.g. it would be difficult to capture the fact that apprehension about disclosing dialysis to a prospective partner may lead patients to abandon diets in social situations – as was the case for Steven in the empirical paper. This would not be detected in quantitative research investigating adherence. The literature review did not find a consistent relationship between adherence and social support; the empirical paper indicates that attempting to understand these aspects of the illness experience by measuring only one or two isolated variables is too simplistic an approach. There still appears to be a need to qualitatively explore different aspects of the dialysis experience before large-scale quantitative research can confidently proceed – especially in the case of young adult experiences. Longitudinal qualitative research is likely to offer greater insight into a number of issues touched upon within the empirical paper: e.g. how patients' experience the move onto home-dialysis, how biographical disruption transitions into biographical repair, and how attitudes towards treatment change over time.

Considering both the systematic review and empirical paper, there is clearly much that can be learnt about the illness experiences of dialysis patients and much still to be discovered: it is hoped that this thesis both contributes to the knowledge base *and* highlights useful means of moving forward.

2) Clinical Implications

The experiences described by young adults on dialysis suggest the need to provide services that are more developmentally appropriate (i.e. tailored to meet needs arising due to the specific stage of life at which patients commence treatment). All healthcare professionals should be aware of the potential for biographical disruption as a result of patients being unable to complete developmental tasks (e.g. leaving the parental home or going to university); they should also be aware of the different ways in which this 'disruption' may be experienced – from the potential for social isolation to the intrapersonal impact of treatment (e.g. on mood and self-esteem).

Clinical psychologists – with both a theoretical and working knowledge of psychosocial development *and* experience of formulation/intervention that takes multiple 'systems' into account – are well placed to help healthcare teams plan and provide developmentally and psychologically informed care. Psychologists could be involved at various levels of renal service planning and delivery to achieve this. At a clinical level psychologists will undoubtedly work *directly* with young people; however, they may also work *indirectly* in services by supporting other healthcare

professionals (e.g. by providing supervision or case-consultation). Psychologists could also provide staff-training to help raise awareness of the specific challenges faced by young patients.

It may be easier to consider the impact of dialysis on the already established lives of older patients; for younger patients, it may be necessary to consider not only what has been lost but also that which was expected and never materialised in life – this calls for healthcare professionals to be mindful of the loss of opportunity too. It is likely that patients will experience new challenges – or losses – as they move through young adulthood and peers undertake new developmental tasks: for example, an eighteen year old patient starting dialysis may not be thinking about having children; however, they may begin to think about this when friends or relatives start families. Knowing that a patient *started* dialysis in young adulthood should trigger sensitivity to these emergent challenges/losses over time. There may also be specific aspects of experience that are currently overlooked by professionals but that need to be on the clinical agenda: for example, sexual dysfunction and body-image disturbance were noted difficulties in the empirical paper, yet are not often considered clinically. Although patients expressed some embarrassment, they had significant concerns; young patients may benefit from talking about these issues and healthcare professionals should perhaps sensitively initiate such discussions. Developmentally, one would expect for these issues to be especially important to young males. Partners also may be affected by these issues and there may be utility in providing advice and support for patients *and* partners.

Renal care primarily focuses on ensuring good *medical* outcomes; however, the wider impact of treatment must be taken into account. Services should perhaps take a more holistic view of patient care, with a greater emphasis on psychosocial aspects of the illness experience. It is also important that services appreciate interactions between psychological and physical wellbeing, with good psychosocial health likely to encourage engagement in positive health behaviours. On a practical note, psychologists may play an important role here in providing appropriate tools for other healthcare professionals to use to detect negative psychosocial consequences of illness in young adults; for example, the ‘Distress Thermometer’ used in cancer populations is currently being validated for use in renal populations and could be routinely administered during medical appointments (Alston, 2014). This measure asks patients to rate psychological distress and then to identify issues causing concern in relation to practical, physical, emotional, spiritual, and family problems – and within any other important domains that patients’ themselves identity. It also encourages patients to problem-solve by considering what strategies they have previously found useful in reducing distress and prompting them to think of additional strategies that they could employ. It is quick to administer but collates a great deal of information for healthcare professionals to consider – indeed, it could be used by staff to initiate discussions about the more sensitive issues outlined (e.g. sexual dysfunction).

A recent study exploring patient transitions from paediatric to adult renal services suggested employing a designated young-adult worker to meet the wider psychosocial needs of this population (e.g. helping them stay in or return to education and advising on matters of sexual health and relationships; Bell & Hope, 2012). It was specifically recommended that this post be filled by an individual from a non-medical background (e.g. youth or social work); this might help patients minimise the sense of disruption across different areas of their lives. Indeed, it was further suggested that services should develop specific young adult care plans to identify the individualised needs of these younger patients and help to ensure their lives retain a sense of forward momentum alongside treatment (Bell & Hope, 2012). Reports of biographical repair in the empirical paper support such an initiative, affirming the need to help young adult patients find a way to restore meaning through reintegration into social networks and by pursuing new interests (e.g. enrolling onto college courses or joining local volunteer schemes; Diaz-Gonzalez de Ferri, 2011). Given the potential risks to health associated with travel and activity identified by young adults in the empirical paper, it is possible that schemes organised by services could provide a 'safe' environment through which young people might explore age-appropriate experiences and socialise with peers.

During interviews patients demonstrating good adjustment to dialysis noted the need to 'find a way' with treatment, learning the rules so that they could safely bend or break them (e.g. drinking whiskey shorts to reduce fluid intake when out with friends); young adults may benefit from more advice tailored to fit with age-appropriate experiences in this way. Services should perhaps consider a more flexible and empathic approach with young adults, especially in relation to non-adherence; young patients clearly face unique challenges in maintaining adherence whilst contending with others' age-related psychosocial changes – responding with compassion, rather than condemnation, when young patients 'lapse' may help to keep young patients engaged and sustain open and honest communication.

There are extremely effective peer-support networks in place for young adults with other long-term and life-threatening illnesses (e.g. cancer; McLaughlin et al., 2012); it may be helpful for renal services to facilitate networking between young dialysis patients within the locality. This may be achieved in a number of ways (e.g. through support groups). A report commissioned by the East Midlands Renal Network (EMRN; 2012) proposed the use of peer-mentoring and also posited dialysis sessions specifically for younger patients, so as to facilitate networking and support within renal units. This may help to normalise the experience of dialysis for young adults, showing them that they are not alone in their experiences. These are suggestions dependent on the individual preferences of patients, as not all may want contact with other young people on dialysis; however, there are other ways and means of connecting young people and sharing information that could be considered: online links and resources could be made available to provide targeted information (e.g. advice around adherence, travel, or navigating social situations whilst on dialysis), an approach that

has proven a successful means of connecting and educating young adults with cancer (Love et al., 2012). Patients could usefully be signposted to the National Kidney Federation (NKF) website, which has a links to the 'Young@NKF' initiative, aiming to connect younger dialysis patients through online social networking sites.

A notable finding in the empirical paper was the difference in experiences and attitudes between patients receiving dialysis within units and those on home-dialysis. Patients dialysing at home noted greater freedom and fewer treatment side-effects, allowing them to begin reconnecting with peers and repairing much of the disruption that dialysis was felt to have caused. These patients spoke positively of dialysing overnight and dialysing for two hours every day; two different approaches to home-treatment. Empowering young adults to take control of the long-term management of their treatment may be an important clinical step with far-reaching psychosocial implications. It is recognised that being younger should not necessarily lead directly to home-dialysis, as this is a process that needs to be considered and negotiated according to each individual patients' needs; however, it is recommended that this should be considered – and the option monitored – early for young adults on dialysis. Nocturnal dialysis at home and kidney transplantation actually have comparable physical outcomes (Pauly et al., 2009); however, less than a quarter of patients dialysing in the UK dialyse at home, with less than 3% using home haemodialysis (Castledine, Steenkamp, Feest, & Tomson, 2010). These are options that should perhaps be explored with more young patients.

These suggestions are made in response to the findings presented in the empirical paper and are intended to illustrate the potential clinical implications of the research; however, it is acknowledged that young people themselves may offer different perspectives on how services could be improved. Given the open and articulate way that patients spoke of their experiences, one final clinical implication of this research may be the suggestion that service users – the young adults themselves – should be consulted as to how best services can meet their needs. Indeed, this may be another part of the empowerment process. Formal mechanisms for achieving this, for example a young patients' forum, could be set up to allow young adults to shape services to best meet their needs. This accords with recommendations for service-user inclusion set out in the National Service Framework and Policy Statement 'Designed to Tackle Renal Disease in Wales' (Welsh Assembly Government, 2007), which recommend that services-users are afforded significant input into renal service development throughout Wales.

3) Personal Reflections

Researcher reflection is an important tenant of IPA research: in recognising that data are not collected or analysed in a contextual vacuum; researchers are encouraged to acknowledge their own

thoughts and feelings about the subject being investigated and also to be mindful of the socio-cultural 'positions' that they might occupy within participants' worlds – a process described in Yardley's (2000) call for *sensitivity to context*. This final section explores my own reflections on the research process.

The importance of patients' age was the central focus of this research and was also the most significant consideration as I reflected on my role as a researcher. The empirical paper explored the experiences of adults aged 18-35 years, which meant that I was the same age as the patients being interviewed. In some respects, this may have been an advantage; implicitly communicating to patients that I could, as a young adult myself, truly understand the nature of the experiences being described – I was afforded 'insider' status. I felt that this generated an unspoken sense of mutual understanding and helped me to develop rapport with patients, vital for facilitating open and honest communication. Patients did seem to assume that we shared – and that I understood – cultural customs and references; for example, they often used colloquial language, felt comfortable swearing, and discussed specific music, film, and social events (e.g. Peter talked about going to Download festival). There appeared to be a shared language between us and this created a shared world: I wondered whether the same content would have been offered if I had been much older than these participants.

Although our shared age seemed to facilitate rapport-building, I was also aware of the risk that patients might perceive interviews as being more informal, perhaps even social exchanges: I needed to stay within the boundaries of my role as interviewer, aware that patients might also perceive me as a peer. Some patients did enquire about my own experiences and I was mindful that my role needed to be clearly defined and maintained; it was vital that my contributions to interviews were appropriately constrained and that I stayed focused on the research objectives – the robust framework provided by IPA was useful in this regard. Within this context, I was also aware that being the same age as participants may have made it harder for them to share difficult experiences with me; if I was perceived to be a peer, they may have wanted to protect a social identity or simply felt too uncomfortable sharing difficult and personal experiences – I felt that there was a certain amount of useful and necessary distance created by the formal structure of the interview situation that created a 'safe' space for patients. The fact that the content of interviews covered a diverse range of topics, and included the kinds of psychological/emotional content that one would not expect to be informally shared, indicates that patients did feel comfortable sharing information with me and understood my role to be that of researcher before peer.

Being the same age as participants also helped me to reflect on the journey that they had undertaken; it encouraged me to think how I might feel if suddenly faced with the challenges of dialysis. This insight made hearing patients' experiences rather more poignant and personal – this

was generally helpful, as I felt I was really able to empathise; however, identifying with patients in this way also meant that I felt great pressure to accurately represent their experiences in the empirical paper. It was a significant source of frustration that I was not able to include all content and analysis and the process of editing this work was especially challenging.

I was also aware that patients may have reflected on our being the same age but having very different lives. I may have been perceived as having access to the opportunities and experiences that they had been deprived of and I was sensitive to the fact that this may have been difficult for them. All were informed that the research was being conducted as part of an educational qualification and I was mindful that patients may have felt that they were helping me to advance in my life by explaining to me how they had not been able to do so in their own. After his interview, Matthew spoke somewhat sadly about his own ambitions to complete a doctorate; he talked at length about his love of science and his disappointment that he only managed to achieve A-Levels by the time he started dialysis. This made his contribution to the project even more meaningful and I was extremely grateful to him for agreeing to take part.

All patients in this study were male; thus, whilst I might have been considered an 'insider' for being the same age as participants, I could also be viewed as having 'outsider' status for being female. There is evidence to suggest that female researchers encourage female participants to be more open, as they assume shared understanding and experiences (Riessman, 1994), with the implication that female/male researchers may gather different data from male/female participants (Gill and Maclean, 2002; Labaree, 2002). This is difficult to confirm in the current study; however, my own feeling was that being female may have been an important factor when specific types of experience were being discussed: patients appeared more hesitant to discuss relationships, sex, and family-planning and I wondered whether being a female researcher made it easier or harder for male patients to discuss these sensitive issues. I certainly felt that these subjects needed to be broached tentatively and noted that there was some initial discomfort from patients when my questions were asked. Indeed, patients seemed to 'test the waters' with these subjects, often speaking briefly at first but returning to them in greater depth later. I attempted to put patients at ease by adopting a confident approach to these subjects, allowing patients to see that they could be discussed openly. I felt that it was a testament to the importance of these subjects that all were prepared to discuss them with a female researcher, despite some obvious embarrassment. Indeed, it is clinically important to note that these males grasped the opportunity to discuss these issues, indicating, perhaps, that these issues have been somewhat neglected elsewhere.

Although it is not possible to say whether patients would have offered different perspectives had they been interviewed by a male researcher, I felt that I needed to be mindful of the fact that gender may have been a salient factor for patients. It is, however, notable that patients engaged in long

interviews that covered a range of highly sensitive issues, indicating that they felt comfortable within the interview situation.

Three patients had seen clinical psychologists within the renal service and described good relationships with these professionals; only one patient (Matthew) expressed negative views of psychology and was concerned that our discussions might go “too deep” – though this was perhaps more revealing of his difficulties at the time. I felt that being identified as a researcher *and* a psychologist encouraged patients to speak openly and to focus more on emotional/psychological aspects of experience. Indeed, patients may have felt that this was *expected* of them. It is possible that had I been a medical professional, the accounts offered by patients would have focused on different elements of experience (e.g. the physical effects of treatment or clinical decision-making around the mode of dialysis used). I suspect that my professional background increased patients’ confidence in my ability to hold/contain distress: all patients spoke of difficult emotional responses to treatment and two patients discussed suicidal thoughts. I believe that my clinical training helped me to explore these issues safely and appropriately – which gave me confidence; I also felt that I had the personal and professional resilience to work with quite difficult content.

Clinical training encourages reflection and I feel that this greatly enhanced data collection and analysis. Halling (2008) notes “In everyday life each of us is something of a phenomenologist insofar as we genuinely listen to the stories that people tell us and insofar as we pay attention to and reflect on our own perceptions.” (pg. 145). In clinical psychology, significant time is spent listening to people’s stories and making sense of what we are being told: this mirrors the IPA process. IPA encourages researchers to acknowledge that their interpretations are made through the lens of their own experience – as a trainee, I had a strong theoretical knowledge-base through which I could understand patients’ experiences (e.g. in terms of loss and grief, adaptation and acceptance, and readiness to change). I felt that this enhanced my understanding and helped me to make connections between different aspects of experiences and across cases.

Coming from a ‘research background’, there was much that I enjoyed about returning to the research process. However, adopting the role of researcher again also reminded me of some of the frustrations that had led me to clinical training. As a researcher, I had often wanted to do more than simply observe and record patient experiences, I also wanted to be able to actively help and support patients. When patients in this study spoke of their negative emotional responses to dialysis, it was difficult not to slip into a problem-solving or therapy mode. I had to consciously stay in researcher role, which was somewhat frustrating at times. Overall, it felt like I was taking and not giving anything back to these patients, which was an uncomfortable feeling. During subsequent analysis this feeling subsided somewhat as I began to see how communicating the experiencing of these patients had the potential to help many other young patients in their situation – I was reminded that

research is undertaken to try to improve the lives of far greater numbers of patients. Although I realise the unique advantage that clinical psychologists hold in being able to undertake both research and clinical work, I found it extremely difficult to separate these roles.

It seems important to reflect in this section on the difficulties experienced in recruitment. It was acknowledged from the start that the population of younger adults on dialysis was small and that recruitment was taking place within a geographical region far less densely populated than neighbouring regions in England – largely because of its rural nature. However, recruitment levels were far lower than anticipated, even in three regional dialysis centres. A number of factors may have deterred potential participants: the fact that the research was being conducted by a female when most dialysis patients were male, that the research was being undertaken as part of an educational qualification, or that patients did not feel physically well enough to take part in an interview (perhaps wanting to save physical resources for more important activities). Informal feedback from nursing staff suggested that most patients simply did not want to talk about their experiences – which is itself important to note. During interviews all patients described distinctly avoidant coping strategies; frequently referring to ‘blocking out’ and ‘not thinking about’ dialysis to avoid distress – preferring to ‘act normal’. It is possible that patients not taking part were exercising a similar approach and that talking about their experiences would have challenged this mode of coping.

Given the idiographic focus of IPA, it was considered sufficient to proceed with a small sample, especially given the length of interviews and the quality of the data collected. Indeed, there was opportunity to go into far greater depth in analysis and interpretation and I found it beneficial to be able to do this. Having previously undertaken longitudinal research, it felt challenging to have only one meeting with each patient; there was limited time to develop rapport and pressure to accurately capture each patient’s experiences in the allotted time. It felt necessary to spend greater time considering the data. I hope that this allowed me to accurately capture and convey the thoughts, feelings, and experiences of each young adult.

It was noted that I referred to people using dialysis as ‘patients’ throughout this thesis, mirroring the terminology used within healthcare services and the wider literature. It is interesting and important to reflect on what influence the use of this term may have had on participants and how it may even have shaped my own interpretation of their experiences. This was a term that I imposed; I did not explore participants’ emotional and psychological responses to the label or whether they would have chosen to spontaneously apply it to themselves.

It is possible that this term strips away something of a person’s individual identity; there is a danger that one becomes a patient rather than a person. As increasing numbers of people are living with

long-term conditions and seeking to integrate physical health changes into existing lives, the use of this descriptor may sustain the idea of deficit and impairment, impeding adjustment and adaptation. Young adults in this thesis spoke movingly of the desire to retrieve a sense of normality and, for those dialysing at home, there was clearly progress in finding ways to repair the biographical disruption caused by treatment. It remains unknown whether these young adults – expressing a sense of having found a way to live *with* rather than *for* dialysis – would subscribe as readily to the use of the label ‘patient’; the label might also feel less appropriate for these participants, as compared to those still regularly attending hospital units to receive treatment. I automatically referred to all participants as dialysis patients, rather than young people using dialysis – I had defined them by an illness, arguably assuming that the illness dominated their identities and life experiences. The issue of how illness identities might evolve, or even fall away, in people living with long-term conditions is one that future research could usefully explore, especially alongside consideration of implications for the traditional doctor/patient roles often assigned in healthcare management. There is a clear push for greater self-care in individuals living with long-term conditions; however, the labels that we apply – especially that of ‘patient’ – connote a somewhat passive role. There is, perhaps, a need to consider more empowering ways of describing individuals living with long-term illnesses.

As the final part of the research process, analysis was discussed with supervisors – two consultant clinical psychologists working within renal services. In respect to Yardley’s (2000) criteria, mapping data onto the findings and demonstrating the ‘paper trail’ generated by analysis was part of the process of ensuring transparency, whilst discussing how findings related to the clinical experiences of my supervisors was needed to ensure impact, importance, and relevance had been achieved. Mays and Pope (2000) suggest that the value of a study should be assessed in respect to its original aims and intended application. Without experience of working in renal services, I experienced a significant degree of apprehension about whether my findings would resonate with my supervisors’ experiences and appear clinically valuable. It was a relief that many of the issues raised were recognisable *and* that new perspectives had emerged. Clinical psychologists undertake research to inform and improve their own practice and to raise awareness of issues that will help other professionals and services to do the same; it is hoped that the research presented in this thesis will be used to fulfil both of these ambitions.

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Ethics Submission Documents

IRAS Form (NHS Ethics)

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

The Experience of Dialysis in Young Adulthood

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- England
- Scotland
- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

-
- England
- Scotland
- Wales
- Northern Ireland
- This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
- Social Care Research Ethics Committee
- Research Ethics Committee
- National Information Governance Board for Health and Social Care (NIGB)
- National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes No

9. Is the study or any part of it being undertaken as an educational project?

- Yes No

Please describe briefly the involvement of the student(s):

The student (Lucy Piggini) is a Trainee Clinical Psychologist employed by Betsi Cadwaladr University Health Board. She will be acting as Principal Investigator and will be responsible for directing recruitment, organising data collection, obtaining informed consent from participants, undertaking research interviews, analysing data, and writing up the results for dissemination. This work will be undertaken under the supervision of two Consultant Clinical Psychologists (Dr Beth Parry-Jones and Dr Paul Gardner) working within Renal Services.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

Integrated Research Application System
Application Form for Research involving qualitative methods only



Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 The Experience of Dialysis in Young Adulthood

Please complete these details after you have booked the REC application for review.

REC Name:
 North Wales REC (Central and East)

REC Reference Number:
 13/WA/0364

Submission date:
 25/10/2013

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Dr	Lucy	Piggin
Address	NWCPP Brigantia Building, Penrallt Road Bangor, Gwynedd		
Post Code	LL57 2AS		
E-mail	lucy.piggin@wales.nhs.uk		
Telephone			
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
 Doctorate in Clinical Psychology

Name of educational establishment:
 North Wales Clinical Psychology Programme (NWCPP), Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Beth	Parry-Jones
Address	Renal & Diabetes Centre Ysbyty Glan Clwyd Sarn Lane, Bodelwyddan		
Post Code	LL18 5UJ		
E-mail	Beth.Parry-Jones@wales.nhs.uk		
Telephone	01745 445655		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Paul	Gardner
Address	Renal Psychology Service Elidir Unit, Ysbyty Gwynedd Penrhosgarnedd, Bangor		
Post Code	LL57 2PY		
E-mail	Paul.Gardner@wales.nhs.uk		
Telephone	01248 384448		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Dr Lucy Piggin	<input checked="" type="checkbox"/> Dr Beth Parry-Jones <input checked="" type="checkbox"/> Dr Paul Gardner

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Dr Lucy Pigginn
Post	Trainee Clinical Psychologist
Qualifications	PhD Health Psychology MSc Research Methods and Statistics MA Experimental Psychology (Oxon)
Employer	Betsi Cadwaladr University Health Board
Work Address	NWCPP Brigantia Building, Penrallt Road Bangor, Gwynedd
Post Code	LL57 2AS
Work E-mail	lucy.pigginn@wales.nhs.uk
* Personal E-mail	pspefa@bangor.ac.uk
Work Telephone	07544750560
* Personal Telephone/Mobile	07544750560
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School Manager, School of Psychology Brigantia Building, Penrallt Road Bangor, Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	+44 (0) 1248 388339
Fax	+44 (0) 1248 38 2599

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number: 2013-10604

Protocol Version: Version 1

Protocol Date: 24/07/2013

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open

access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

The majority of patients receiving dialysis are older adults (<65 years), however, the treatment is offered to all patients whose kidney function is significantly compromised and there are subsequently a growing number of young adults (18-35 years) successfully established in its use. Existing research has tended to focus on the experiences of older adults and so relatively little is known about what it is like for young adults using dialysis. This study seeks to explore the impact of dialysis on the lives of these younger patients in psychological, emotional, and social terms.

Our interest in this subject is informed by an understanding that successful dialysis requires a significant commitment from patients; it is extremely time-consuming, requires adherence to rigid fluid/dietary restrictions, and there are many negative physical 'side-effects' to its use (e.g. fatigue, low blood-pressure, muscle-cramps, insomnia, pain, decreased libido, sexual-dysfunction, and infertility). We would like to know what impact these challenges have on the lives of patients in early adulthood because we know this to be a formative period in life, where individuals might still be building a sense of identity and self-esteem and establishing relationships and life-plans. We suspect that the experiences of young adults might differ markedly from those of older adults.

We intend to ask younger patients about these issues. All patients aged 18-35 years who have been using dialysis for ≥3 months will be invited to take part in a semi-structured interview either at hospital or in their own homes. The information gathered will be summarised to create a descriptive narrative of life on dialysis and the impact that the treatment has had on their lives/identities. This will be used to raise awareness of the needs of this population amongst professionals within renal services.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Physical Health Needs

Dialysed patients may present with a number of physical health needs, both as a result of various underlying medical conditions and as 'side-effects' associated with dialysis use. A degree of flexibility will be required to accommodate patient's physical health status, which may vary from day-to-day. We will ensure that patients are aware that any scheduled interviews can be postponed or rearranged at any point, including during the interviews themselves. It will be made clear to patients that they can withdraw from the study at any time and do not need to provide a reason for doing so. All patients will be given the option of conducting interviews over multiple sessions if they become too tired or unwell to continue – this is in addition to being offered as many breaks as needed during the interview process. The interviewing researcher (Dr Lucy Pigginn) has experience of conducting research interviews with patients who have serious and chronic physical illnesses and is aware of the need to be mindful of non-verbal signs that patients are experiencing fatigue or physical discomfort.

Distress

This study will explore a number of potentially emotive issues and it is possible that some patients may experience emotional/psychological discomfort or distress. Patients will be fully informed about the subjects to be covered in interviews prior to consent being obtained; however, it will also be made clear that patients are not obliged to reveal any information that they do not want to and that they do not have to discuss any subjects that they find particularly upsetting. It will be stressed to all patients that they have the right to decline to answer questions and may stop or withdraw from interviews at any point. An interview schedule will be used to guide interviews, however, patients will remain in control of their content and direction at all times in accordance with the principals of Interpretative Phenomenological Analysis (IPA).

A degree of distress may be expected given the nature of the subjects being discussed. This is not necessarily something that needs to be prevented; it is possible that some patients may find the interview process of therapeutic benefit. Patients should feel able to freely express whatever it is they feel – whether this is positive or negative – and all possible efforts will be made to ensure that interviews are a safe space for patients to do this. Patients will be given a choice between being interviewed at hospital or at home and will be ensured anonymity and confidentiality. Patients will be able to meet the researcher before interviews and sufficient time will be afforded to establishing rapport and putting patients at ease.

Where emotional or psychological reactions displayed by patients appear to be extreme or to reflect an enduring difficulty, it is possible that a referral to a Clinical Health Psychologist may be appropriate. This would only be considered after discussion with the patient and with their expressed consent. The interviewing researcher (Dr Lucy Piggin) is a second-year Trainee Clinical Psychologist and will be supervised by two experienced Consultant Clinical Health Psychologists (Dr Beth Parry-Jones and Dr Paul Gardner).

Specific checks will be made to ensure that no patient is left in a state of distress after an interview; patients will be asked to appraise how they found the interview process and time will be allotted to diffuse any negative affect. Patients will always be given the opportunity to ask questions after an interview. Patients will be advised to contact the researcher if research related questions or concerns arise after the interview and will be encouraged to contact a member of their clinical team if they have any questions or concerns relating to their physical health needs.

Language/Diversity

In this study, all information sheets, opt-in slips, and consent forms will be provided in English and Welsh language formats. However, it will not be possible for the research team – all of whom are English-only speakers – to offer patients the option of completing interviews in Welsh. This will be stated on all information sheets.

Efforts have been made to consider ways of accommodating Welsh speakers in interviews by using a simultaneous translator; however, this would pose insurmountable challenges to both data collection and subsequent analysis. The generative nature of interviews conducted within an IPA framework – in which the interviewer composes unique questions based on the patient's immediate responses rather than referring to a prescribed list of questions – relies on the researcher's ability to respond instantly and fluidly to what the patient has said. This would not be feasible with a translator; the flow of interviews would undoubtedly be interrupted and there is a strong possibility that meaning would be lost in this process. The presence of a third 'intermediary' person would also change the dynamics of the relationship between interviewer and interviewee, potentially challenging the safe space created to encourage patients to openly share their experiences. There are additional issues of confidentiality and potential distress in translators to be considered.

Qualitative research relies on the 'quality' of the data produced. It is essential that researchers are able to interpret the precise meaning that spoken words hold for the individual being interviewed and to be confident that they are communicating this meaning accurately and fully through their analysis. Translating data from Welsh into English risks a loss of meaning, as the translation is no longer the patient's own words and is open to misinterpretation by a researcher who does not speak Welsh. In IPA it is essential that the researcher establishes a close relationship with the text produced; analysis occurs at a broad thematic level but also at the level of individual words and the nuances of the individual's linguistic style. IPA researchers also incorporate contextual information into analysis (e.g. a patient's body language or facial expression as a particular word or phrase is used), which would not be feasible if interviewees were responding in a language not understood by the interviewer.

Researcher Safety

All patients will be given the option of undertaking interviews at home. As such, it is necessary to consider researcher safety. The interviewing researcher will adhere to guidance set out in the BCUHB lone-worker policy. The 'Reliance Protect' badge for lone-workers will also be worn on all research visits.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

- Yes - proportionate review No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply.*

- Case series/ case note review
 Case control
 Cohort observation
 Controlled trial without randomisation
 Cross-sectional study
 Database analysis
 Epidemiology
 Feasibility/ pilot study
 Laboratory study
 Metanalysis
 Qualitative research
 Questionnaire, interview or observation study
 Randomised controlled trial
 Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

This study seeks to explore the lived experience of dialysis in young adults (aged 18-35 years), directly asking these patients to provide a subjective account of what life on dialysis is like for them and what overall impact the treatment has had. Although this is an exploratory study - so does not seek to impose a restrictive or leading framework to interviews - it will specifically prompt patients to consider the emotional, psychological, and social aspects of life on dialysis. This will include an evaluation of the impact that dialysis has on patient's sense of identity, self-esteem and body image, changes in how they initiate and sustain relationships (including within families, social networks, and with intimate/sexual partners), and whether using dialysis has influenced the way that they think about, and plan for, the future (including treatment/health, education, career, and family planning). A clearer understanding of what it is like to live with dialysis is sought to help healthcare professionals better support this unique population.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

N/A

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Dialysis patients are now living longer and demonstrating improved physical functioning as a result of treatment; this has shifted emphasis onto quality of life and subjective experience as important new clinical outcomes (Rebello & Ortega, 2002). Qualitative methods are ideally suited to explore these aspects of care and there is a growing qualitative research base describing the experiences of older patients living with dialysis. This research captures a sense of disruption to life: difficulty adapting to the treatment because of its chronic nature (Harries, 1996) and negative reactions to the relentless "ongoingness and uncertainty" that it brings (Polaschek, 2002). Recent qualitative studies

suggest that older patients feel that they lack space for "normal" life alongside the treatment (Hagren, Petersen, Severinsson, Lozen, & Clyne, 2005), with dialysis imposing an overwhelming sense of restriction on their personal and social lives (Smith, 1996; King, Carroll, Newton, & Dorman, 2002; Al-Arabi, 2006). There are additional reports of patients feeling deprived of hope and lacking control/autonomy (Lindqvist, Carlsson, & Sjöden, 2000).

Dialysis can also challenge sense of self and identity in older adults, largely due to physical changes in the body that result from prolonged treatment (Martin-McDonald, 2003). Large quantitative studies indicate that all dialysis patients are at increased risk of negative body-image, which is directly linked to higher levels of anxiety and depression in this population (Partridge & Robertson, 2011). Dialysis may also impact on intimate relationships; a recent qualitative study explored attitudes towards sexual relationships in married couples, reporting that dialysis negatively impacted on frequency of sexual contact, levels of intimacy, and even notions of sexuality (Yilmaz & Özalın, 2011). Negative responses to treatment (e.g. sadness, resentment, anger, hopelessness, and guilt) may be observed in both patients and partners (White & Grenyer, 1999), with partners sharing problems such as role-change and restricted lifestyle (Brunier & McKeever, 1993). A longstanding relationship with a partner who can provide effective emotional support is a known protective factor against psychological distress in older renal patients (Gee, Howe, & Kimmel, 2005), demonstrating the important role that established relationships play in defining psychological outcomes.

Much of the existing research has focused on older adults for good reason - the median age for patients requiring treatment in the UK is 64.8 years, while in Wales this is slightly older at 68.6 years (Gilg et al., 2011). Of the estimated 2511 patients established on dialysis in Wales in 2009, 14.7% were aged 18-39 years, 49% were aged 40-64 years, 19.8% aged 65-74 years, and 16.4% were aged over ≥75 years (Steenkamp et al., 2011). This is representative of patterns observed across England, Scotland and Northern Ireland. It is notable, however, that young adults form a significant proportion of the patients that enter renal services, when our understanding of this group is significantly less well established. Younger adults are at different stages of life: early adulthood is a formative period and many younger patients may be presented with the prospect of dialysis at a time when they do not yet have established relationships, careers, families, and may still be developing ideas about identity, self-esteem, body-image and sexuality. For these reasons they may experience the disruption to life brought about by dialysis in different ways to patients using it in later years. It remains unclear what impact dialysis has on young adults in these respects.

There have been no published studies – quantitative or qualitative – focusing specifically on the experiences of young adults on dialysis. As such, little is known about the lived experience of dialysis in young adult populations and what impact the treatment has on the way that they see themselves in their personal and social worlds. This study seeks to address these issues for the first time, exploring the physical, emotional and social selves that young adults create as dialysis patients. We hope that this insight can be used to inform all professionals supporting young adults in renal services.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study seeks to discover the impact that dialysis has on the lives of young adults. A lack of existing research in this area makes the study exploratory in nature; this is why a qualitative design that allows participants themselves to guide the research 'agenda' has been chosen. There are no predetermined hypotheses to be tested. We want to allow patients to indicate what aspects of experience they feel researchers and clinicians should know about and what issues they feel are most important to them.

We are interested in exploring the lived experience of dialysis – that is, what it is like to actually live with the treatment. Consequently, we have elected to employ a design and methodology that is guided by the principals of Interpretative Phenomenological Analysis (IPA). IPA provides a theoretical framework that focuses on how individuals make sense of events and find meaning in their personal experiences - in this case, dialysis (see Smith et al., 2009). IPA aims to capture participants' subjective interpretations rather than to establish factual statements. This approach recognises that each individual may perceive/experience dialysis differently.

This will be a small-scale cross-sectional study in which patients will be asked to take part in a single semi-structured interview, the content and direction of which will be guided by participants. Patients will be offered a choice of where they would like the interview to take place: either in a private hospital room free of disruption or at home. It is estimated that interviews will take between 60-90 minutes. Patients will be offered as many breaks as they require. We are aware that dialysis patients may experience fatigue or other physical symptoms that require interviews to be conducted over two sessions and this option will be made available to all patients. Interviews conducted over two time-points will be analysed as one interview rather than two. Interviews will be guided by an interview schedule; however, this will be a general topic guide rather than a prescriptive list of questions. Patients will be able – and encouraged – to talk about whatever aspects of their experience they feel is important. All interviews will be audio-recorded and transcribed verbatim by the interviewing researcher. Once the interview has been completed, patient participation will end.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

Although there has been no direct service-user involvement in the planning of this study, it should be noted that the research aims emerged as a response to a clinical need for better understanding in this area - as identified by clinicians working with this patient group. As such, it may be considered that service-users have indirectly shaped the project through their presentation in services.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

This study will include patients who:

- 1) Are aged between 18-35 years.
- 2) Have been established on dialysis for a period of ≥3 months.

It should be noted that 'dialysis' may be haemodialysis or peritoneal dialysis and that this may be performed at a hospital unit (including satellite clinics) or at home.

Patients who are 35 years old at the time of recruitment but have a 36th birthday before they are interviewed will still be included.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

This study will exclude patients who:

- 1) Started using dialysis before the age of 18 years.
- 2) Are unable to speak English to a sufficient level to participate in interviews.
- 3) Have cognitive impairment or psychiatric conditions that compromise ability to give informed consent.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Single semi-structured interview.	1	1	Approx. 60-90 minutes	<p>All interviews will be conducted by the student researcher (Dr Lucy Piggin), who is independent of all clinical teams. Interviews will be audio-recorded.</p> <p>Patients will be offered the choice of completing interviews in either a private room at a hospital (Ysbyty Glan Clywd, Ysbyty Gwynedd, or affiliated satellite clinics) or in their own homes.</p> <p>It should be noted that although only one interview will be completed, patients will be given the option of completing this over two occasions if they wish to do so (e.g. if they experience fatigue or do not feel well enough to complete in one sitting).</p>

A21. How long do you expect each participant to be in the study in total?

As this study is cross-sectional in design, it is expected that direct participation will end after the single semi-structured interview is complete. Efforts will be made to keep the time between recruitment and interview brief, such that patients will all be seen within four to six weeks of initial consent being obtained.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

This study will explore a number of potentially emotive issues and, as such, it is possible that some patients may experience emotional/psychological discomfort or distress. To limit the potential for distress, patients will be fully informed about the subjects to be covered in interviews prior to consent being obtained. It will also be made clear that patients are not obliged to reveal any information that they do not want to and that they do not have to discuss any subjects that they find particularly upsetting. It will be stressed to all patients that they have the right to decline to answer questions and may stop or withdraw from interviews at any point. An interview schedule will be used to guide interviews, however, patients will remain in control of their content and direction at all times in accordance with the principals of Interpretative Phenomenological Analysis (IPA).

Realistically, a degree of distress may be expected given the nature of the subjects being discussed. This is not necessarily something that needs to be prevented. It is possible that some patients may find that being able to express negative emotions during the interview process has therapeutic benefit. Patients should feel able to freely express whatever it is they feel – whether this is positive or negative – and all possible efforts will be made to ensure that patients feel able to do this. Patients will be offered the option of whether they would like interviews to take place at hospital or within their own homes and will be ensured anonymity and confidentiality. Patients will be able to meet the researcher before interviews and sufficient time will be afforded to establishing rapport and putting patients at ease.

Where emotional or psychological reactions displayed by patients appear extreme or to reflect an enduring difficulty, it is possible that a referral to a Clinical Health Psychologist may be appropriate. This would only be considered after discussion with the patient and with their expressed consent. The interviewing researcher is a second-year Trainee Clinical Psychologist and will be supervised by two experienced Consultant Clinical Psychologists (Dr Beth Parry-Jones and Dr Paul Gardner). It is likely that a number of the patients recruited will already be known to these psychologists; these clinicians may be actively involved in their care or have been involved in the past.

Specific checks will be made to ensure that no patient is left in a state of distress after an interview; patients will be asked to appraise how they found the interview process and time will be allotted to diffuse any negative affect. Patients will always be given the opportunity to ask questions after an interview. Patients will be advised to contact the researcher if research-related questions or concerns arise after the interview and will be encouraged to contact a member of their clinical team if they have any questions or concerns relating to their physical health needs. Patients will be made aware that any concerns about the research can be registered with the North Wales Clinical Psychology Programme (NWCPP). Contact details for NWCPP will be provided.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

As stated in A22, this study will explore a number of potentially emotive issues and it is possible that some patients may experience psychological/emotional discomfort or distress. Subjects that patients may find distressing include: the chronic nature of their condition and subsequent adjustments, physical changes and body image, the impact of treatment on intimate/sexual relationships, how dialysis might influence/impede future plans (e.g. developing careers or having children).

A24. What is the potential for benefit to research participants?

It is possible that patients may find that the interview process is of therapeutic benefit, especially as it offers the opportunity to talk confidentially about their experiences with someone who is independent of their clinical team and outside of their friends/family. Patients will not receive any direct incentives or rewards (i.e. payment) for taking part in the research and will not necessarily benefit directly from the findings.

A26. What are the potential risks for the researchers themselves? (if any)

All patients will be given the option of undertaking interviews at home. As such, it is necessary to consider researcher safety. The interviewing researcher (Dr Lucy Pigginn) will adhere to guidance set out in the BCUHB lone-worker policy. The 'Reliance Protect' badge for lone-workers will also be worn on all research visits; this badge connects to a 24-hour control centre that can contact appropriate emergency services when activated.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Potential participants will be identified by the two research supervisors (Dr Beth Parry-Jones and Dr Paul Gardner), who are Consultant Clinical Psychologists working within renal services at Ysbyty Glan Clwyd and Ysbyty Gwynedd respectively. They will be aided by nursing staff within these services, all of whom are members of direct clinical care teams. Permission to identify/approach patients has been obtained from Consultant Nephrologists responsible for overseeing patient care within each service.

Identification of potential participants will be made through patient databases held at each unit; all individuals tasked with identifying potential patients will already have clinical authorisation to access this database. Checks may also be made through review of patient medical records; individuals performing these checks will already be authorised to access medical records as part of their clinical roles within direct care teams in the renal service. Individuals that do not hold a clinical role in the renal service (e.g. Dr Lucy Pigginn) will not be authorised to identify potential participants.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

As above: information contained on patient databases held at each dialysis unit will be used to identify potential participants according to the inclusion/exclusion criteria (e.g. age, duration of time since dialysis was commenced); review of medical records may also be undertaken to confirm that the exclusion criteria are not met (e.g. experience of dialysis before the age of 18 years). This information will only be accessed by individuals already part of a direct clinical care team within the renal service (i.e. psychologists and/or nursing staff).

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

Yes No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Information about the research will be disseminated amongst nursing staff at the two dialysis units where recruitment will take place (Ysbyty Glan Clwyd and Ysbyty Gwynedd); this will include hospital-based nurses and those visiting patients in the community (e.g. Renal Specialist Nurses). These nurses will be provided with an information sheet that outlines inclusion/exclusion criteria and the role they are being asked to fulfil in identifying eligible patients. Nurses will also be offered a verbal overview of the research and be given the opportunity to discuss the research with the research team during pre-research visits to each unit.

Patients meeting criteria will be asked by nurses whether they would be interested in being given information about a research project; those that respond affirmatively will be given a study information pack. It will be made clear to patients that nursing staff providing these information packs do not have any direct involvement with the research and are not members of the research team. Information packs will contain: 1) an information sheet outlining the research goals and protocol; 2) an opt-in form for patients who are interested in taking part; and 3) a pre-paid envelope to enable patients to send the opt-in form to the interviewing researcher (Dr Lucy Piggin) to register their interest in the study.

Patients will be asked to complete the opt-in form and return it to the researcher if they are interested in taking part in the research. They will be asked to provide contact details so that the researcher can contact them directly to further discuss the research or to make arrangements for participation to commence. Contact details for the researcher will be provided on the information sheet and patients will be encouraged to make contact if they require any further information to aid their decision making. No patient will be contacted directly by the researcher without consent.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

By completing and returning an opt-in slip patients indicate that they consent to being approached directly by the researcher. On the opt-in slip patients will be asked to provide contact details so that the researcher can contact them to make arrangements for participation to commence. Once contacted, verbal consent will be sought to make a face-to-face interview appointment – at this meeting written consent to take part in the research will be formally obtained. All patients will be asked to sign a written consent form. Written consent will be obtained by the interviewing researcher immediately prior to the interviews taking place.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

No strict time limit will be imposed on patients to make a decision about participation; however, as this is a time-limited study, it will clearly be necessary for a decision to be reached in a relatively timely manner. All patients meeting inclusion/exclusion criteria will be offered information sheets that detail the recruitment time-frame (including a

suggested last 'entry point' date tailored to each batch of research information packs given out by nursing staff). Patients will be encouraged to take as much time as they feel they need to make their decision and will let the researcher know if/when they feel they have made their choice; however, we would hope that this would be within 2-4 weeks of being given the information (the suggested last 'entry point' date will be within this time-frame).

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

The exclusion criteria for this study states that participants must be able to speak English to a sufficient standard to take part in the interview process. Any patients unable to do so - due to physical or cognitive impairments or due to language restrictions - will not be eligible for inclusion. Exclusion on the grounds that communication is impaired by physical/cognitive factors primarily reflects the practical difficulties inherent in performing qualitative interviews with these individuals. However, it is also likely that a specific communication impairment would have a separate impact on the life of a young person that would confound our efforts to isolate the effects of dialysis alone. Exclusion on the grounds of language (i.e. non-English speakers) reflects practical difficulties that exist because the research team only speak English (see below and A6-2).

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

In this study, all information sheets, opt-in slips, and consent forms will be provided in English and Welsh language formats. However, it will not be possible for the research team – all of whom are English-only speakers – to offer patients the option of completing interviews in Welsh. This will be stated on all information sheets - the reasoning behind this decision is further explained in Question A6-2. The patient summary of results provided after completion of the study will be available in English and Welsh language formats.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA

- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files including X-rays
 - NHS computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

Personal information provided by patients on opt-in slips (e.g. names, addresses, and telephone numbers) will be stored in a site-file in a locked cabinet in a private office at Ysbyty Glan Clwyd (YGC). This information will be retained until after completion of the study, when a summary of results will be posted to those patients who have requested one.

All patient interviews will be audio-recorded with consent. These recordings will be transcribed verbatim by the interviewing researcher as soon as possible after each interview. During transcription all information that might make it possible to identify a participant will be removed (e.g. names, locations, dates) so that each transcript is fully anonymised. Unique study numbers (e.g. P1, P2, P3) will be used to identify participants on transcripts. These transcripts will be line numbered and will also record non-verbal communication (e.g. laughter, pauses). Only the interviewing researcher and the two supervising researchers will be authorised to listen to recordings; the latter doing so to undertake a verification of recordings against transcripts to ensure accuracy, as is good practice. Once transcription has been completed and verified, all audio-recordings will be erased/destroyed. Whilst awaiting transcription/verification, recording will be stored electronically on an encrypted NHS storage device and in a password protected file on a private password protected NHS computer. Anonymised transcripts will be stored in password-protected files on NHS computers and on encrypted NHS memory-sticks. Transcripts will be printed to allow analysis to take place. Some analysis of (fully anonymised) transcripts will take place at the School of Psychology, University of Bangor - paper transcripts may be transported from NHS hospitals to the School of Psychology for this purpose but will not be stored at this location.

Quotations used in subsequent reports/publications will be entirely anonymised to ensure that it is not possible to identify individual patients. Pseudonyms will be used in the reporting of data, as is usual in IPA research. Where pseudonyms are used, the gender of the participants will not be anonymised (i.e. female participants will be given female pseudonyms).

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All personal data will be stored according to the Data Protection Act (1998), as described above: all electronic files will be password protected and stored on encrypted devices and on private password-protected NHS computers that can only be accessed by the research team. Paper files will be stored in a locked filing cabinet in a private NHS office with restricted access.

During transcription all information that might make it possible to identify a participant will be removed (e.g. names, locations, dates) so that each transcript is completely anonymous. Unique study numbers (e.g. P1, P2, P3) will be used to identify participants on transcripts. Quotations used in subsequent reports/publications will be entirely anonymised to ensure that it is not possible to identify individual patients. Pseudonyms may be used in the reporting of data, as is usual in IPA research.

The usual levels and limits of confidentiality that apply in routine clinical practice will apply in this study: patients will be informed prior to consent being obtained that all information shared will be anonymised and kept within the research team (i.e. not shared with any member of their medical care team). However, it will be made clear that any information that patients provide that indicates an intention to harm themselves or others – or a risk that this might occur - will result in confidentiality being broken and supervisors and/or medical staff being informed.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Only Dr Lucy Piggin will have access to participants' personal data during the study. Participants will provide personal data (e.g. name, address, telephone number) to this researcher directly via the opt-in slip if they consent to take part in the research.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

- Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

- Yes No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

The study will be reported in a doctoral thesis submitted to Bangor University, which will ultimately become a public document.

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

Patients will be offered a choice as to whether or not they would like to receive a written summary of the results once the study has been completed. Patients who would like to receive feedback will be sent a 1-2 page summary outlining what the study has found. They will also be given the opportunity to contact the researcher/s within a specified time-frame should they have any queries about the overall findings.

This summary will include any relevant details about potential publication. Summary sheets will be available in both English and Welsh language formats.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

A full research protocol for this study has been reviewed and approved by:

- The Board of Ethics within the School of Psychology at Bangor University.
- Clinical supervisors (Consultant Clinical Health Psychologists) working in the

Renal Service across Betsi Cadwaladr University Health Board (BCUHB).
 - Senior research supervisors within the North Wales Clinical Psychological Programme (NWCPP) at Bangor University.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
 Total international sample size (including UK): 10
 Total in European Economic Area: 10

Further details:

This study aims to recruit a total of ten participants across two renal services in North Wales (Ysbyty Glan Clwyd and Ysbyty Gwynedd).

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

This study is being conducted within an Interpretative Phenomenological Analysis (IPA) framework. IPA adopts an idiographic focus that enables rich descriptions of data at the level of the individual - moving away from nomothetic approaches that analyse at the level of groups and populations. IPA studies recruit far smaller numbers of participants so that analysis can be performed in greater detail; it is suggested that a sample of no more than ten is required to undertake IPA in sufficient depth (Smith et al., 2009), with greater numbers risking a loss of meaning within the data. This guidance was followed when deciding on the sample size for this study (a total of ten patients).

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Data generated in interviews will be analysed using Interpretative Phenomenological Analysis (IPA). This is a qualitative approach that seeks to explore the subjective rather than objective elements of experience – designed to uncover the lived experience of phenomena (e.g. what it is really like to live with dialysis). It has an idiographic focus that enables rich descriptions of data at the level of the individual, rather than seeking to describe behaviours at the levels of groups or populations - this allows researchers to look in greater depth at the unique experiences of a small number of patients. In-depth interviews are analysed to identify themes that can be summarised and communicated in a narrative style. Direct quotations are then used to illustrate different aspects of the themes identified. The narrative account of themes produced will communicate the experiences of young adults living with dialysis.

Analysis first involves reading and re-reading transcripts so that they are familiar to the researcher; note-making directly onto transcripts is then encouraged where aspects of interviews appear important or interesting (this can include comments that are descriptive, notes about the language used, and more conceptual comments about what is being communicated by the patient). These notes are used to develop 'emergent themes' that reduce the volume of data without losing complexity or meaning (i.e. communicating in 'short-hand' what the patient is trying to say). Once a list of potential themes has been constructed, connections between themes can be identified and a 'map' of how themes cluster and fit together can be constructed. This process is completed for each transcript. Time is then spent looking for patterns across cases, including similarities/differences in patient experiences and responses. 'Super-ordinate' (major) and 'sub-ordinate' (minor) themes that reflect the experiences found within the sample – at varying levels of interpretation and complexity - can then be modelled and finally written up in a narrative account.

Once completed, Smith, Flowers, and Larkin (2009) propose the use of an independent audit method of ensuring that validity and reliability can be proven in IPA research. This approach advises that data should be filed and presented in such a way that a 'chain' of evidence can be followed, leading from original documents (e.g. interview transcripts) to final report. In this study, an internal audit will be conducted by the researcher's supervisors. This will involve inspecting documents that describe and explain the research process, including annotated transcripts, ideas from category construction, master documents of quotes/themes and final narrative analysis. This will display the thoughts and ideas that guided analysis along each step of the process to ensure that analysis provides a credible account of the data.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

Title Forename/Initials Surname
Post
Qualifications
Employer
Work Address
Post Code
Telephone
Fax
Mobile
Work Email

A64. Details of research sponsor(s)

A64-1. Sponsor**Lead Sponsor**

- Status: NHS or HSC care organisation Commercial status: Non-Commercial
 Academic
 Pharmaceutical industry
 Medical device industry
 Local Authority
 Other social care provider (including voluntary sector or private organisation)
 Other

If Other, please specify:

Contact person

Name of organisation Bangor University
Given name Charles
Family name Leek
Address Brigantia Building, Penrallt Road
Town/city Bangor, Gwynedd
Post code LL57 2AS
Country UNITED KINGDOM
Telephone 01248 382948
Fax 01248 382599
E-mail e.c.leek@bangor.ac.uk

Is the sponsor based outside the UK?

Yes No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- Funding secured from one or more funders
 External funding application to one or more funders in progress
 No application for external funding will be made

What type of research project is this?

- Standalone project
 Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Dr Rossela Roberts
Organisation	Clinical Governance Officer, Betsi Cadwaldr University Health Board
Address	Ysbyty Gwynedd Penrhosgarnedd Bangor
Post Code	LL57 2PW
Work Email	rossela.roberts@wales.nhs.uk
Telephone	01248 384 877
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2013
 Planned end date: 01/09/2014
 Total duration:
 Years: 1 Months: 0 Days: 1

A71-2. Where will the research take place? *(Tick as appropriate)*

- England
 Scotland
 Wales
 Northern Ireland
 Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?

Yes No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

- NHS organisations in England
 NHS organisations in Wales 1
 NHS organisations in Scotland
 HSC organisations in Northern Ireland
 GP practices in England
 GP practices in Wales
 GP practices in Scotland
 GP practices in Northern Ireland
 Social care organisations
 Phase 1 trial units
 Prison establishments
 Probation areas
 Independent hospitals
 Educational establishments
 Independent research units
 Other (give details)

Total UK sites in study: 1

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the

arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
 Other insurance or indemnity arrangements will apply (give details below)

Insurance/indemnity for this study is provided by the School of Psychology, Bangor University.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
 Other insurance or indemnity arrangements will apply (give details below)

Insurance/indemnity for this study is provided by the School of Psychology, Bangor University.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
 Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	Ysbyty Glan Clywd	First name/ Initials	Beth
Street address	Sarn Lane	Surname	Parry-Jones
Town/city	Bodelwyddan		
Post Code	LL18 5UJ		
Institution name	Betsi Cadwaladr University Health Board	Title	Dr
Department name	Ysbyty Gwynedd	First name/ Initials	Paul
Street address	Penrhosgarnedd	Surname	Gardner
Town/city	Bangor		
Post Code	LL57 2PY		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator
 Sponsor

- Study co-ordinator
- Student
- Other – please give details
- None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Dr Lucy Piggin on 25/10/2013 12:58.

Job Title/Post: Trainee Clinical Psychologist

Organisation: BCUHB

Email: lucy.piggin@wales.nhs.uk

Signature:

Print Name: Lucy Piggin

Date: 24/10/2013 (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 25/10/2013 13:07.

Job Title/Post: School Manager for Psychology
Organisation: Bangor University
Email: h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Paul Gardner on 25/10/2013 12:37.

Job Title/Post: Consultant Clinical Psychologist
Organisation: Betsi Cadwaladr University Health Board
Email: paul.gardner@wales.nhs.uk

Academic supervisor 2

This section was signed electronically by Dr Beth Parry-Jones on 25/10/2013 13:07.

Job Title/Post:
Organisation:
Email:

Research Information Sheet

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Dr Lucy Piggin; Dr Beth Parry-Jones; Dr Paul Gardner

You are being invited to take part in a research study exploring the impact of dialysis on the lives of young adults. This study is being undertaken by Lucy Piggin as part of an educational qualification (Doctorate in Clinical Psychology) at Bangor University. 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 there is anything that seems unclear or if you would like more information.

What is this study about?

Most adults on dialysis are approaching older age when they start using the treatment, typically in their fifties or sixties; however, a small but significant number are much younger than this. We would like to know more about what life is like for this group of young adults (18-35 years) and to learn about what impact using dialysis has on their lives. It is possible that the experience of using dialysis is very different when you are younger – we hope that this study will help us to find out.

We would like to ask you about your experiences of dialysis. This information will be used to help people working in renal services to better understand the challenges faced by younger patients.

Who is being invited to take part?

This research is open to all patients who:

- Are aged between 18-35 years old.
- Use dialysis (either haemodialysis or peritoneal dialysis) at home or in a hospital unit.
- Have been using dialysis for at least three months.

Unfortunately, we are unable to include patients who started using dialysis before the age of 18 years.

All patients that agree to take part will be asked to talk about their experiences in interviews conducted in English - we are sorry that we are unable to undertake these interviews in Welsh.

Do I have to take part?

No. It is entirely up to you to decide whether or not you would like to take part in this research. The treatment and care that you receive will not be affected either way.

What would I have to do if I did take part?

If you do agree to take part in this research you will be asked to discuss your experiences of dialysis in an interview. You will be offered a choice as to whether this interview takes place at the hospital or in your own home. The interview will contain around ten questions that will encourage you to talk about life on dialysis: we are particularly interested to know if/how you feel the treatment has changed different aspects of your life (e.g. education, work, social life, personal relationships) and also whether it has changed the way you feel about yourself (e.g. your self-esteem and body-image). We will also ask you whether your plans for the future have changed as a result of starting dialysis. You do not have to answer any questions that you do not want to and you do not have to discuss any subjects that you feel are sensitive or upsetting. You can also choose to 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.

We estimate that the interview will take approximately 60-90 minutes to complete. You will be able to take as many breaks as you need. If you feel tired or unwell during the interview you will have the choice of completing it over two sessions (i.e. on two different days). 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 recording will be erased as soon as the transcripts are completed. Only the researchers will be able to listen to these recordings.

What will happen to my interview?

All of the interviews that we conduct will be summarised into ‘themes’ that describe what life is like for the young adults we have spoken to. We will use direct quotes (i.e. things that people have said) to illustrate these findings - we may use your words for this purpose but we will always do our best to ensure that it is not possible to identify you if we do (e.g. we will not include names or any personal details). We will then let people know what we have found. We hope that we will be able to publish the results of this research. If you would like to receive a summary of our results once the study is complete, we would be happy to provide this.

What about confidentiality?

No member of your medical care team will know whether or not you have taken part in this study. All personal information (e.g. names, addresses) will be removed from interviews. We will try our best to ensure that it is not possible to identify you. The only time that information might be shared is if you were to say something that suggested you or someone else was at risk of harm. We would always tell you if we thought we needed to share information in these cases.

Are there any risks involved?

We foresee no physical risks associated with taking part in this research; however, it is possible that you may find it upsetting to talk about dialysis and its impact on your life. We would like to reassure you again that you do not have to talk about anything that you do not want to and have the right to refuse to answer any of our questions. You can also choose to stop the interview or withdraw from the study at any point. If you feel that you are struggling to adjust to dialysis or are finding the experience particularly distressing, you can also ask to be referred to a Clinical Psychologist in the renal service. This referral would only be made with your permission. At the interview stage you can ask Lucy to refer you directly and she will contact the appropriate Clinical Psychologist on your behalf. If you prefer, you can also approach any member of your usual medical care team (e.g. renal nurses) and ask them to refer you – you are able to access Clinical Psychology this way at any time.

Who is doing this research?

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

Who has reviewed this research?

This research has been reviewed by the Board of Ethics at the School of Psychology, Bangor University (Ref: 2013-10604), and by the North Wales Research Ethics Committee (Central & East; ref: 13/WA/0364). If you have any concerns about this research you are encouraged to discuss them with the researchers in the first instance. You may also contact Mr Hefin Francis at the School of Psychology (Bangor University) if you have any concerns or complaints – his contact details appear at the end of this information sheet. You may also contact staff at the North Wales Clinical Psychology Programme (NWCPP) directly. The details of how to contact NWCPP also appear at the end of this information sheet.

What next?

If you decide that you would like to take part in this study you will first be asked to return the 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 research we will contact you directly. Only patients returning an opt-in slip will be contacted. We will then arrange to meet with you. At this meeting you will be asked to sign a consent form and will be given a copy of this to keep. Once you have signed a consent form, you can take part in an interview.

We aim to contact you within two to four weeks of receiving your opt-in slip. 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.

If you are still unsure and feel that you would like more information or would like the opportunity to ask questions, please feel free to contact Lucy:

Lucy Piggin
Trainee Clinical Psychologist

North Wales Clinical Psychology Programme
Brigantia Building
Penrallt Road
Bangor
Gwynedd
LL57 2AS

Tele: 01248 388068
Email: pspefa@bangor.ac.uk

If you have any concerns or complaints about this research, you can also contact Hefin Francis at the School of Psychology (Bangor University):

Mr Hefin Francis
School Manager
School of Psychology
Bangor University
Brigantia Building
Penrallt Road
Bangor
Gwynedd
LL57 2AS

Tele: 01248 388339
Email: h.francis@bangor.ac.uk

Research Opt-In Slip

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Thank you for reading the 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 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:  _____

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!

Research Consent Form

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Please read each statement carefully and tick each box.

I have read and understood the information sheet for this study (Version 2, dated 18/11/13) and have had the opportunity to ask about anything that I do not understand.

I understand that my participation is voluntary and I am free to withdraw from the study at any time, without giving a reason, and that this will not affect my treatment or care.

I understand that participating in this study involves taking part in an interview that will be audio-recorded.

I understand that anonymised quotes (i.e. things I say in my interview) may be used when the results of this study are being reported.

I agree to take part in this study.

Patient

Name: _____

Signature: _____

Date: _____

Researcher

Name: _____

Signature: _____

Date: _____

Please note: one copy for the patient and one copy to be retained by the researcher.

Research Study: Nurses Information

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Aims

We would like to let you know about a new research study being undertaken within renal services at Ysbyty Glan Clwyd (YGC) and Ysbyty Gwynedd (YG). This study is being undertaken by Lucy Piggin as part of an educational qualification (Doctorate in Clinical Psychology) at Bangor University. Lucy is being supervised by Dr Beth Parry-Jones (YGC) and Dr Paul Gardner (YG). The study aims to explore the life experiences of young adults using dialysis, focusing on the emotional, psychological, and social impact of the treatment (e.g. how receiving treatment affects social networks and close relationships and whether starting dialysis changes the way that young people plan for the future). All participants will take part in an interview where they will be asked to talk about their personal experiences of dialysis.

Recruitment

We are currently looking for patients to take part in the study and are asking for your help in finding them. We are looking for patients who:

- ✓ Are aged between 18-35 years old.
- ✓ Use dialysis (either haemodialysis or peritoneal dialysis) at home or in a hospital unit.
- ✓ Have been using dialysis for at least three months.

We are not able to include patients who:

- ✗ Started using dialysis before the age of 18 years.

We would be very grateful if you could ask patients who match our criteria whether they would be interested in taking part in research and giving a 'research pack' to those patients who are. You do not need to give packs to those who are not interested in taking part in research. Packs are clearly labelled in A4 envelopes and can be found at nursing stations within each dialysis unit. Each pack contains: an information sheet that describes the study in detail, an opt-in slip for patients to return if they would like to take part, and a pre-paid envelope to return the opt-in slip. Patients who are given these packs should be advised to read the information sheet carefully and complete and return the opt-in slip if they would like to take part. Once an opt-in slip is received, Lucy will contact the patient directly to arrange an interview.

Contact

If you have any questions/queries please feel free to contact Lucy: lucy.piggin@wales.nhs.uk.

Thank you for your help and support.

Research Study: Poster (Nursing)

The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Dr Lucy Piggin, Dr Beth Parry-Jones, and Dr Paul Gardner

We are currently looking for patients to take part in our research study and are asking for your help in finding them. We are looking for patients who:

- ✓ Are aged between 18-35 years old.
- ✓ Use dialysis (either haemodialysis or peritoneal dialysis) at home or in a hospital unit.
- ✓ Have been using dialysis for at least three months.

We are not able to include patients who:

- ✗ Started using dialysis before the age of 18 years.

We would be very grateful if you could ask patients that match this criteria whether they might be interested in taking part in research and then give a research pack to those who **are** interested. These packs contain information to help patients decide whether or not they would like to take part in this study. Packs are clearly labelled in A4 envelopes and can be found at nursing stations within this dialysis unit.

If you have any questions or queries please do not hesitate to get in touch (lucy.piggin@wales.nhs.uk).

Thank you for your help and support.



Research Protocol

Study Title

The experience of dialysis in young adulthood: /a qualitative exploration of the impact of treatment in patients aged 18-35 years.

Researchers

Dr Lucy Piggin, Trainee Clinical Psychologist, BCUHB
 Dr Beth Parry-Jones, Consultant Clinical Psychologist, BCUHB
 Dr Paul Gardner, Consultant Clinical Psychologist, BCUHB

Background

Dialysis

Renal replacement therapy (RRT) is offered to all patients experiencing acute or chronic renal failure - those whose kidneys are no longer able to maintain sufficient levels of function. This may be in the form of dialysis – which artificially replicates kidney function – or kidney transplantation. It is estimated that approximately 49,080 people in the UK are in receipt of RRT at any one time and that around 52.6% of these individuals are established on some form of dialysis (Steenkamp, Castledine, Feest & Fogarty, 2011). There are two primary modes of dialysis: haemodialysis (HD) and peritoneal dialysis (PD).

In HD, blood is removed and cleansed in a dialysis machine before being returned to the body. Access to the bloodstream is achieved via a catheter inserted into a large vein or via a fistula made by joining a vein to an artery. This procedure is performed three times a week in sessions lasting 3-5 hours (Thomas, 2004). It is typically performed in hospital units; however, a small but increasing number of patients now elect to receive HD at home (Thodis & Oreopoulos, 2011). In PD, a catheter is permanently inserted into the abdomen so that dialysing fluid can be drained into the peritoneal cavity. The lining of the abdomen then acts as a membrane through which dialysis occurs and the fluid is drained out of the body after full dialysis is complete. Patients typically carry out this process at home approximately three times per day; however, the process may also be carried out overnight. HD is the most commonly used method by a significant margin (Brady & O'Donoghue, 2011); however, the popularity of PD is increasing (Gill, Castledine, Fogarty, & Feest, 2011). Many people remain on dialysis on a long-term basis and although a significant minority will aim to achieve successful kidney transplantation, most will continue to use dialysis until death.

The Impact of Dialysis

Dialysis is life-saving and life-sustaining for patients experiencing renal failure; however, the impact of the treatment may also be seen as life-limiting in many respects. Dialysis leaves patients susceptible to fatigue, low blood-pressure, muscle cramps, insomnia, bone/joint pain, decreased libido, sexual dysfunction, and infertility. It is also notable that alongside significant commitment to the time-consuming process of dialysis itself, renal patients face incredibly rigid restrictions on fluid and dietary intake. These are all consequences that can significantly limit the lifestyle choices open to renal patients using dialysis. Many patients report understandable difficulty adapting to life on dialysis and to the chronic nature of the intervention (Harries, 1996).

The sense of 'disruption' to life that dialysis may incur has been captured and communicated through a growing body of quantitative and qualitative research. Recent qualitative studies have reported that dialysed patients often feel that they lack space for 'normal' life alongside busy treatment regime (Hagren, Petersen, Severinsson, Lozen, & Clyne, 2005) and that dialysis imposes a sense of personal restriction on their lives (Smith, 1996; King, Carroll, Newton, & Dornan, 2002; Al-Arabi, 2006). Patients have reported feeling deprived of hope and frequently present as lacking control and autonomy (Lindqvist, Carlsson, & Sjöden,

2000), many patients struggle to integrate dialysis into existing lifestyles and react negatively to the relentless 'ongoingness and uncertainty' that the treatment brings (Polaschek, 2002). It is noteworthy that quantitative studies have also indicated that mortality is higher amongst patients who feel that treatment interferes with social activities, those who perceive themselves to be socially isolated, and those who are dissatisfied with the support available from family members (Untas et al., 2011). The treatment is frequently presented as necessitating personal sacrifice and significant social upheaval.

Dialysis is also known to present a risk to patients' sense of self and to constructs of personal identity (Martin-McDonald, 2003). A small number of studies have aimed to establish how psychological appraisals of the self are influenced by the physical impact that dialysis has on the body. The physical changes associated with dialysis extend beyond the presence of fistulas and catheters; patients may experience significant weight gain/loss, discolouration of the skin, visible signs of premature aging, and oedematous limbs – all highly visible indicators of the toll that dialysis takes on the body (Galpin, 1992). Quantitative data suggest that levels of body-image disturbance are significantly higher in dialysis patients than in community samples and that negative body-image is associated with higher levels of anxiety and depression (Partridge & Robertson, 2011). Although there have been no qualitative studies exploring this subject, a number of review papers have also highlighted the clinical importance of understanding and addressing body-image in patients receiving dialysis (e.g. Muringai, Noble, McGowan, & Chamney, 2008).

There have also been case-studies addressing feelings of 'sexual unattractiveness' as a consequence of dialysis and the deleterious impact that this can have on patients' self-esteem (e.g. Tanyi, 2002). Further studies have qualitatively explored attitudes towards sexual relationships in married couples, reporting that dialysis can negatively impact on frequency of sexual contact, levels of intimacy, and even notions of sexuality in established relationships (Yilmaz & Özalın, 2011). A growing number of studies have explored the impact of dialysis on couples and families as a means of further understanding the patient experience; these studies report that negative affective responses to treatment (e.g. sadness, resentment, anger, hopelessness, and guilt) occur in both patients and partners (White & Grenyer, 1999). Partners of patients appear to share the problems experienced by patients, including role-change and loss of lifestyle (Brunier & McKeever, 1993). It is suggested that partners can play an important role in enabling successful dialysis, with the individual adjustment of a spouse predictive of patient adjustment over time (Horsburgh, Rice & Matuk, 1998); a longstanding relationship with a partner who can provide effective emotional support is a known protective factor against psychological distress in older renal patients (Gee, Howe, & Kimmel, 2005).

Limitations of Existing Research

The existing research base contains a combination of qualitative and quantitative studies that have explored a diverse range of the psychosocial consequences that may result from dialysis. However, one significant limitation is that the field has tended to consider dialysis patients as a homogenous group, ignoring important differences within samples. The most important variable that has been missed thus far is that of age. Renal failure may occur at any time of life; however, dialysis is typically presented as a later-life intervention. The median age for patients requiring dialysis in the UK is 64.8 years, while in Wales this is slightly older at 68.6 years (Gill et al., 2011). Of the estimated 2511 patients established on dialysis in Wales in 2009, 14.7% were aged 18-39 years, 49% were aged 40-64 years, 19.8% aged 65-74 years, and 16.4% were aged over ≥ 75 years (Steenkamp et al., 2011). This is representative of patterns observed across England, Scotland and Northern Ireland. The experiences of young adults receiving dialysis are not well represented within the literature, yet they form a significant proportion of the patients that enter renal services.

It is not uncommon for research studies to include age-ranges that span the third to the eighth decades of life. This is problematic because it is known that younger adults, compared to older adults, perceive different challenges when confronted with chronic illness (Falvo, 2005). These individuals are also at different stages of life: early adulthood is a formative period and many younger patients may be presented with the prospect of dialysis at a time when they do not yet have established relationships, families, or careers, may not yet have a firm sense of identity, and may still be developing ideas around self-esteem, body-image, and sexuality. For these reasons they may experience the disruption to life brought about by dialysis in different ways to those patients using it in the later years of life. It remains unclear what impact dialysis has on young adults in respect to identity, self-esteem, body-image, ability to form and/or maintain intimate relationships, and plans for the future (including education, employment, and family-planning). There have been no published studies – quantitative or qualitative – focusing specifically on the experiences of *young* adults on dialysis. As such, little is known about the lived experience of dialysis in young adult populations and what impact the treatment has on the way that they see themselves in their personal and social worlds. This study seeks to address these issues for the first time, exploring the physical, emotional and social selves that young adults create as dialysis patients.

Research Aims

This research will explore the experiences of young adults (aged 18-35 years) successfully established on dialysis. It will focus on the psychological, emotional, and social impact of treatment (e.g. the impact of treatment on social networks, intimate/sexual relationships, identity, self-esteem, body-image, and how plans for the future are made). The lack of existing research in this area means that this study is necessarily exploratory in nature – as such, it does not seek to test any a priori hypotheses. It is intended that the findings will be used to inform healthcare professionals who support young adults in renal services.

Methods

Design

This small-scale qualitative study will adopt a cross-sectional design. Single semi-structured interviews will be conducted with a purposively selected sample of participants.

This study will be guided by the principles of Interpretative Phenomenological Analysis (IPA). This is an approach that aims to describe and interpret how individuals make sense of their lived experiences (see Smith et al., 2009); it provides a framework by which qualitative data may be collected and analysed to extract personal meaning, allowing researchers to construct narratives that communicate a subjective understanding of events – in this case, the experience of dialysis. IPA aims to capture participants' unique perceptions and interpretations rather than to establish objective/factual statements about events and experiences, making it congruent with the aims of investigating what impact dialysis has in psychological, emotional, and social terms. Unlike other qualitative approaches (e.g. Grounded Theory), IPA aims to illuminate and offer insight rather than to establish rules, theories or frameworks. As such, it must be stated that this study seeks to raise awareness of clinically relevant aspects of experience rather than to define these experiences in absolute or generalizable ways.

Participants

All Betsi Cadwaladr University Health Board (BCUHB) patients registered within the renal services at Ysbyty Glan Clwyd (YGC) and Ysbyty Gwynedd (YG) who meet the inclusion/exclusion criteria will be invited to take part in the research.

The inclusion criteria state that this study is open to patients who:

- Are aged 18-35 years.
- Have been using dialysis for <3 months.

It should be noted that dialysis can be either be HD or PD and may be received in a hospital unit or at home. Patients who are 35 years old at the time of recruitment but have a 36th birthday before they are interviewed will still be included.

The exclusion criteria state that this study is not open to patients who:

- Started using dialysis before the age of 18 years or had experience of using the treatment before this age.
- Are unable to speak English to a sufficient level to participate in interviews.
- Demonstrate cognitive impairment or psychiatric conditions that might compromise their ability to give informed consent.

Sample size

This study aims to recruit ten participants. This sample size has been guided by the principals of IPA, which adopts an idiographic focus to enable rich descriptions of data at the level of the individual. This moves away from the nomothetic approach traditionally favoured by quantitative health research, in which a broader analysis takes place at the level of groups and populations. IPA studies recruit smaller numbers of participants to enable analysis to be performed in greater detail.

Recruitment

Potential participants will be identified by the two research supervisors (Dr Beth Parry-Jones and Dr Paul Gardner), who are Consultant Clinical Psychologists working within renal services at Ysbyty Glan Clwyd and Ysbyty Gwynedd respectively. They will be aided by nursing staff within these services, all of whom are members of direct clinical care teams. Permission to identify/approach patients has been obtained from Consultant Nephrologists responsible for overseeing patient care within each service.

Identification of potential participants will be made through patient databases held at each unit; all individuals tasked with identifying potential patients will already have clinical authorisation to access this database. Checks may also be made through review of patient medical records; individuals performing these checks will already be authorised to access medical records as part of their clinical roles within direct care teams in the renal service. Individuals that do not hold a clinical role in the renal service (e.g. Dr Lucy Piggin) will not be authorised to identify potential participants.

Nurses in regular contact with patients – both within hospital units and in the community – will be provided with an information sheet that defines the inclusion/exclusion criteria and outlines their role in identifying/recruiting eligible patients. This will be offered in an information sheet that outlines the research goals and in a briefer ‘poster’ version that focuses on the inclusion/exclusion criteria. A meeting will also be arranged so that the research team can present this information to the nursing staff verbally and can answer any questions that they might have. These nurses will be asked to approach consecutive patients who meet the criteria and ask them whether they would be interested in being given information about a research project. Those that respond affirmatively will be given a study information pack. Nurses will play no further role. It will be made clear to patients that nursing staff providing these information packs do not have any direct involvement with the research and are not members of the research team.

Information packs will contain:

- One information sheet outlining the research goals and protocol.
- One opt-in slip for patients who are interested in taking part.
- One pre-paid envelope to enable patients to send the opt-in form to the interviewing researcher (Lucy Piggin) to register their interest in the study.

Nurses will initially be given information packs in batches of five at each unit. This is intended to control the rate of recruitment but might be revised depending on the numbers of patients recruited over time. It is intended that recruitment will take place between December 2013 and April 2014.

Patients will be asked to complete the opt-in form and return it if they are interested in taking part in the research. They will be asked to provide contact details so that the researchers can contact them directly to arrange interviews. Contact details for the researcher will be provided on the information sheet and patients will be encouraged to make contact if they require any further information to aid their decision-making. No patient will be contacted directly by the researcher without consent. Written consent to take part in the research will be formally obtained immediately prior to the interview. All patients will be asked to sign a written consent form.

Procedure

Participants will be invited to take part in a single semi-structured interview. It is estimated that interviews will take 60-90 minutes. As dialysis patients may experience fatigue or other physical symptoms, it is possible that they will require interviews to be conducted over a number of sessions – this option will be made available to all patients. Interviews conducted over two or more appointments will still be considered as a single data set.

Participants will be offered a choice of interview location: either in a private clinic room in a hospital or at home. Following IPA guidelines, outlined by Smith, Flowers and Larkin (2009), an interview schedule will be used to guide interviews according to the research aims; however, the overall content of interviews will be controlled by each patient. This schedule is intended to guide interviews across potential areas of interest; it is

not a prescriptive list of questions to be asked of each participant. All interviews will be recorded using a digital audio-recording device.

Data Management

Digital recordings of interviews will be transferred from the audio-recorder to a password-protected (encrypted) data-storage device as soon as possible after each interview; audio-files will then be deleted from the audio-recorder. Interviews will be transcribed verbatim by the interviewing researcher. During transcription all information that might make it possible to identify a participant will be removed (e.g. names, locations, dates) so that each transcript is fully anonymised. Transcripts will be line-numbered to facilitate analysis and will also record non-verbal communication (e.g. laughter, pauses). Once transcription has been completed and verified, all audio-recordings will be erased/destroyed. Transcripts will be stored on the same data-storage device but in a separate password-protected folder. They will also be stored on a private BCUHB computer. Paper copies will be stored at a secure location (in a locked filing-cabinet in a locked office with restricted access) at YGC and will only be accessed by the research team. Participants will be assigned a random number identifier (e.g. P1, P2, P3) according to the order in which they enter the study. Personal information provided by patients on opt-in slips (e.g. names, address, and telephone numbers) will be kept in a site file stored in a locked cabinet in a private office at YGC. This information will be retained until after completion of the study, when a summary of results will be posted to those patients who have requested one.

Data Analysis

Data will be analysed according to the principles of IPA. This first involves reading and re-reading transcripts so that they are familiar to the researcher; note-making directly onto transcripts is then encouraged where aspects of interviews appear important or interesting (this can include comments that are descriptive, notes about the language used, and more conceptual comments about what is being communicated by the patient). These notes are used to develop 'emergent themes' that reduce the volume of data without losing complexity or meaning (i.e. communicating in 'short-hand' what the patient is trying to say). Once a list of potential themes has been constructed, connections between themes can be identified and a 'map' of how themes cluster and fit together can be constructed. This process is completed for each transcript. Time is then spent looking for patterns across cases, including similarities/differences in patient experiences and responses. 'Super-ordinate' (major) and 'sub-ordinate' (minor) themes that reflect the experiences found within the sample – at varying levels of interpretation and complexity – can then be modelled and finally written up in a narrative account.

Once completed, Smith, Flowers, and Larkin (2009) propose the use of an independent audit method of ensuring that validity and reliability can be proven in IPA research. This approach advises that data should be filed and presented in such a way that a 'chain' of evidence can be followed, leading from original documents (e.g. interview transcripts) to final report. In this study, an internal audit will be conducted by the researcher's supervisors. This will involve inspecting documents that describe and explain the research process, including annotated transcripts, ideas from category construction, master documents of quotes/themes and final narrative analysis. This will display the thoughts and ideas that guided analysis along each step of the process to ensure that analysis provides a credible account of the data.

Feedback

Participants will be offered a choice as to whether or not they would like to receive a written summary of results once the study has been completed. Patients that would like to receive feedback will be sent a 1-2 page summary outlining what the study has found. They will also be given the opportunity to contact the researcher/s within a specified time-frame should they have any queries about the overall findings. This summary will outline any plans for publication.

Diversity

Efforts will be made to ensure that the research is open and accessible to all patients meeting the clinical inclusion/exclusion criteria. Information-sheets, opt-in slips, and consent forms will all be available in English and Welsh language formats. The written summary of results provided to patients will also be available in English and Welsh versions. As the researchers are all English-only speakers, it will not be possible to offer patients the option of completing interviews in Welsh. This is an acknowledged limitation.

Funding

All costs incurred will be met by the North Wales Clinical Psychology Programme (NWCPP) at Bangor University.

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NHS Ethics - Approval letter from North Wales (Central & East) REC.

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

**North Wales REC (Central & East)**

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Wrexham Technology Park
Wrexham LL13 7YP

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27 November 2013

Dr Lucy Piggin
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
NWCPP
Brigantia Building, Penrallt Road
Bangor, Gwynedd
LL57 2AS

Dear Dr Piggin

Study title: The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18-35 years
REC reference: 13/WA/0364
Protocol number: 2013-10604
IRAS project ID: 111740

Thank you for your letter of 22 November 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

Revised documentation

Participant Consent Form	2	18 November 2013
Participant Information Sheet	2	18 November 2013
Participant Information Sheet: Nurses	2	18 November 2013
Nurses Information Poster	2	18 November 2013

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Tracy Biggs, Tracy.Biggs@wales.nhs.uk.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

Non-NHS sites

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

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

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		25 October 2013
Covering Letter		22 November 2013
Interview Schedules/Topic Guides	1	25 October 2013
Investigator CV	LP	25 October 2013
Investigator CV	BPJ	25 October 2013
Investigator CV	PG	
Nurses Information Poster	2	18 November 2013
Other: Research Participant Opt in slip	1	25 October 2013
Participant Consent Form	2	18 November 2013
Participant Information Sheet	2	18 November 2013
Participant Information Sheet: Nurses	2	18 November 2013
Protocol	1	25 October 2013
REC application	1	25 October 2013
Summary/Synopsis	1	25 October 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WA/0364

Please quote this number on all correspondence

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

With the Committee's best wishes for the success of this project.

Yours sincerely

T.a. Biggs.

B

**Professor Alex Carson
Chair**

E-mail: tracy.biggs@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mr Hefin Francis
Dr Dr Rossela Roberts, Betsi Cadwaladr University Health Board*

R&D Approval Letter (Betsi Cadwaladr University Health Board)



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Betsi Cadwaladr
University Health Board

**Panel Arolygu Mewnol Y&D
R&D Internal Review Panel**

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Dr Lucy Piggin
Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Bangor University
Brigantia Building, Penrallt Rd
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Chairman/Cadeirydd - Dr. Mike C Jackson, CPsychol, DClinPsych, DPhil
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lucy.piggin@wales.nhs.uk

10 December 2013

Dear Dr Piggin

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title The experience of dialysis in young adulthood: a qualitative exploration of the impact of treatment in patients aged 18 – 35 years
IRAS reference 111740
REC reference 13/WA/0364

Thank you for submitting your R&D application and supporting documents.
The above study was eligible for Proportionate Review and was reviewed by the R&D Manager and Chairman of the Internal Review Panel West.

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Proportionate Review Committee is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Document:	Version	Date
R&D Form – 111740/520217/14/661	3.5	14/11/2013
SSI Form – 111740/520141/6/16/167059/284384	3.5	
R&D Checklist	-	-
SSI Checklist	-	-
Protocol	1	25/10/2013
Protocol – Flow Chart	1	25/10/2013
Interview Schedule	1	25/10/2013
Nurses Information Poster	2	18/11/2013
Nurses Information Sheet	2	18/11/2013
Opt-In Slip	1	25/10/2013
Participant Information Sheet	2	18/11/2013
Consent Form	2	18/11/2013
REC Favourable Opinion letter	-	27/11/2013
Bangor - Insurance Indemnity 30-10-13	-	11/07/2013
SSI Signature page – Dr Elghenzai	-	11/11/2013
CV – CI – Dr L Piggin	1	25/10/2013
CV – Dr B Parry-Jones	1	25/10/2013
CV – Dr P Gardner	1	25/10/2013

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crnc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

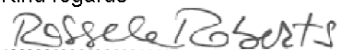
Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact wendy.scrase2@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Kind regards



RJ
 Dr. Mike C Jackson
 Associate Director of R&D
 Chairman IRP-West

Copy to: Sponsor: Mr Hefin Francis
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