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Exploring Psychological Distress in Renal Services: Health Care Professionals and Patient Experiences

Shakespeare, Margaret

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Exploring Psychological Distress in Renal Services: Health Care Professionals and
Patient Experiences

Bangor University

2016

Margaret Kate Shakespeare

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Thesis Summary

This thesis explores psychological distress in health care professionals (HCP) and patients in renal settings across three chapters. Chapter one systematically reviewed the quantitative literature on burnout and job satisfaction in renal HCPs. The chapter pays particular attention to features of the environment which contribute to burnout and dissatisfaction. This paper found moderate to severe levels of burnout in renal HCPs, with multiple environmental contributors, including high workload and poor organisational and leadership support and perceived professional progression. The second Chapter qualitatively explored the lived experiences of patients who received the ‘Moncrief-Popovich Technique’ in preparation for transition to peritoneal dialysis (PD). This cross-sectional study utilised Interpretative Phenomenological Analysis (IPA), with semi-structured interviews. Four participants of equal gender split were recruited. Analysis revealed four interrelated super-ordinate themes capturing the participants’ experience of transition to PD; *End of part of your life*, *Control the direction, not the outcome*, *Protection of the self* and *Moving onto the next step*. Each super-ordinate theme carried sub themes which elaborated participants’ experience of fragmentation, identity fragility, adaptive coping and relationship forming related to decision making and perceived control. Participants used the embedded period as a time for maintaining normality and feelings of safety and containment; however, distress was present, as was expected when exploring transition. The third chapter explored implications for theory and clinical practice which emerged from the previous chapters. This chapter highlighted the importance of a dual approach to addressing distress in HCPs in order to adequately support patients’ distress. Organisational interventions based on psychological theory and national policy are recommended, including a psychologically informed implementation model. Personal reflections of the research process and outcomes are also considered.

Declarations

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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A DClin.Psy thesis not only represents the end of three years of clinical training but a longer journey towards long held aspirations. My clinical journey started with Dr Paul Gardner and Dr Beth Parry-Jones some years ago and I can't thank you enough for your encouragement, support, coaching and mentoring at various stages of my professional and academic career.

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Chapter 3. Contributions to Theory and Practice

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Chapter 1
Literature Review

Burnout, job satisfaction and the working environment in renal Health Care Professionals. A systematic review of the literature.

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Abstract

Aim: This systematic review aimed to collate literature examining the relationship between burnout, job satisfaction and the working environment in renal Health Care Professionals (HCPs). **Methods:** Three databases, PsycInfo, Medline and CINAHL were searched for quantitative studies reporting the statistical relationship between features of the working environment and burnout and job satisfaction in renal HCPs. **Results:** Twelve papers met the inclusion criteria and were included in the final sample. The HCP groups consisted of haemodialysis nurses (88%), health care technicians (5.1%) and dieticians (1.8%). Moderate to severe burnout was reported across the papers, yet most HCPs reported satisfaction in their role. Environmental factors associated with burnout and job dissatisfaction included workload, poor resources, lack of opportunity for advancement, poor leadership and feeling unsupported. Mediation analyses demonstrated that burnout was predicted by job dissatisfaction (related to the environment) when mediated by job stress. **Conclusions:** Burnout in renal HCPs was comparable to other health care specialisms. Other renal HCPs including other renal specialist nurse groups, doctors, social workers, dieticians and clinical psychologists, were under represented in this review. Features of the working environment were linked to dissatisfaction and burnout, which if ameliorated could improve overall HCP wellbeing, working practices and patient outcomes. Therefore, more research needs to be conducted exploring burnout, job satisfaction, and what aspects of the environment affect these in other renal professional groups.

Key words: Renal, Burnout, Satisfaction, Environment, Review.

1. Introduction

Burnout is a syndrome widely acknowledged within the health sector. Health care professionals (HCPs) are considered vulnerable to burnout due to the highly intensive and often emotive environment in which they operate (Schaufeli, 2007). Burnout encompasses three constructs: emotional exhaustion, leaving HCPs depleted in resources to provide compassionate care; depersonalisation which reflects emotional detachment to work, colleagues and patients; and reduced personal accomplishment which is measured by feelings of poor self-efficacy and failure in one's role (Maslach, 1993). Burnout develops as a result of chronic interpersonal stressors in an organisational context, whereby HCP's resources are insufficient to meet demands imposed by patients and the organisation (Maslach, Leiter & Schaufeli, 2001). Burnout leaves HCPs depleted in their ability to provide empathic care, leading to reduced quality of care (Shanaflet, Bradey, Wipf & Bach, 2002), poor patient satisfaction (Aiken et al., 2012) and higher rates of patient mortality and morbidity (Gardner, Thomas-Hawkins, Fogg & Latham, 2007).

Multiple causes of burnout include feeling overburdened with the demands of work, poor working relationships, and perceived lack of autonomy or decision making power (Lambert & Lambert, 2001). Contributory organisational factors include poor leadership and management as well as role ambiguity which impact on patient care (Khamisa, Peltzer & Oldenburg, 2013; Rydon-Grange, 2015).

Consequences of burnout include absenteeism, presenteeism (HCPs are in work but not operating at full capacity) and reduced job satisfaction (Onyett, 2011). It also extends beyond working life, contributing to familial discord and reduced quality of life (Burke & Greenglass, 2001). Physical consequences of burnout include heightened anxiety, low mood, and physical health conditions such as cardiovascular disease, hypertension, and somatic difficulties (Ericson-Lidman & Stanberg, 2007).

Within renal care, haemodialysis (HD) nurses are the largest professional group and their experience of stress and burnout has been widely researched. Two previous systematic reviews suggest HD nurses are not exposed to more stressors compared to nurses in other environments, but do experience moderate levels of burnout (Böhmert, Kuhnert & Nienhaus, 2011; Hayes & Bonner, 2010). These levels were lower than that of nurses in other medical fields. Job satisfaction was also higher than in other nursing groups. These reviews reported on nurses' experience of burnout, psychological stress and contributing factors including working relationships, patient care tasks and organisational factors, such as lack of access to professional progression. Factors specific to renal nursing, which make their working experience unique; these include the chronic and complex health status of patients requiring consistent support and understanding, the use of highly technical equipment (dialysis machines), the intimate and dependant nature of relationships with patients and their families, and the subsequent losses associated with this patient population. When HCPs are depleted in their resources and inadequately supported an attempt at self-preservation is to detach emotionally; however, HCPs detach from the very emotions necessary to promote compassionate and safe care relationships (Lyth, 1990, cited in British Psychological Society, 2014).

There are a range of other renal professionals who are exposed to the same or similar working conditions as HD nurses, whose roles are also subject to stressors, such as high patient to HCP ratios and depleted organisational resources (Bogatz, Colasanto & Sweeney, 2005). Renal HCP groups are considered a specialist cohort of health professionals and in the UK generally compose of Consultant Nephrologists, Junior Doctors, Clinical Nurse Specialists (Pre-dialysis, home dialysis and transplantation, vascular access and anaemia), Dieticians, Pharmacists, Nurses (hospital dialysis) and Health Care Workers. More recently, renal departments include Social Workers and Clinical Psychologists as part of a biopsychosocial

provision of care (NHS England, 2015; The National Renal Workforce Planning Group, 2002). Renal professionals work in multiple settings including outpatient dialysis units and clinics, inpatient wards, satellite dialysis units and patients' homes. The research literature on HD nurses does not represent these other renal HCPs and to date there is no review looking at organisational factors contributing to burnout and job satisfaction in these other renal HCPs. Job satisfaction is recognised as a direct and indirect predictor of burnout across many HCP groups (Kalliath & Morris, 2002; Ogresta, Rusac & Zorec, 2008), and is often cited alongside burnout when describing HCPs psychological distress in relation to their working experience. An understanding of renal HCPs' views of their working environment and how this affects burnout and job satisfaction would be of value in contributing to any future recommendations to ameliorate burnout in renal settings.

1.1 Aim

Previous reviews have commented on the prevalence of factors contributing to burnout and satisfaction in HD nurses. This paper aims to review the current quantitative literature on burnout and job satisfaction in all renal HCPs and consider what environmental factors may be associated with burnout and job satisfaction. Strengths and limitations will be considered including recommendations for future research.

1.2 Research questions

1. What environmental factors are associated with burnout and job satisfaction in different renal HCPs?

1. Method

2.1 Search strategy

A systematic search was performed between September and December 2015. Three electronic databases were searched: PsycInfo, CINAHL and Medline.

The following search terms were used:

(‘renal’ OR ‘nephrology’ OR ‘chronic kidney disease’ OR ‘end stage kidney disease’)

AND

(‘nurse’ OR ‘Health care professional’ OR ‘nursing’ OR ‘nephrologist’ OR ‘doctor’ OR ‘dietician’ OR ‘social worker’ OR ‘clinical psychologist’)

AND

(‘burnout’ OR ‘satisfaction’ OR ‘stress’ OR ‘compassion fatigue’ OR ‘psychological distress’)

AND

(‘environment’ OR ‘working environment’ OR ‘organisation’)

These search terms were used as they were key words in previous reviews and reflected in an initial scan of the literature. The terms aimed to capture all HCPs working in renal settings whose experience may be explored in relation to burnout, satisfaction or stress. Job satisfaction and stress were included in this criteria due to the acknowledged predictor relationship between these variables and burnout.

No restrictions were placed on time period. After the initial search, title and abstracts were reviewed and subjected to the following inclusion and exclusion criteria. Qualitative papers were scanned for their possible inclusion; however, as they were mainly representative of HD nurses, this may have further over biased the data in mainly reporting on HD nurses experience, thus they were not included in this review.

2.2 Inclusion criteria:

1. Peer reviewed
2. Quantitative methodology only
3. Use of validated measures of burnout or job satisfaction and the working environment
4. Primary participants were renal HCPs
5. Studies reported in English

Exclusion criteria

1. Non-empirical papers, dissertations or discussion/periodicals
2. No measure of the environment
3. Non-reporting of statistical outcomes.
4. Non-reporting of vital information on measures – names, origins or evidence of validation.

As this review is primarily concerned with the environmental factors associated with renal HCP burnout or job satisfaction, papers were only included if they had a measure of the environment and a measure of either burnout or job satisfaction. A hand search of references identified 13 additional papers which were read and reviewed according to the above criteria. Three papers were not included in this review due to the researcher being unable to obtain access. In total 12 papers were included in the final review. Figure 1 (Appendix 1, Page 43) below illustrates the review and screening process including exclusion of non-eligible papers; this is based on the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009).

[INSERT FIGURE 1 HERE]

2.3 Data extraction and quality assessment

A data extraction summary form (Appendix) was used to summarise key information and findings in each paper. Authors were contacted via any known email and on research and academic networking sites when key information was missing, such as statistics vital for interpretation or when it was unclear which version of a measure was used. Table 1 (Appendix 1, Page 44) below includes key information extracted from each study including an overview of the findings.

Quality assessment utilised an adapted Downs and Black (1998) schedule (Appendix) paying particular attention to aims and hypotheses, recruitment methods, bias and internal and external validity. Items pertaining to randomised controlled trials or interventions were disregarded. Quality ratings are found in Table 1 (Appendix 1, Page 44) below, scores ranged from 50% to 91%.

[INSERT TABLE 1 HERE]

2.3 Data synthesis

This review focused on the working environment and its relationship with burnout and job satisfaction in renal HCPs. Due to the heterogeneous nature of these studies and the variety of measures it was not possible to conduct a meta-analysis hence a narrative account of the data is given. Means (m), standard deviations (SD) and probability (p) values are reported throughout.

3 Results

3.1 Study Characteristics

All 12 studies included in this review were cross-sectional. Harwood, Ridley and Wilson (2010a) used secondary data from Ridley, Wilson, Harwood and Laschinger (2009);

Hayes, Douglas and Bonner (2014; 2015) also use the same sample. In both instances data was expanded upon and not repeated, thus providing additional, valuable contributions to this review.

Across the 12 studies, the total HCP sample size was $n=2127$. HD nurses made up 88% ($n=1876$, range 31-422 per study) and six papers report on HD nurses exclusively. One paper reported on a range of nurses including HD, PD, transplant, CKD and mixed roles. One paper reported on and compared outcomes for dialysis nurses ($n=131$) and renal technicians ($n=109$) and one other reported on renal dieticians ($n=40$). All papers report outcomes from dialysis units; however, two considered satellite units or home settings. Therefore, other nurse roles were included; PD ($n=4$), CKD ($n=6$) and transplant nurses ($n=3$), and nurses who had multiple roles ($n=29$). Consequently, the reporting of outcomes in this review will be mainly representative of HD nurses, with the main place of work being dialysis units. Since this review aimed to expand the literature to all renal HCPs, outcomes reported for professionals other than nurses will be highlighted throughout. See Table 2 (Appendix 1, Page 47) for HCP characteristics.

[INSERT TABLE 2 HERE]

Three studies reported outcomes for burnout and environmental factors without looking for an interaction (Arikan, Köksal & Gökçe, 2007; Kapucu, Akkus, Akdemir & Karacan, 2009; Ridley, Wilson, Harwood & Laschiger, 2009). Four studies considered job satisfaction and the environment (Kersten, Kozak, Nubling, Nienhaus, 2014; Perumal & Sehgal, 2003; Sullivan, Janeen, Leon, Ashwini & Sehgal, 2006; Uğur, Acuner, Göktaş & Şenoğlu, 2007). Six studies used correlation, mediation or structural equation modelling to explore the relationship between burnout, satisfaction and the environment (Flynn, Thomas-Hawkins & Clarke, 2009;

Harwood, Ridley, Wilson & Laschinger, 2010a; Hayes, Douglas & Bonner, 2014; 2015; Perumal & Sehgal, 2003; O'Brien, 2011).

3.2 Measures

Multiple measures were used to report burnout, job satisfaction and perceptions of the working environment. Table 3 (Appendix 1, Page 49) details constructs and psychometric properties of each measure. All studies evidenced psychometric properties of each measure. Where 'self-developed' measures were used, validation trials were explained and referenced. Three subsections below will describe measures used in the papers and the overall outcomes of burnout and job satisfaction.

Eight studies used the Maslach Burnout Inventory (MBI; Maslach and Jackson 1981), and two versions were used: The MBI-Human Services Survey (MBI-HSS) and the MBI-General Survey (MBI-GS; Schaufeli, Leiter, Maslach & Jackson, 1996). The MBI has three subscales designed to measure the three constructs of burnout: Emotional Exhaustion, Depersonalisation (or cynicism) and Personal Accomplishment (efficacy). The emotional exhaustion scale was used most often as the primary measure of burnout.

INSERT TABLE 3 HERE

Ten studies measured job satisfaction with three different measures. The Index for Work Satisfaction (IWS; Stamps & Piedmonte 1986, Stamps 1997); the Minnesota Work Satisfaction Questionnaire (MWSQ; Weiss, Dawis, England et al., 1967) and The Conditions of Work Effectiveness Questionnaire II (CWEQ-II; Laschinger, Finegan, Shmian & Wilk, 2001). Intent to leave was also used as an indicator of dissatisfaction.

All studies included in the review measured HCPs perceptions of their working environment. The Conditions of Work Effectiveness Questionnaire (CWEQ-II; Laschinger,

Finegan, Shamian & Wilk, 2001) is based on Kanter's structural theory of empowerment (Kanter, 1977, cited in; Harwood et al., 2010a; Hayes et al., 2014; O'Brien, 2011; Ridley et al., 2009), which suggests the working environment (including leadership) shapes work practices and attitudes of HCPs. The theory suggests the environment should provide support, information, resources and opportunities for advancement, thus fostering wellbeing and protecting HCPs against burnout. Four papers discuss HCP experience in relation to Kanter's theory.

Three studies used questionnaires which captured job satisfaction specifically in relation to the HCPs' perceptions of the working environment (Perumal & Sehgal, 2003; Sullivan et al., 2006; Uğur et al., 2007), these measures used validated items derived from other measures and which combined were then independently validated (Baltas, Baltas, 2000; Yimazcan & Saglik, 1999, cited in Uğur et al., 2007). Kersten et al. (2014) used the Copenhagen Psychosocial Questionnaire (COPSOQ; Nubling, Stöbel, Hasselhorn, Michaelis, Hofmann, 2005), which measures psychosocial stress in the workplace over 25 constructs.

3.3. Findings

The sections below describe key findings from the papers included for review. Although a brief description will be given to prevalence rates of burnout and job satisfaction, the main focus of this review will be dedicated to an in depth exploration of aspects of the working environment which contribute to burnout and job satisfaction. The sections below describe the prevalence and relationship between these three areas.

3.3.1 Burnout

In this review mean emotional exhaustion scores across the papers suggest nurses experienced moderate to severe levels of burnout. More recent studies reported higher burnout

scores. Where reported, depersonalisation scores ranged from low to severe. Personal accomplishment mean scores suggested professionals experienced low self-efficacy on the MBI-HSS. On the MBI-GS nurses scored in the high range for personal accomplishment suggesting their perceived self-efficacy in their role was not affected despite 40% of the sample falling in the severe range for exhaustion. Table 4 (Appendix 1, Page 51) below reports means and standard deviations for each MBI subscale reported in each paper included in this review.

[INSERT TABLE 4 HERE]

Burnout was shown to be influenced by demographic variables including age and gender, with females reporting higher stress or burnout. Older nurses reported lower emotional exhaustion compared to their younger colleagues (Arikan et al., 2007). Hayes et al. (2015) reported HD Nurses aged 31-40 years old presented with significantly higher depersonalisation scores ($M=13.67$, $SD=7.17$) than those aged 52-60 ($M= 10.83$, $SD=5.80$; $p \leq 0.05$). Uğur et al. (2007) found a significant difference between nurses in high and low stress groups and educational level, where the high stress group were more likely to have a high school education only ($\chi^2=8.835$, $p=0.012$). Flynn et al. (2009) and Kapucu et al. (2009) reported no differences in mean emotional exhaustion scores with demographic variables.

Length of time working in renal settings was routinely reported, but only three studies considered this as an influencing variable. Arikan et al. (2007) found nurses in the first 10 years of their profession reported higher job stress, emotional exhaustion, depersonalisation and low personal accomplishment.

3.3.2 Job Satisfaction

Factors associated with reduced job satisfaction include pay, younger age, less experience in a renal setting, increased hours worked (40-48 per week), and low and high HCP to patient ratios and working in centre dialysis hospital settings. These factors were also associated with higher reported emotional exhaustion, depersonalisation and lower personal accomplishment. Overall, HCPs reported being satisfied in their work, with 78% of renal dieticians reporting being satisfied (Sullivan et al., 2006). Perumal and Sehgal (2003) also found 72% of nurses and 77% of technicians satisfied with their work. The authors also noted highest dissatisfaction for 'Pay' and highest satisfaction for 'Delivery of Patient Care', 'Chance to do something for others' and 'Job Security'. Hayes et al. (2015) reported HD nurses' satisfaction on the IWS was high ($M=191$, $SD=31.19$) with least satisfaction reported for 'Pay' ($M=3.53$, $SD=1.11$) and 'Organisational Policies' ($M=3.68$, $SD=1.11$), and highest satisfaction for 'Professional Status' ($M=5.35$, $SD=0.89$). The authors also found nurses who had worked in a renal setting for longer periods had significantly higher job satisfaction ($M=4.70$, $SD=0.65$) compared to nurses who had worked for fewer years ($M=4.28$, $SD=0.64$; $p \leq 0.05$). Younger nurses also reported higher dissatisfaction than older nurses. Kersten et al. (2014) found mean job satisfaction scores on the COPSQ in dialysis nurses ($M=62$, $SD=14$) comparable with general nurses ($M=61$, $SD=15$), but significantly lower than for geriatric nurses ($M=67$, $SD=15$, $p<0.001$).

Intent to leave as a measure of satisfaction was related to burnout: burned out nurses were three times more likely to report intending to leave their current position compared to those not burned out ($OR = 3.0$ (1.7, 5.0), $p=>.01$). Perceived high workload was also a predictor of intent to leave in this sample (Flynn et al., 2009). Hayes et al. (2015) found emotional exhaustion was significantly negatively related to job satisfaction ($r = -0.56$, $p \leq 0.01$) suggesting that when burnout was prevalent job satisfaction was impaired.

3.3.3 Working Environment

Where reported, general perceptions of the working environment were positive. However, specific factors associated with the working environment were highlighted as contributors to dissatisfaction and burnout including workload, the physical environment, leadership and empowerment. These areas are discussed in more detail below.

3.4 Workload. Five studies reported on the impact of workload on burnout and satisfaction. Factors related to workload include case load, amount of work assigned and number of hours worked. Renal dieticians, technicians and nurses all reported dissatisfaction in relation to high work demands (Perumal & Sehgal, 2003) and caseloads over 145 (Sullivan et al., 2006). Perumal and Sehgal (2003) found technicians reporting feeling significantly more satisfied with their workload and feelings of accomplishment compared to nurses. Kersten et al. (2014) found 48% of nurses reported being under severe stress due to non-nursing demands.

A measure of ‘care tasks left undone’ (Flynn et al., 2009) was used to assess the level of work experienced by HD nurses. Nurses who reported three or more ‘tasks left undone’ at the end of their shift were significantly more likely to experience burnout compared to nurses who did not (*OR* 8.75 (4.50, 17.01), $p < .001$). Hayes et al. (2015) also found moderate correlations between emotional exhaustion and ‘workload’ ($r = 0.44$, $p < 0.01$), ‘getting things done’ ($r = -0.48$, $p < 0.01$) and ‘task requirements’ ($r = -0.46$, $p < 0.01$). Logistical regression models indicated that higher ‘patient to nurse ratios’, and ‘three or more activities left undone’ were significantly associated with nurse burnout. ‘Workload’ also had the largest unadjusted significant effect on odds of nurses becoming burned out (*OR* 12.37 (5.86, 26.07), $p < .001$); and these burned out nurses were three times more likely to report intent to leave their current employer (*OR* = 2.70 (1.59, 5.86), $p = .00$).

Arikan et al. (2007) also found nurses working more than 49 hours per week reported lower perceived personal success and job satisfaction, and higher emotional exhaustion. Interestingly, the same nurses also experienced higher burnout scores, lower personal success and lower satisfaction when caring for fewer than 10 patients. Dissatisfaction with high workload (patient to nurse ratios, task requirements) or leaving tasks unfinished reported by HCPs may be a useful indicator of burnout. However, a balance may be required to keep HCPs suitably stimulated and to ensure they have the time and resources to complete core professional tasks, thus protecting against burnout and maintaining perceived personal accomplishment.

3.4.1 Physical environment. Dieticians and over half of nurses and technicians reported satisfaction in their physical environment (Perumal & Sehgal, 2003; Sullivan et al., 2006). However, four studies highlighted in-centre¹ working as contributing to higher emotional exhaustion (Flynn et al., 2009; Hayes et al., 2015; Kapucu et al., 2009; O'Brien 2011) compared to their community or satellite-based colleagues.

HD nurses working in in-centre dialysis units had poorer work environment perceptions ($M=3.47$, $SD=0.62$) than nurses working in satellite centres ($M=3.63$, $SD=0.60$; $p < 0.02$). Home HD nurses reported more satisfaction ($M=4.52$, $SD=0.73$) and lower emotional exhaustion ($M=28.29$, $SD=10.46$); this was attributed to more professional autonomy and status when operating in the community, although emotional exhaustion remained in the severe range (Hayes et al., 2015).

Features of the working environment which increased the likelihood of HCPs becoming burnt out included, an unsupportive working environment (OR 12.13 (5.90, 24.9) $p < 0.01$; Flynn et al., 2009), lack of resources ($\beta = -0.241$, $p = 0.002$; O'Brien, 2011), lack of written patient care plans and concerns regarding poor infection control (Kersten et al., 2014). Eighty

¹ Refers to working in dialysis unit in a main hospital setting and not a satellite unit.

percent of nurses felt a health threatening problem was present in their working environment and 76.2% reported this to be infectious diseases (Arikan, et al., 2009).

3.4.2 Leadership, Empowerment and Professional Progression. All studies reported on staff perceptions of leadership or their feeling supported in their professional progression. Sullivan et al. (2006) reported 50% of dieticians feeling dissatisfied with how employees were treated by management. Correlation analyses found a significant relationship between emotional exhaustion and perceived support ($r=.185, p=0.05$; Harwood et al., 2010a). These findings were replicated by O'Brien (2011) who found 'lack of formal support' was a predictor of burnout ($\beta= -0.341, p>.01$). Hayes et al., (2014) found a strong correlation between 'professional development' and 'managerial support' ($r = 0.70, p\leq 0.01$) and a moderate correlation between emotional exhaustion and less perceived support in work ($r = 0.47, p\leq 0.01$). This suggests satisfaction with the level of professional development is linked with perceived level of managerial support. Burnout was also associated with lack of perceived support. Kapucu et al. (2009) also found significant differences in burnout related to nurses who perceived themselves as suitable or unsuitable for their role (EES mean 14.73 ± 5.50 to $19.07\pm 7.00, p=0.002$). This suggests these nurses did not feel adequately supported nor confident in their skills and abilities to perform their duties, suggestive of low self-efficacy (a domain in the burnout construct) and a lack of perceived leadership in fostering skills and confidence.

Therefore, if support is not present, not only will HCPs feel lacking in support of their professional development, they are also at risk of experiencing burnout. Additionally, Hayes et al. (2015) found ratings of the 'work environment'² significantly correlated with job

² B-PEM work environment subscale domains 'feeling valued', 'managerial support', 'professional development'.

satisfaction ($r=0.70, p<0.01$) and higher perceived personal accomplishment ($r= 0.35, p<0.01$), suggesting when HCPs feel they are supported they report higher satisfaction and efficacy, a protective factor in the burnout construct. Ridley et al. (2009) also found renal nurses ranked the following predictors of burnout as least present in their workplace; ‘visible and accessible chief nursing officer’, ‘up to date plans of care’ and ‘assignments to foster continuity of care’, these are key features of an organisation designed to protect HCPs and patients.

Structural empowerment pertains to the fostering of competencies in a workforce, and this is facilitated by providing ‘formal support’, ‘resources’ and ‘opportunities’ for HCPs. The CWEQ-II was used to measure workers’ perceived empowerment in their environment (Kanter, 1977). For structural empowerment to be present, HCPs must feel they have an internal sense of professional efficacy and psychological empowerment fostered by the environment they operate in. Thus, these constructs are linked and necessary to enable HCPs to provide high level care (Leiter & Laschinger 2006). There was evidence in the papers included in this review of perceived structural empowerment. Ridley et al. (2009) reported the highest scoring subscale on the CWEQ-II to be ‘opportunities’ suggesting nurses felt sufficiently challenged and had opportunities to gain and use their knowledge and skills. Harwood et al. (2010a) found empowerment significantly negatively correlated with emotional exhaustion ($r= -.276, p<0.001$), suggesting when HCPs do not feel empowered by their environment they experience emotional exhaustion. Significant correlations between individual subscales on the CWEQ-II and emotional exhaustion included ‘support’ ($r= -.185, p<0.05$), ‘resources’ ($r= -.310, p<.001$) and one’s perceived relationship with the organisation ($r= -.279, p<.001$). Multiple linear regression showed 20% of the variance in burnout scores were predicted by lower perceived empowerment and educational training level ($\beta=.540, p <.05$). ‘Resources’ ($\beta= -0.241, p=0.002$) and ‘formal power’ ($\beta= -0.341, p >.01$) was also found to significantly predict burnout (Hayes et al., 2014).

O'Brien (2011) explored the relationship between structural and psychological empowerment³ and found 'lack of formal power' significantly predicted burnout in private and main hospital settings. ($\beta=0.341, p>.01$). Structural empowerment was also a significant predictor of burnout ($\beta= -0.364, p>.01$) when mediated by psychological empowerment.

Hayes et al. (2014) used structural equation modelling for Kanter's (1993; cited in Hayes et al., 2014) theory in order to predict burnout in HD nurses. The researchers found nurses' perceptions of their work environment significantly affected their job satisfaction ($\beta= 0.094, p<0.01$) and higher job satisfaction predicted lower job stress ($\beta=0.91, p<0.05$). Job satisfaction had an indirect effect on emotional exhaustion through its relationship with job stress. However, higher job stress predicted higher burnout ($\beta=0.65, p\leq 0.05$). Therefore, job stress is a significant risk factor for burnout in HD nurses when the work environment is insufficiently empowering.

4 Discussion

The aims of this review were to ascertain which features of the working environment contributed to burnout and job satisfaction. Some attention was also given to reporting prevalence of burnout and job satisfaction. The following sections will discuss the prevalence findings then the research question.

With regards to burnout the reviewed papers suggest renal HCPs (nurses, technicians and dieticians) experience moderate levels of burnout. There was also evidence of severe burnout in some samples. These were the same levels reported in previous systematic reviews of dialysis nurses (Böhmert et al., 2011; Hayes & Bonner, 2010). Burnout or poor satisfaction has been found previously in other renal professionals including Nephrologists (Argentero, Dell'Olivo & Ferretti, 2008; Klersy et al., 2007); and Social Workers (Bogatz et al., 2005). In

³ Psychological empowerment pertains to individuals' perceptions their job has meaning and they are competent, able to influence outcomes and have a perceived sense of autonomy (Spreitzer 1995a).

the UK, Ross, Jones, Callaghan, Eales and Ashman (2009) considered a broader pool of renal professions and reported lower job satisfaction and burnout scores yet personal accomplishment scores were also low, suggesting risk factors for burnout were present. Therefore, burnout experience is consistent across the papers included in this review and reflects burnout reported in other renal HCPs across many countries, suggesting burnout in renal professionals could be a global issue.

This review indicates there was general satisfaction across the HCPs, including over half of renal dieticians and technicians. Variables such as age, level of education and experience suggest potential risk factors for burnout and dissatisfaction, which impact on HCPs. These risk factors, in particular level of education, are not consistently reported in the renal burnout literature, and there is little evidence pertaining to different nursing levels and burnout experience (Cañadas-De la Fuente, et al., 2015; Kersten, et al., 2014). Therefore, this reviews adds to the literature and reflects a gap in understanding how education level affects burnout and satisfaction in renal nurses. This is particularly interesting given the different training levels for nurses (e.g. on the job training versus bachelor's degree) across counties.

Nurses experiencing low job satisfaction and burnout were more likely to express intent to leave, with younger or less experienced nurses at greater risk. This may be due to lower level training, thus lower levels of self-efficacy or autonomy, or lack of acclimatisation to their working environment. Dieticians and Technicians interestingly reported higher satisfaction than nurses. The review not only suggests nurses are emotionally depleted when working with their patients, they are also more at risk of distancing themselves (depersonalisation) from care and increased feelings of low self-efficacy (personal accomplishment) in their work, and thus more likely to leave their current job or profession. The average turnover for HD nurses in the UK is currently 20% (Skills for Care, 2015). High nurse turnover has cost implications for recruitment and induction phases where productivity is reduced. Hospitals with higher turnover

rates can also have higher risk-adjusted mortality (Gardner et al., 2007). This places a significant financial burden on health providers in terms of ‘bed days’ and treating acute admissions. These are all factors known to contribute to poor patient satisfaction, which has been shown to reduce as nurse turnover increases (Gardner et al., 2007).

The research question sought to ascertain which aspects of the working environment impacted on burnout and job satisfaction in renal HCPs. While the environment was generally perceived positively by HCPs, all papers reported dissatisfaction with one or more features of the working environment, and some of these features predicted burnout. Different renal settings impacted on burnout and satisfaction with nurses working in satellite and community settings reporting more favourable outcomes (although remaining in the severe range for burnout). Other aspects of the environment associated with burnout and low satisfaction included high workload, high working hours, lack of resources and the physical environment. Dissatisfaction and burnout arose from HCPs feeling overworked with high caseloads, unable to complete their core professional tasks or having to leave tasks left undone. HCPs also reported feeling the environment did not provide adequate resources or support which correlated with burnout and dissatisfaction.

The job demands-resources (JD-R) model (Demerouti, Bakker, Nachreiner & Schaufeli, 2001) may be a useful framework for understanding how burnout has developed in these renal HCPs. In this model there are two categories, job demands and job resources, which contribute to burnout experience. Job demands refer to the physical, psychological, social and organisational features of a job such as irregular working patterns, time pressures and needing to attend to too many patients which incur a physical and psychological cost. Job resources refer to the physical, psychological, social or organisational features of a job that can be useful in achieving goals, reduce job demands and reduce the consequent physical and psychological costs and promote growth, learning and development. These job resources may be at the level

of the overall organisation in the form of pay, opportunity for advancement and job security; the immediate environment in the form of role clarity and decision making; at the interpersonal or social level such as with one's supervisor, colleagues or the team climate; and at the level of the task, for instance the skill variety, autonomy and performance feedback (Bakker & Demerouti, 2007). The literature asserts that long-term exposure to job demands can lead to burnout (Demerouti et al., 2001). The demands listed in the JD-R model were highlighted in this review and in wider literature have been shown to predict burnout and depersonalisation in other nursing groups (Montgomery, Spanu, Baban & Panagopoulou, 2015). Therefore, in a climate of high demands the organisation needs to provide adequate resources to support renal HCPs in their role.

Job resources may protect against the impact of high job demand (Bakker, Demerouti, Taris, Schaufeli & Schereurs, 2003). Therefore, if HCPs have sufficient resources they may be protected from burnout symptoms. The Marmot Review (2010) and the National Institute for Health and Care Excellence (NICE; 2006) recommend a number of features which should be addressed by organisations such as the NHS and dialysis providers in order to ameliorate HCP burnout. These include increasing job autonomy and security, opportunities for flexible working and promoting staff wellbeing and better line management. It is the responsibility of health care organisations to implement interventions that are recommended on an individual and organisational level, including addressing organisational cultural and working practices. Changes to workload and working practices have been shown to reduce risk factors for burnout (Public Health England, 2016). Therefore, addressing these in renal HCPs is vital to reducing risk of burnout and the consequential lowering of patient care and satisfaction.

The effort-recovery model (Meijman & Mulder, 1998) suggests that if an environment provides multiple resources, such as supervision, feedback and supportive colleagues, workers are more likely to complete a task with success which leads to greater engagement in the task

and protects against cynicism. Obvious leadership hierarchies with structured and clear care plans, ward protocols and regular appraisal of HCPs could ameliorate stress and promote perceived efficacy in the workplace. This in turn helps reduce ambiguity around responsibility, and promote opportunities for professional advancement, which increases satisfaction, retention and ultimately improves patient satisfaction (O'Brien, 2011).

Theories from work related stress may help to elaborate on the above models in that they consider the interactions between the individual and the environment. Lazarus' Transactional Model of Stress suggests stress (a precursor to burnout) can arise from the appraisal of environmental demands which may tax individual resources and thus impact on wellbeing (Holroyd & Lazarus, 1982, cited in Dewe, Driscoll & Cooper, 2012). Primary (threat) and secondary (solution) appraisals govern how people think and react during stressful encounters, thus these transactions are process-oriented and reflect the changing person-environment relationship. These appraisals rely on cognitive processes to seek information and meaning during stressful encounters and the evaluation of coping resources which may be available during this time. This suggests an individuals' appraisal and response to changing stressors in one's environment will be individual based on how they themselves understand their environment. It may help supervisors or managers to explain why one HCP appears to cope well in one context whereas another may experience stress.

Building on the above theory and the notion of subjective experience of the environment is Person-Environment Fit (P-E fit; French, Caplan & Harrison, 1974; cited in Edwards, 2008). The P-E fit concept has been extensively used within occupational stress literature to conceptualise the match between the individual and their environment. In this literature *fit* is conceptualised as having two components, first, as the level of congruence between the demands placed on a worker and their ability to meet that demand, the *demand-ability fit*; secondly, the congruence between the workers needs and the resources available to

them, the *needs-supplies fit*. The model and literature posit if there is a *misfit* in either of these constructs then the individual is at risk of stress or psychological strain. What this model adds, which the Job Demands-Resources model does not is the level of *stimulus* a person prefers to have and the actual level they experience. P-E fit posits that high stress will occur when an individual desires a particular feature in their work (such as interactions, resources, supervision) but it is not available to them. Therefore, this theory suggests that there needs to be a match between what people feel they need and what they receive, as well as a match between with skills and abilities and the level of demand placed on them (Dewe et al., 2012). Harrison (1985; cited in Edwards, 2008) extended the theory to consider how organisational shortcomings can hinder productivity and acknowledges that organisational strain is a consequence of workers' abilities not meeting the role demands (Edwards, 2008). This theory has been extended to include outcomes for not only mental health, but job satisfaction, job performance and organisational effectiveness. Therefore, P-E fit has utility in this review as HCPs highlighted resources they wanted that were not available to them, such as training and supervision. HCPs also highlighted a lack of professional progression or having to leave tasks left undone which positively correlated with burnout scores suggestive again of a mismatch between skills and abilities and level of demand.

Clinical psychologists have much to offer in using psychological and organisational models of understanding risk factors for burnout, from individual to organisational levels. Psychological theory such as the JD-R model and the effort-recovery model can provide useful translations for understanding and addressing unhealthy relationships between HCPs and their environment. Attachment theory (Bowlby, 1973) has also been usefully applied to understand the coping strategies of HCPs in highly demanding, competitive and anxiety provoking environments (Cassidy & Shaver, 2008). Individuals in these environments often seek support from a secure base, which should provide reassurance, promote confidence, containment and

empowerment. In the NHS this role should be provided by leadership figures in the immediate and broader organisation. When this is not available, as reported in this review, or leaders are too stressed themselves to provide containment this creates dissonance between HCPs and the organisation, with HCPs feeling unsupported. In these instances, HCPs will seek reassurance in their relationships with their patients, which is in line with their professional values. However, as shown in this review HCPs often feel pulled towards tasks not related to their core professional role, such as paperwork. This conflict can leave HCPs feeling psychologically harmed by the environment which should be supporting them (Wren, 2012; cited in BPS, 2014).

Organisational interventions should include promoting communication, manager and peer support, increased learning and staff participation in service development. Where managerial involvement and support is present interventions typically have greater positive effects (Public Health England, 2016), this suggest top down support for organisational change will likely increase positive change. This may be as it communicates a message to individual HCPs the organisation supports changes which are aimed to enhance HCP wellbeing and working practices.

Individual interventions include training and workshops, cognitive behavioural interventions, relaxation, meditation and yoga, all of which have demonstrated moderate positive effects on burnout reduction in HCPs (Public Health England, 2016). The 'Schwartz Centre Round' (Wren, 2012, cited in BPS, 2014) model promotes reflective practice, recognising the emotional impact of care work including stressors such as job structure, job roles and teams. These interventions help to create working conditions in which compassionate care is promoted, and staff are provided a psychologically safe environment in which they are able to disclose their experiences.

Therefore, in order to address or prevent burnout in renal HCPs, organisational and individual interventions informed by psychological theory and supported and promoted by management are necessary. Future research however, needs to establish the different environmental factors associated with burnout and low satisfaction in all renal HCPs in order to provide tailored support per professional group.

4.1 Limitations

The renal literature on burnout is dominated currently by HD nurse experience. A major limitation of this review was the lack of representation of all renal professions. The papers included in this review that reported on experiences of other professional groups (technicians and dieticians) did not use a burnout measure, but a measure of satisfaction in relation to their working environment (job satisfaction is a predictor of burnout). Papers reporting on burnout experience in other renal groups were filtered out as they did not include a measure of the working environment. No studies to date report on experiences of renal Clinical Psychologists or pharmacists and there is limited research looking at medics' experience in relation to the environment. Therefore, there is no way to understand the individual stressors, which may be inherent in each professional population. This review was unable to fill in any gaps in understanding beyond reporting on renal dieticians and technicians; however, these papers suffered from limited statistical analyses or small sample sizes.

Sample sizes in the papers reviewed varied, and no paper reported a power analysis to ascertain if their sample was sufficient for the analyses conducted. Recruitment in some papers utilised national nursing databases; therefore, there is risk of bias in outcomes, which may only be relevant to that group working within that organisation. Opportunistic recruitment is also at risk of bias due to the type of professionals which may be more inclined to undertake the

survey, with burnt out HCPs possibly being less likely to engage in extracurricular tasks, such as research.

Correlational analyses were the main outcomes reported which infer relationships between variables but do not reflect causality in terms of what variables may contribute to burnout. Cross-sectional analyses are useful snapshots of information regarding a population; however, considering the current world health climate (ageing populations and reduced health care resources) patient populations and work environments are changing. Therefore, a longitudinal view of these changes and their impact on HCPs' experiences of burnout and satisfaction would be useful and would help in the identification of causal factors or interactions.

The recommendations in this review are drawn from UK based guidelines which are situated in context of the National Health Service (NHS); however, no papers from the UK were included in this review, and to date only one paper (Ross et al., 2009) report on job satisfaction in renal HCPs. Therefore, from a UK perspective much more needs to be done to understand burnout renal HCPs, in order to adequately tailor and implement UK based policy and interventions.

4.2 Conclusions

This paper aimed to review the literature looking into the relationship between burnout, job satisfaction and the working environment. This review added to the existing literature and previous reviews by providing an in depth narrative of the environmental factors which impact on burnout and job satisfaction. This in depth review also including the addition of more recent publications, which utilised mediation analyses, demonstrating the working environment and job satisfaction predicted burnout in renal nurses. Risk factors included age, poor professional progression, the physical setting, workload and lack of clear leadership. Given the recent high

profile incidents of poor patient care in ward contexts the working environment plays an integral contributing role affecting HCPs' experience at work and their wellbeing (BPS, 2014). Clinical Psychologists can play an important role in supporting renal professionals to ameliorate burnout through psychologically informed individual and organisational interventions. The Job Demand-Resources model offers an evidenced-based insight, which can help explain the interaction between demands on HCPs and (lack of) resources available to them and how this relationship promotes burnout and dissatisfaction.

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Appendix 1

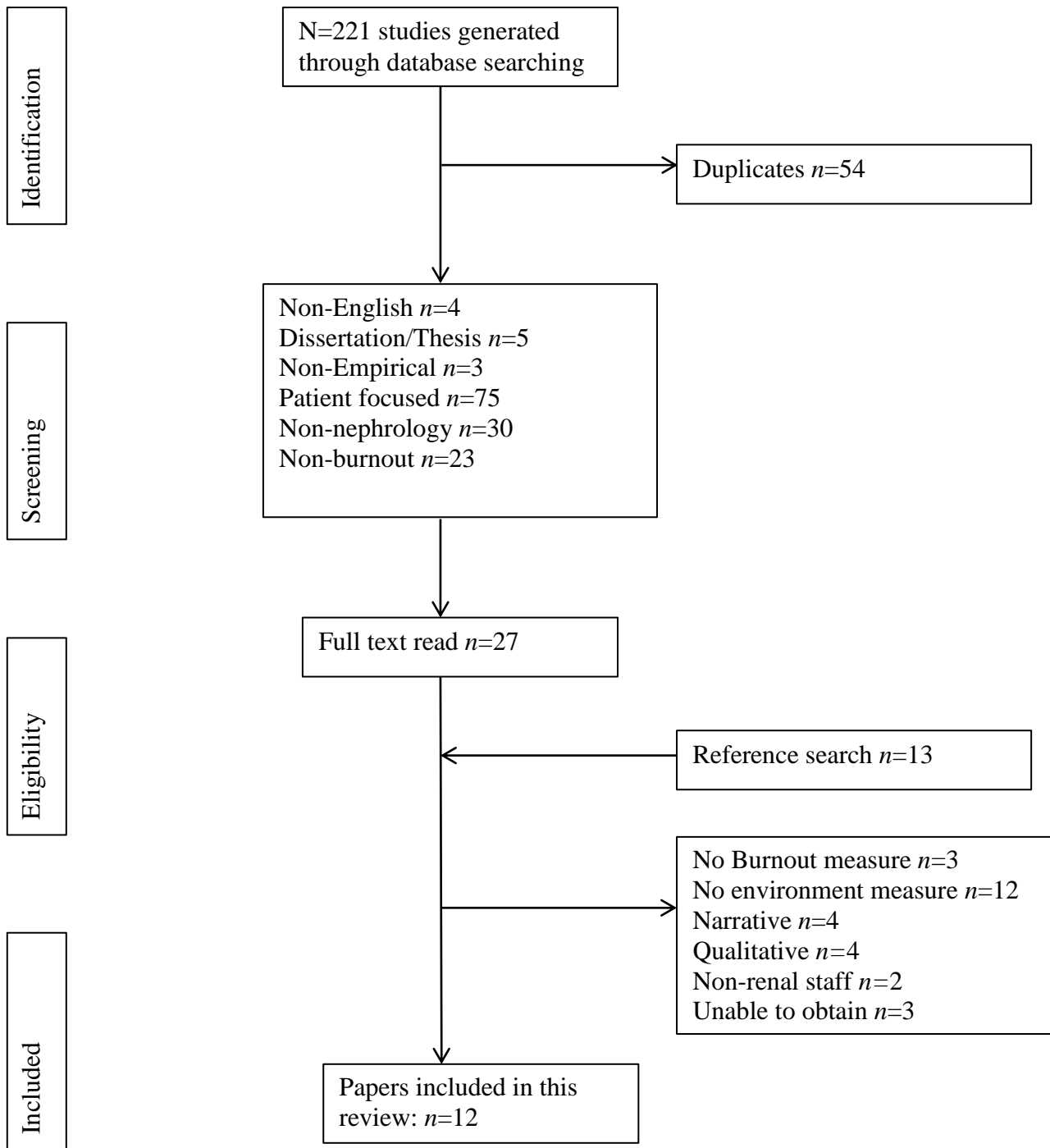


Figure 1: PRISMA flow diagram demonstrating study selection process

Table 1. All 12 studies' vital information including summary of findings and quality assessment rating.

| No | Study | Country | Population | Renal Setting n (%) | Design and Analysis | Measures ⁴ | | | | Quality % |
|----|--|---------|--|------------------------------|---------------------|-----------------------|------------------------|--------------------------|---|-----------|
| | | | | | | Burnout | Job Satisfaction | Environment | Summary findings | |
| 1 | Arikan, Kösal, Gokçe (2007) | Turkey | Nurses: n=31 HD nurses n=100 ICU n=49 ward | Dialysis (HD) unit 31 (100) | CS ⁵ | MBI-HSS ⁶ | MSQ ⁷ | WRSI ⁸ | Factors including working hours, patient numbers and age contribute to burnout experienced. Job stress is positively correlated with burnout and negatively correlated with job satisfaction. | 75 |
| 2 | Flynn, Thomas-Hawkins, Clarke (2009) | USA | HD Nurses n=422 | Dialysis (HD) unit 422 (100) | CS Correlational | MBI-HSS | 'Intent to Leave' | IWPS ES-NWI ⁹ | One in three nurses report severe burnout consistent with other hospital based nurses. Higher burnout correlated with high patient staff ratios, unsupportive environment, higher workloads and tasks left undone. | 91 |
| 3 | Harwood, Ridley, Wilson, Laschinger, (2010a) ¹⁰ | Canada | Nurses n= 121 HD n=79 HD/PD n=9 PD n=4 CKD n=6 Transplant n=3 Mixed/other n=20 | Range: HD unit, home (PD) | CS Correlational | MBI-GS ¹¹ | CWE-Q-II ¹² | CWEQ-II | Severe burnout present in 41% nurses. Burnout had significant negative association with total empowerment, resources, support, job activities and organisational relationships. 20% of the variance in burnout scores was predicted by empowerment and educational level. | 75 |

⁴ All papers using self-developed measures have described validation methods such as pilot studies/focus groups.

⁵ Cross-Sectional

⁶ Maslach Burnout Inventory – Health Services Survey (Maslach & Jackson 1981; Maslach & Jackson, 1986; Maslach, Schaufeli & Leiter (2001)

⁷ Minnesota work Satisfaction Questionnaire (Weiss, Dawis, England, Lofquist, 1967)

⁸ Work Related Strain Inventory (Revicki, May, Whitley, 1991)

⁹ Individual Workload Perception Scale (Cox, 2003); Nursing Work Index-Practice Environment Scale (Lake, (2002)

¹⁰ Same data as study 10; Ridley, Wilson, Harwood, Laschinger (2009)

¹¹ Maslach Burnout Inventory - General Survey (Maslach, Jackson, Leiter 1996)

¹² Conditions of Work Effectiveness Questionnaire (Laschinger, Finegan, Shamian and Wilk 2001)

| | | | | | | | | | | |
|---|---|--------------------------|---|--|---|----------------------|-------------------|---------------------|--|----|
| 4 | Hayes, Douglas, Bonner (2014) | Australia New Zealand | HD Nurses <i>n</i> =417 | In-centre 187 (44.8) Satellite 202 (48.4) Home 28 (6.7) | CS Structural Equation modelling | MBI-HSS | IWS | B-PEM | Mediation analysis of work environment and burnout. Work environment predicted job satisfaction job stress predicted high emotional exhaustion. | 83 |
| 5 | Hayes, Douglas, Bonner (2015) ¹³ | Australia New Zealand | HD Nurses: <i>n</i> =417 | In-centre 187 (44.8) Satellite 202 (48.4) Home 28 (6.7) | CS Correlational | MBI-HSS | IWS ¹⁴ | B-PEM ¹⁵ | Older more experienced nurses report higher job satisfaction, and remain in post longer. Higher incidents of burnout in In-Centre compared to Satellite units. Burnout significantly associated with lower job satisfaction, higher stress, lack of support, feeling valued. | 75 |
| 6 | Kapucu, Akkus, Akdemir, Karacan (2009) | Turkey | HD Nurses <i>n</i> =95 | Dialysis Unit 95 (100) | CS | MBI-HSS | | Self-developed | Significant difference in mean burnout scores for nurses who perceived themselves adequate compared to inadequate for the role. Environmental stressors include ward layout, exposure to infectious diseases and poor relationships. | 65 |
| 7 | Kersten, Kozak, Nubling, Nienhaus (2014) | Germany | Renal Nurses <i>n</i> =307 Other <i>n</i> =60 | Dialysis unit 307 (100) | CS | COPSOQ ¹⁶ | COPSOQ | COPSOQ | Nurses report stress due to non-nursing tasks and emotional strain due to patient suffering or death. Dialysis nurses reported minimal professional freedom and 'possibilities for development' compared to generic and geriatric nursing groups. | 83 |
| 8 | Perumal & Sehgal (2003) | USA | HD Nurses <i>n</i> =131 Technicians <i>n</i> =109 | | CS Correlational | | Self-developed | Self-developed | Nurses were more satisfied than technicians with pay, opportunity to progress and freedom to use | 83 |

¹³ Same data as study 4; Hayes, Douglas, Bonner (2014).

¹⁴ Index for Work Satisfaction (Stamps & Piedmonte, 1986)

¹⁵ Brisbane Practice Environment Measure (Flint, Farrugia, Courtney, Webster 2010)

¹⁶ Copenhagen Psychosocial Questionnaire (Nübling, Stöbel, Hasselhorn, Michaelis, Hofmann 2005)

| | | | | | | | | | | |
|----|--|--------|--|---------------------------|--------------|---------|----------------|---------------------------|--|----|
| | | | | Dialysis Unit 240 (100) | | | | | judgment. Technicians were more satisfied with workload. | |
| 9 | O'Brien (2011) | USA | HD Nurses n=233 | Dialysis unit 233 (100) | CS Mediation | MBI-HSS | CWEQ-II | PEI ¹⁷ CWEQ-II | Mediation analyses shows structural empowerment is a significant predictor of burnout. Lack of resources and formal power significantly correlated with burnout scores on EES. | 83 |
| 10 | Ridley, Wilson, Harwood, Laschinger (2009) | Canada | Nurses n= 121 HD n=79 HD/PD n=9 PD n=4 CKD n=6 Transplant n=3 Mixed/other n=20 | Range: HD unit, home (PD) | CS | MBI-GS | CWEQ-II | PMI PES-NWI CWEQ-II | Forty percent of respondents experienced symptoms of burnout symptoms a few times a month. Staff reviewed working environment favourably. | 50 |
| 11 | Sullivan, Janeen, Leon, Ashwini, Sehgal (2006) | USA | Renal Dietician n=40 | Dialysis Unit 40 (100) | CS | | Self-Developed | Self-developed | Seventy-eight percent of dieticians report good job satisfaction. Dissatisfaction was reported for <i>workload, opportunities for advancement and supervisors handling of employees</i> subscales. | 65 |
| 12 | Uğur, Acuner, Göktaş, Şenoğlu (2007) | Turkey | HD nurses n=161 | Dialysis Unit 161 (100) | CS | | Self-developed | Self-developed | Educational level of HD nurses reported higher 'stress' levels, as well as place of work, compared to the 'low stress' group. The outcomes are derived in the context of stress due to environmental stressors e.g. pollution, unpleasant smells, smoking. | 65 |

¹⁷ Psychological Empowerment Instrument (Spreitzer 1995a)

Table 2. Sample characteristics for each study

| No | Study | Gender <i>n</i> (%) F / M | Age M (SD) ¹⁸ | Ethnicity <i>n</i> (%) | Education <i>n</i> (%) | Years qualified M (SD) | Years in nephrology M (SD) |
|----|--|------------------------------|------------------------------------|---|---|---------------------------|--|
| 1 | Arikan, Kösal, Gokçe (2007) | - | - | -- | - | - | - |
| 2 | Flynn, Thomas-Hawkins, Clarke (2009) | 394 (93.4) 26 (6.2) | 48.6 (8.1) | Black – 29 (6.9) Asian/Pacific Islander – 31 (7.4) Hispanic – 8 (1.9) Caucasian 346 (82) Misc – 8 (1.8) | Diploma – 76 (18) Associates degree – 153 (36.3) BSc – 173 (41) MSc – 11 (2.6) Misc – 9 (2.1) | 21.2 | 13.2 (8.6) In current position 7.8 (6.8) |
| 3 | Harwood, Ridley, Wilson, Laschinger, (2010a) | 125 (96.9) 4 (3.1) | 46.3 (7.87) | - | Diploma – 76 (59.7) BSc – 46 (35.7) Msc – 6 (4.7) | - | 12.6 Range 1-36 years. |
| 4 | Hayes, Douglas, Bonner (2015) | 379 (9.09) 38 (9.1) | >40 years <i>n</i> =310 (74.3%) | - | Cert ¹⁹ - 85 (20.4) Diploma 56 (12.4) BSc -74 (17.7) Post Grad Diploma – 170 (40.8) Msc/Doctorate – 32 (7.7) Specialist renal qualification - 73% | - | >6 years <i>n</i> =314 (75.6%) |
| 5 | Hayes, Douglas, Bonner (2014) | 379 (9.09) 38 (9.1) | >40 years <i>n</i> =310 (74.3%) | - | Cert - 85 (20.4) Diploma 56 (12.4) BSc -74 (17.7) Post Grad Diploma – 170 (40.8) Msc/Doctorate – 32 (7.7) Specialist renal qualification - 73% | - | >6 years <i>n</i> =314 (75.6%) |

¹⁸ Mean and Standard Deviation

¹⁹ Certificate in Nursing

| | | | | | | | |
|----|--|---------------------------------------|---|---|--|--|--|
| 6 | Kapucu, Akkus, Akdemir, Karacan (2009) | - | 21-29 years - <i>n</i> =79 (83.1%) | - | M (SD) Health occupational high School 59 (62.1) School of nursing 32 (33.7) Course Nurse 4 (4.2) | 8 (4.8) | 4.5 (3.6) |
| 7 | Kersten, Kozak, Nubling, Nienhaus (2014) | 329 (90) 38 (10) | 43.7 (10.4) | - | - | - | ≥15 <i>n</i> =228 (62%) 16-20 <i>n</i> =139 (38%) |
| 8 | Perumal & Sehgal (2003) | Nurses: F-91% Technicians: F – 85% | Nurses: 41 (22-63) ²⁰ Technicians: 37 (21-61) | Nurses: White 80% Black 12% Other 9 % Tech: White 59% Black 25% Other 16% | - | Nurses: 8.5 (0.1-32) Tech: 7.7 (0.2-34) | Current facility Nurses: 4.6 (0.1-28.4) Tech: 4.3 (0.1-34) |
| 9 | O'Brien (2011) | 217 (93) 16 (6.9) | 49.6 (8.6) | Caucasian – 163 (70) Black – 19 (8.0) Asian – 21 (9) Filipino – 7 (7.3) Other – 3 (1.3) | Diploma – 42 (18) Associates Degree – 80 (34.3) BSc – 106 (44.5) MSc – 4 (1.70) | 22.6 (10.1) | Current position: 9.6 (7.9) |
| 10 | Ridley, Wilson, Harwood, Laschinger (2009) | F – 125 (96.9) M – 4 (3.1) | 46.3 (7.87) | | Diploma – 76 (59.7) BSc – 46 (35.7) Msc – 6 (4.7) | - | 12.6 Range 1-36 years. |
| 11 | Sullivan, Janeen, Leon, Ashwini, Sehgal (2006) | F-39 (98) M-1 (2) | 40 (8) | White 95% | - | - | 10 (8) |
| 12 | Uğur, Acuner, Göktaş, Şenoğlu (2007) | - | <30 <i>n</i> =119 (73.9%) >31 <i>n</i> =42 (26.1%) | -- | High school 81 (50.3) Associates Degree 59 (36.6) School of Nursing 18 (11.2) MSc/PhD 3 (1.9) | - | 0-5years 17.41 (4.51) 6-10 - 17.78 (3.67) ≥11 – 17.50 (3.45) |

²⁰ Range

Table 3. Constructs and reliability of measures used within the papers

| Measure | Constructs measured | Reliability |
|---|---|--|
| <i>Staff wellbeing (Burnout/Stress)</i> | | |
| Maslach Burnout Inventory – Health Services Survey (MBI-HHS; Maslach & Jackson 1981; Maslach & Jackson, 1996) | Emotional Exhaustion Depersonalisation (towards patients) Personal Accomplishment | α .71-.91 Test retest: α .60-.82 Emotional Exhaustion α .65 Depersonalisation α .60 Personal Accomplishment α .67 |
| Maslach Burnout Inventory -General Survey (MBI-GS; Maslach, Jackson, Leiter 1996) | Emotional Exhaustion Cynicism (towards patients) Personal Efficacy | α .91 |
| Copenhagen Psychosocial Questionnaire (COPSOQ; Nübling, Stöbel, Hasselhorn, Michaelis, Hofmann 2005) | Domains of work Influence and Development a work Interpersonal relations and leadership Strains | Internal Consistency Correlations subscale range: .70-.89 |
| Psychological Empowerment Instrument (PEI; Spreitzer 1995a) | Psychological empowerment: meaning, competence, self-determination and impact. | α .91 |
| <i>Job Satisfaction</i> | | |
| Minnesota Work Satisfaction Questionnaire (MWSQ; Weis, Dawis, England, Lofquist 1967) | Intrinsic job satisfaction: perceptions of nature of job tasks. Extrinsic job satisfaction: situation job aspects i.e. pay | α .81 |
| Index for Work Satisfaction (IWS; Stamps & Piedmonte, 1986) | Job Satisfaction: Pay, autonomy, task requirement, organisational policies, interaction and professional status. | Subscale range α 0.72-0.85 |
| Conditions of Work Effectiveness Questionnaire-II (CWEQ-II; Laschinger, Finegan, Shamian and Wilk 2001) | Access to: information, support, resources, opportunity, formal power and informal power | α .92 |
| <i>Organisational/Environment</i> | | |

| | | |
|--|---|---------------------------------|
| Work Related Strain Inventory (WRSI; Revicki, May, Whitley, 1991) | Measure perceptions of strain in occupational settings. | α 0.77 |
| Nursing Work Index-Practice Environment Scale (NWI-PES; Lake, (2002) | Nurse participation in hospital affairs Nursing foundations of quality of care Nursing manager ability, leadership, support Collegial Nurse-Physician relations Staffing and resource adequacy. | α .94 |
| Individual Workload Perception Scale (IWPS; Cox, 2003) | Four Subscales: Manager Support (MS) Peer Support (PS) Unit Support (US) Workload (WL) Combined to calculate Intent to Leave (ITL) | Subscale range α .61-.83 |
| Brisbane Practice Environment Measure (B-PEM; Flint, Farrugia, Courtney, Webster 2010) | Getting things done Flexibility of management support Feeling valued Professional development | α .91 |

Table 4. Maslach burnout Inventory mean and standard deviation (SD) subscale scores

| No | Studies | MBI measure | MBI Emotional Exhaustion (EES) Mean (SD) | MBI Depersonalisation (DP) Mean (SD) | MBI Personal Accomplishment (PA) Mean (SD) |
|----|--|-----------------------|--|--------------------------------------|--|
| 1 | Arikan, Kösal, Gokçe (2007) | MBI-HSS ²¹ | 13.19 (6.12) | 2.77 (2.51) | 22.39 (3.40) |
| 2 | Flynn, Thomas-Hawkins, Clarke (2009) | MBI-HSS | 21.3 (11.1) | - | - |
| 3 | Harwood, Ridley, Wilson, Laschinger, (2010a) | MBI-GS ²² | 2.66 (1.43) 40% >3²³ | 1.79 (1.46) | 4.94 (0.82) |
| 4 | Hayes, Douglas, Bonner (2015) | MBI-HSS ²⁴ | 29.59 (12.11) | 39.9 (7.29) | 11.89 (6.51) |
| 5 | Hayes, Douglas, Bonner (2014) | MBI-HSS | 29.59 (12.11) | 39.9 (7.29) | 11.89 (6.51) |
| 6 | Kapucu, Akkus, Akdemir, Karacan (2009) | MBI-HSS | 16.03 (6.28) | 4.72 (3.20) | 20.97 (4.61) |
| 7 | O'Brian (2011) | MBI-HSS | 27.5% 17-26 33% >27 | - | - |
| 8 | Ridley, Wilson, Harwood, Laschinger (2009) | MBI-GS | 2.66 (1.43) 40% >3 | 1.79 (1.46) | 4.94 (0.82) |

²¹ Cut off severe range ESS ≥ 26 , DP ≥ 9 , PA ≤ 33 for studies No. 1, 2, 6 and 7

²² Cut off EES Low < 1.77 , Average 1.78-2.88, High 2.87; DP Low < 6 , Average 1.4-2.59, High > 2.6 ; PA low > 3.99 , average 4-4.87, high < 4.88 , for studies No. 2 and 8

²³ Bold indicates severe burnout

²⁴ Cut off severe range ESS ≥ 28 DP ≥ 10 , PA ≤ 40 for studies No. 4 and 5

Chapter 2
Empirical paper

It looked after me:

Patients' lived experience of transition to peritoneal dialysis following the Moncrief-Popovich technique.

Short title: Qualitative exploration of transition to peritoneal dialysis.

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1. Article types Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas: Description and analysis of the illness experience Experiences of caregivers Health and health-seeking behaviors Health care policy Sociocultural organization of health care A Variety of Perspectives QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation. In-Depth Timely Coverage Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness. Look Out for These Regular Special Features

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Abstract

This article aimed to qualitatively explore the lived experiences of patients transitioning onto Peritoneal Dialysis (PD) following the Moncrief-Popovich Technique. Four participants who had transitioned onto PD were recruited and semi-structured interviews were conducted. Interpretative Phenomenological Analysis (IPA) was used to analyse the accounts of each participant. Four super-ordinate themes, each with sub-themes were generated: End of part of your life; Control the direction not the outcome; Protection of the self; Moving onto the next step. Themes highlighted experiences of loss, fragmentation and re-appraisal of the self, complex relationships with health care professionals in relation to decision making, autonomy and control. Coping strategies were highlighted during the embedded period between receiving the Moncrief-Popovich technique and starting dialysis. These strategies supported integrity of the self, pursuit of normality and incorporation of the illness self. Starting dialysis signalled a new transition in which participants' expectations were challenged as they began life with PD. Psychological theories including the lifecycle and attachment theory help inform understanding of the participants' experiences. This is the first qualitative exploration of patients' experience of transition to PD, and of receiving the Moncrief-Popovich technique, and highlights key themes in patient's navigation of this transitional journey. Implications for future research, limitations of this paper and clinical implications are explored.

Key Words: Moncrief-Popovich Technique, Peritoneal Dialysis, Transition, Qualitative

End Stage Renal Disease (ESRD) refers to a status in which the kidneys are no longer able to sustain vital function and patients require renal replacement therapy (RRT) in order to survive. In the UK 58,968 adults were receiving some form of RRT in 2014 (MacNeill, Casula, Shaw & Castledine, 2016). Transplantation was the most common form of treatment (53%), followed by haemodialysis (HD; 41%) and peritoneal dialysis (PD; 6%). PD is a form of dialysis that utilises the peritoneum to draw out the toxin built up as a result of reduced kidney function. Fluid is drained into and out of the peritoneal cavity via a Tenckhoff catheter, which protrudes from the abdomen. PD is considered the first choice of dialysis for patients with residual kidney function and who are without significant co-morbidities (National Institute for Health Care Excellence, CG125; NICE, 2011). PD is undertaken in the patients' home; therefore, it is usually associated with patients wishing to maintain their current lifestyle with preference for independence, autonomy and managing their own treatment (Lew & Piraino, 2005).

The medical management of ESRD has seen many advances in the last four decades. However, the psychological connotations are complex with patients reporting poor quality of life, loss of vitality and loss of physical and social function, depression and anxiety (Clearly & Drennan, 2004; Cukor et al., 2007a; Cukor et al., 2008). NICE guidelines recommend patient-centred care that offers patients sufficient time and information to make an informed choice regarding dialysis options (NICE Guidelines, 2011).

Harwood et al. (2005) suggest difficulties for individuals with ESRD will occur during transition onto dialysis. Starting dialysis requires a re-evaluation of the self in light of this new changed illness status and reliance of technology for survival. Multiple transitions are normal throughout the lifespan and psychosocial adaptation is necessary for successful transition. As such, it is a period of internal and external disruption encompassing a disintegration and reforming of the self in relation to one's world before successful resolution

(Hutchinson, 2005; Mitchell et al., 2009). Therefore, sufficient preparation is key to reducing psychological distress and improving wellbeing during major life transitions, such as transition to dialysis (Mahler & Kulik, 1998; Rosenkoetter & Garris, 2001).

Qualitative research suggests one challenge for individuals with ESRD is having sufficient time to adjust during and following transition. Patients receiving PD report low self-esteem, perceived family burden, invisible suffering and an inability to fulfil social roles. This is in addition to the emotional upheaval in attempting to adjust to a life with PD including the medicalisation of the home (Baillie & Lankshear, 2014; Morton et al., 2010; Tong et al., 2013). Therefore, starting dialysis places burdens which challenge coping resources and resilience (Hutchinson, 2005; Mitchell et al., 2009).

Two renal units in Wales have introduced the ‘Moncrief-Popovich Technique’ which pre-emptively inserts the Tenckhoff catheter into the Patients’ peritoneum and embeds the external segment under the skin before dialysis is needed²⁵ (Moncrief et al., 1993). The medical rationale for this is that the embedded period allows more time for the body to adjust to the internal segment of the catheter, reducing the risk of acute treatment whilst increasing success and reducing pain with initial exchanges (Crabtree & Burchette, 2013). While the medical advantages of this technique are documented, the psychological impact has not yet been considered. There has been no exploration of patients’ experiences of receiving this Technique thus far. Better insights into patient psychological experiences during this period may help with implementation of the technique as clinicians can consider potential patient responses or risk factors.

²⁵ This is referred to as the embedded period

Study Aims

This study aims to be the first to explore the lived experiences of patients who have received the Moncrief-Popovich technique as part of their transition to PD.

Research Question

Does the 'Moncrief-Popovich Technique' shape patients' experience of transition to PD?

Methods

Design

A cross-sectional qualitative design using Interpretative Phenomenological Analysis (IPA) was considered the most appropriate methodology. IPA emphasises the views of participants as the experts of their own experiences and facilitates an in-depth exploration of how participants attach meaning to their journey (Smith, Flowers & Larkin, 2009).

IPA is ideographic in its interpretation through analysis, of the 'phenomenology', and it seeks to understand the experiences of a small purposive sample. As such, the methodology aims to retain and illuminate the nature and context in which these individuals experience their transition to PD.

Recruitment

Despite two renal units utilising the Moncrief-Popovich technique, only one unit was recruited from as no patients from the second unit had transitioned onto PD during the recruitment phase of this research. Therefore, Participants were recruited from one renal unit in Wales. Access to patients was arranged via the lead Consultant Nephrologist. The Home Therapies Renal Nurses were provided with an Information sheet (Appendix), which included eligibility criteria and identified potential participants.

Eligibility:

- Adults (18years +) who have received the Moncrief-Popovich Technique and transitioned onto PD.
- PD is their first experience of RRT.
- Participants are sufficiently fluent in English to take part in the interview.

All patients who met the above criteria ($n=8$) were approached. Seven patients expressed an interest and were sent a research pack (Appendix). This included a Patient Information sheet and an Opt-in form to be completed and returned to the researcher. Patients who returned the opt-in slips were contacted by the researcher and a time to meet was arranged. The researcher reiterated the study aims, confidentiality and potential risks and all participants signed consent forms.

Four patients returned opt-in slips and were recruited. Although this number is small, this is considered sufficient for a successful IPA which fosters an in-depth analysis of rich data. In IPA, sample sizes are recommended according to the richness of the data and not necessarily numerically (Smith & Osborn, 2003). Smith, Flowers and Larkin (2009) also recommend 4-10 participants is sufficient for Doctorate of Clinical Psychology studies dependant on richness of the data. The data obtained in this study was discussed in supervision and considered sufficiently rich.

Participants

Table one (Appendix 2, Page88) below reports sample characteristics including the embedded time period, time on PD and current form of RRT. Maintaining anonymity for a small sample can be a challenge; therefore, ages of the sample have not been quoted, but

reference to their life stage, which is pertinent in the later findings. Two participants worked and two were retired. All names were changed and pseudonyms given

[INSERT TABLE 1 HERE]

Data Collection

The lead researcher conducted individual semi-structured interviews with each participant. The interview schedule was designed by the research team; questions were broad but ensured each stage of the journey was covered (Appendix 4, Ethical Submission). Supplemental questions were guided by participants' responses. One participant was interviewed at home and three in their local renal unit. Interviews were audio recorded and transcribed verbatim. Pauses, stutters, tone of voice, laughs and non-verbal information (gestures, eye contact) were recorded in the transcripts as per IPA convention to aid analysis (Smith, 2003). Interviews ranged from 62 to 108 minutes.

Data Analysis

Transcription and analysis of interviews were conducted consecutively. Transcripts were read and re-read in order to immerse the lead researcher in the data. Line by line analysis identified linguistic, descriptive and conceptual elements to the data, which facilitated abstraction, generation of emergent and cluster themes and ultimately the development of super-ordinate themes (Appendix 2, Page 89).

The 'double hermeneutic' in IPA acknowledges that the researcher's ideas and preconceptions are essential in order to attempt to understand the internal world of the participants (Smith, Flowers & Larkin, 2009). Consequently, considerable time was given to reflexivity before, during and after data collection, analysis and write up, to consider where on the hermeneutic circle the lead researcher found herself during each phase of the research.

Quality

A reflexive diary was used throughout to not only aid awareness of the lead researcher's fluctuating and subjective thoughts, but to also remain open to the new. Transcripts and theme tables were checked for richness, accuracy and triangulation of themes was conducted with a supervisor (P.G.), as advocated by Yardley (2000). Monthly peer supervision was gained via an IPA group.

Ethical Considerations

Ethical approval was granted by Bangor University Ethics Committee and North Wales NHS Research Ethics Committee and the study was subject to site-specific NHS R&D approval after full review (Appendix).

Findings

Below is a narrative of the main findings from the analysis. There are four superordinate themes, each with sub-themes, which relate to: (a) the experiences of the participants; (b) how they made sense of themselves; and (c) related to others and their treatment planning during their transition to PD (See Table 2 below). Throughout analysis the 'lifecycle' (Eriksson, 1997) was considered as a context when exploring how experiences of distress and control are understood during the transitional journey. Superordinate themes are not mutually exclusive and encompass participants' individual experiences of transition.

1. End of part of your life

Beginning of the end

All participants experienced a sense of their lives been disrupted, and consequently there is grief at the loss of their life as they have known it. It was a period of necessary change that came with emotional upheaval:

It is just like a grief reaction and I think from the beginning it has been because my lifestyle changed, my life, my future, my you know hopes and dreams and that kind of thing was, was in jeopardy really, (...) was having to change. - Jane

Different causes were cited for this experience of disruption, represented as a perceived loss of way of life, and facing mortality, which prevailed throughout the journey and indicated how catastrophic this new reality was viewed. David stated “You know I could die here you know this could be the beginning of the end for me and that was probably the worst part of it”.

Decline in bodily function and the need to rely on an outside source to sustain life was seen as central to this disruption:

Well it's bit disappointing really when you realise (...) it's a major thing because um it an end of part of your life whereas you think you've accepted things have been quite normal um kidney functions been perfectly normal thing um and then suddenly you find that you're going to be without them an' you've got to rely on something else. - John

For Nia, timing was the significant component in which her life changed, she was a vibrant young person on Friday and by Monday she was an inpatient “It was a bit shock as I was I was only (age) at the time and I was just thinking wow this has happened so quickly in a weekend.”

Participants experienced grief, shock, fear and disappointment as a result of this changed life path, one that reflects a loss of their aspirations and their body's ability to sustain

vitality. Thus, there was turmoil in this new reality and a need to integrate this into how they perceived themselves.

The fragmented self

Participants described a breakdown of the known self. The life stage of participants seemed to play an important role in this fragmentation. Nia reflected the loss of her child self when thrust into an adult world:

I was only (age) coming in at first and when I went in at first and I felt I was just a baby and I even asked the nurses at () ward ‘can I go to the children’s ward? ‘Cause I felt so, especially in a ward with older women over 60 and I thought I was only (age) sitting in the middle of them.

Jane articulated a shift in how she identified herself as strong and resilient, and now in a role which to her represented vulnerability. Adaptation was required on her part: “you know it all just awful I just had to be become the patient then, if you know if difficult as well really.” Vulnerability represented the opposite of strength, the loss of autonomy, agency and resilience.

It’s quite sad really, um I always felt when I was younger I was invincible but I’ve I suddenly felt very vulnerable (p) um even though I knew it was gonna happen at some point. As a child I remember um telling people I was gonna live forever you know I was healthy, strong, I really did, I was convinced I was would live forever (...) and now we’d gotten to the point where it was happening it was quite sad, looking back on it – David

Loss of the person they thought they were in light of this new context required a reappraisal of the self and their physical health. For Jane and David this fragmented self,

related to being once strong and now vulnerable. For Nia this was slightly different in that as a “baby” she would be cared for, but now she was expected to cope in an adult setting. This turmoil represented transition in which the fragmentation of the known self is necessary to rebuild and successfully complete the journey into resolution.

I could die from this

Facing mortality was expressed by all participants and reflected the fearfulness and insecurity of their perceived future including the acknowledgement of the fragility of their lives during this period. This was reflected by Jane, who feared for her life and a looming uncertainty of her future: “But yeah I do think you do you do think of your own mortality and um (p) of what’s gonna happen you know along the way really.” Fear is represented in helplessness and questioning regarding survival potential:

So that was a scary time and I didn’t know where my future was going, you know would I survive, how long would I survive, how long could I survive, you know that kind of stuff, so yeah, I didn’t know. – David

Mortality for Nia was understood in the context of her youth and the injustice of this threat happening to one so young: “Why, why happen so young d’you know that was the main thing I was only (age) and I thought oh my gosh I could die from this.” – Nia. For John, progression into older adulthood and later life, resulted in fatalism and resignation of life now drawing to an end:

Life in general is slowing down um it’s probably an age related thing as well um, (p) I don’t think things will have improved or will improve as regards my general health I can only hope really for, um a continued on an even keel basis type

of thing I don't think there's ever there's gonna be any real improvement in anything.

These themes represent the perceived losses associated with participants' kidney's failing, their future, their youth or their golden years. There is loss, fear and anger as ESRD signifies the failure of their body to sustain their life.

2. Control the direction not the outcome.

(He said) It would all be alright

Professionals were the guides and the experts for participants. They delivered the life changing news of ESRD, but they were also saviours. John reflected how the Doctor sustained and reassured him towards dialysis: "I don't really think I was depressed all that much because uh Dr () was so keen on getting his job done and uh it just reassured me it would all be alright and I should be back to normal." These early encounters with health care professionals (HCPs) and the information taken in while reassuring for participants, caused distress when their reality did not match their perceptions. David described an experience in which the "gold standard" of care, transplant, was 'promised' to him. However, when this was not realised he was despairing: "You know I was never, I was never meant to go on dialysis, why, why am I gonna go on dialysis?" Nia also reflected the rapid change in her initial prognosis and having been told:

You're in early, early stages of kidney failure you don't have to worry about it now' so I thought oh that's a good sign and um he said oh you'll be able to back and study your degree and don't worry about it.

While this reassurance was protective in the short term when bad news was delivered, it left her unprepared and conflicted in how to makes sense of this change.

Dr () just looked at me and said something's gone horribly wrong as in your, your, your health had deteriorated so badly in the last two years we haven't seen this before and I thought oh my gosh cause he told me at first that I would be about 30-35 maybe even older having a transplant you know we didn't even think about a transplant before. – Nia

The way participants used information provided by health professionals was vital. The reassurances and predictions were apparently held onto by participants in order to feel safe and secure and protect against the emotional upheaval of ESRD. However, this was shattered when “return to normal”, “gold standard” or “you don't have to worry” was taken away.

There really wasn't any choice to be made

This sub-theme concerns the role patients played in shaping their treatment plan. Jane and David had clear ideas about which treatment modality they wanted and why. This gave them a sense of control and agency throughout their journey. “I could um I knew I could cope better emotionally really on um peritoneal dialysis than I could have ever coped on haemodialysis I didn't feel that would be an option for me at all really.” David used personal drivers which guided his decision making: “there really wasn't any choice to be made, it was PD, it had to be PD and I wanted to do it at home.”

John and Nia describe a much more passive experience in decision making. John described a traditional, hierarchical relationship between him and his Consultant: “Um and he, he highly recommended that I had a catheter rather than go in for the um three times a week uh hospital treatment. Uh um so I said I'd go along with that.”

Nia also indicated decisions were made on her behalf, for her personal benefit. One must consider the nature of these decisions in relation to her life stage and the extent of autonomy she felt in being able to express herself during this life changing phase:

When I first saw someone on the haemodialysis machine I just, I just I had to go out I couldn't look at it 'cause I don't know the blood and everything like that and they said "oh don't worry we're not going to put you on the haemodialysis we're going to start you on the PD" and I thought oh that that sounds a bit better.

Jane and David played a more active role, perhaps reflected in their need to retain control and responsibility over their life; whereas, Nia and John were seemingly carried along in the process. The lifecycle may have played a role here. Nia's young adult self perhaps being perceived (by herself and others) as unable to make such major life decisions. Thus, her Doctor took on the role of responsible adult and decision maker. John, in the later stages of life, had a more traditional perspective of the Patient-Doctor relationship and thus passivity in these decisions. David and Jane in middle adulthood had cultivated a sense of self in relation to their adult identity, and with that autonomy and responsibilities. Therefore, they had stronger drivers to maintain this and be active participants, they had agency and they did not want to lose it.

No control versus complete faith

Control was a very clear theme and one that participants battled with throughout their journey. There was tension in trying to exert control and yet as the inevitable drew closer, seemingly slipped away.

It start, started to hit me, and it was quite mind numbing in a sense and each stage is a little bit more mind numbing if you like just a little bit more like that, it was something I had no real control over, I could control the direction we

went, but I couldn't control the outcome if you like, it was dialysis and or transplant there was no other option. - David

Jane reflected the same feeling but in relation to giving herself over to HCPs. There was reluctance and an implication that this meant "doing as she's told". This reflects a perceived didactic relationship with HCPs in which to receive care she is no longer able to exert any control.

So I think I just have to sit back and I have, I think I have anyway (laughter joint) I have, I have done as I'm told I think, you know um yeah I don't like that sort of loss of control I suppose.

During their journey, a trusting relationship was essential. Participants handed over their bodies to HCPs to receive life sustaining treatment. Thus, trust was necessary in order for the participants to have confidence in the decisions the HCPs were making, Jane commented: "I trust his [judgement] completely so I know that that he would only do what was best really." This was further exemplified by John gauging the success of his treatment based on the Consultants satisfaction: "So it had all healed up it was all working normally um (p) that was it really I mean Dr () seems quite happy with the situation and (p) he was the one that counted I suppose". Their emotional experience appeared to be guided by the Doctors. John further elaborates on this when describing discontent with his APD²⁶ machine. John was prepared to distance his own feelings regarding his treatment in order to concede to the expert Doctor:

I should have to speak to uh the uh the consultant about whether I stay on this method or not, I think he's quite happy it but uh I'll see what he has to say (...) yes I think I'll be guided by him, he's the expert when all said and done.

²⁶ Automated Peritoneal Dialysis – refers to machine facilitated PD generally utilised during the night.

The gravity of this trusting relationship was also reflected in the loss experienced when care was transferred to another professional:

Yeah quite bizarre to think that he was actually looking after me, and he was actually making the decisions for me to start dialysis, and go for a transplant and it was just yeah. But the scary thing is I'm not under him anymore here, I'm under another transplant consultant so every time I see him I'm like I miss you (shared laugh). - Nia

This theme reflects the complex nature of the relationship between Doctor and patient the tension between trust, control and the power differentials inherent in this. Trust was important for feeling reassured by the HCPs decision making. Yet it appeared to be at the expense of perceived control, at least for David and Jane. Nia and John appeared never to have considered they had control, their care was in the hands of the Doctors who they were guided by. Thus, they never felt the loss of feeling they had to relinquish control.

3. Protection of the self

I'll carry on for as long as I can

The need to “carry on” represented adaptive coping to retain key features of participants’ lifestyle and responsibilities, which symbolised their preferred identity. It signified resilience in light of this devastating situation:

I wanted to carry on the way I am, I'm a strong person you know, a single parent looking after my children, holding down a job and I wanted to do that and that's exactly what I set out to do. - David

Work is an important feature in an adult's life in terms of carving out meaning, identity and mastery and a sense one is contributing to wider society. Jane reflected the protective nature of work in reducing rumination and promoting coping:

I had thought ooh I'll have to retire, (I) can't work and do this, and I thought no 'cause that wouldn't have been healthy for me because I'd have probably dwelled on it too much. (and) So I did keep on working for as long, well I had thought of going in October, and then I thought no I'll carry on for as long as I can and that's it and so I did.

There was an indication that 'carrying on' enabled participants to retain a sense of normality, and protect against the new vulnerable: "So anyway I just kept on going went back to university carried on with my course." – Nia. Routine represented resilience and a retained identity protecting against perceived vulnerability and helplessness. It also illuminated a protective coping style, in that being able to retain previous routines represents usefulness which is necessary to maintain resilience and worth.

Lifeline

Lifeline reflects the relationship participants had with the embedded catheter. In all instances the participants explained having the Tenkoff embedded to protect against emergency treatment:

So it me feel if I become unwell then I'm not gonna have a worry 'cause my dread you know (...) but um so to me that was uh a lifeline I suppose really because I knew if I became unwell the access that was there for dialysis (...) so yeah I made me feel a lot safer really. - Jane

This was another act of protecting oneself and using the embedded period to provide protection from acute decline whilst also fostering emotional reassurance:

It was a comfort, it was definitely a comfort, because I knew if I suddenly, I use, I used the word crash sometimes at home (p) or when talking to people um in my op. In my mind my kidneys could crash any time an' just stop functioning. - David

The lifeline also reduced uncertainty through planning and preparation while participants were not acutely unwell:

Yes I could see the uh well wisdom of it or the forethought of it um because it's there when it's needed then rather to start rushing around and having it all done at one go um (p) as he said at the time it's preparation ready for when you do need it. - John

The semantics used to describe this relationship are of interest, in that participants used the words 'crash', 'rushing around' and 'dread' reflected their conceptions of the stability of their health and the type of care they would need. In contrast the Tenkoff is a 'comfort' and 'lifeline' a security blanket and the provider of stability, a calming presence which reduces the threat of chaos.

Pursuit of normality

The Tenkoff served another function as participants also felt able to continue their lives and thus protect their identity:

From uh March till June uh odd cause there was nothing sticking out so to think that this thing was inside me for three months and me actually not thinking about it every day I didn't actually think about it every day to be honest with you 'cause I just felt normal I felt just like me. - Nia

This period provided a restorative function in which participants were "normal" again. This (protective) foreign body facilitated a (protective) coping style, which kept them nearer to their preferred reality, their healthy and capable selves. John recalled "Um from what I can remember it was perfectly normal I just did everything as I'd done before, um cut the grass, cut the hedges, take the dogs for a walk whatever, uh do the shopping."

The Moncrief-Popovich technique provided security against distress associated with declining kidney function and facing mortality:

I had it done and that was it then I tried to forget about it but I knew it was there and at the back of my mind I knew that it would be my safety net really so but I didn't dwell on it you know so I just wanted to get on with things really. – Jane

It's there now it's quite serious

The Tenkoff and the embedded period also signified a profound connotation in which the participants made a definite step towards starting dialysis: “(he said) you will need it in the future and he's right I did so yes it went alright that did.” – John. The Tenkoff being embedded was the signal of what was to come:

Once we had it embedded dat was (p) a definite step into you know moving onto the next step if you like. Whereas up until the point where it's done, it's all something you're planning but now it's done, it's done isn't it, you know it's there now it's um (cough) it quite serious (p) yeah. - David

The Moncrief-Popovich technique allowed participants to plan their treatment progression, which reduced unpredictability and provided them with a role in their care: “by doing it scheduled ahead of time it was in our control which made perfect sense to me it's exactly what I wanted.”- David

Pragmatism was present in their descriptions of this planning and an implicit removal of the anticipated emotional experiences in preparation for a major life transition:

No it was just matter of thinking how long it would be before I actually start dialysis now I mean I was prepared for it I knew I'd got to start sometime but uh I think it was about six months before I decided that uh I needed to start it (p). – John

There was a clinical focus on the utility of this period. Jane exemplifies this when she referred to ‘the patient’ instead of herself. This period was a signal to the start of something

scary, and triggered a dampening of the emotional experience with a shift in focus to the pragmatic:

It was something I didn't want nobody would want would they? I mean a lot of people don't even have the choice do they? and I felt that this had been amazingly um planned you know and I think that that's just the amazing part of the Tenkoff really um is that the patient does have an element you know. - Jane

The embedded period pulled together many facets of the participants' experience of coping, planning and decision making. It marked a significant step towards that which they feared. The emotional dampening and focus on the pragmatics of this period indicate another protective strategy to reduce distress during this time.

4. Moving onto the next step

A bit two sided really

While the embedded period provided a reprieve from the dangers of acute care, fear of the inevitable remained: "The actual decision to start dialysis it filled me with dread because I didn't want to start dialysis but you know it was something I had to accept really and I was scared." – Jane.

However, there was ambivalence in the conception of what PD would bring. While starting PD signalled the end of their kidneys ability to sustain vitality, it also brought with it the prospect of a return to normal, of feeling better:

The thought of dialysis itself was, it was a bit two sided really because although I didn't want to go on dialysis at the same time I did want to go on dialysis 'cause I was expecting it would make me feel better coz although my body had gotten used to things over the ten years I knew that my body was tired. - David

As expectations of feeling better following the commencement of treatment mounted, so did more positive emotions associated with starting dialysis: “The promise of a miracle uh sudden boost if you like by filtering my blood and getting rid of these toxins I would suddenly feel great um so that was quite exciting the prospect of that.”- David.

However, it also brought the participants closer to a future filled with dread and uncertainty: “I suppose trepidation, um something new something you’ve got to worry about, would it take? Would I pull it out? Would I hurt myself?” – John. With this imminent future comes the realisation of responsibility for their care, for the life sustaining treatment they were due to start:

Then thought that this thing had want to (laugh), been inside me for 3 months and to think that I didn’t even feel it inside me to be honest at the time then when it was took out I thought oh my gosh what am I going to do with this thing? and how is it is stuck? and is it going to fall out? and how do I keep it clean? and it’s just all things going through my mind - Nia

This is it

All participants transitioned onto PD. It was at this point preconceptions were challenged and the future that was painted either by themselves or others came to pass. Participants spoke of radical shifts in their lives and with that a new wave of turmoil:

The realisation that this was your life for the foreseeable future was very difficult you know. So and because I was near to retirement age you know, I had so many plans (laugh) that I felt this had all been scuppered and but you know but you just had to accept it although I think I was in denial for a long time really - Jane

There was also a realisation of how PD would affect them and their lives: “I thought this was very draining and I felt oh I’ve got to do this, every day, every single day, every single week, for the next year.” – Nia. Repetition in this quote reflects the relentless nature of

PD for Nia. From here was the reconciliation of their perceived effectiveness of the treatment and their reality: “I think it took probably a couple of weeks for it to even start but once it started it was it was kind of constant if you know what I mean, it didn’t, didn’t get better and better and better it just stayed kinda at the level it was.” – David. The treatment modality participants had felt was their best option for the life they wished to lead had not delivered – there was no miracle cure and the radical effects of PD were underwhelming:

I would like to do more, I would like to see more, I’d like to get out more probably but um I’m tied down A. with doing dialysis and B. because uh I don’t think I can cope with going too far, doing too much at any one time, is it any help? - John

This left participants feeling disappointed, frustrated and trapped with a treatment modality that failed to return them to normal. This additional wave of turmoil and adaptation was necessary to find reconciliation with this new life phase.

Discussion

This paper aimed to explore the lived experiences of patients who received the Moncrief-Popovich technique to transition to PD. The findings revealed a number of themes relating to participants’ changing perceptions of themselves in light of ESRD and needing dialysis. The superordinate themes ‘End of part of your life’, ‘Control the direction but not the outcome’ ‘Protection of self’, and ‘Moving onto the next step’ elucidate the experience these participants had in their transitional journey. They capture oscillating processes of disruption inherent in imposed change, and the processes of fragmentation and re-evaluation of self-identity. Participants utilised the embedded period as a time of stability and reduced fear that facilitated coping. While this period was a primer for dialysis it allowed participants to retain some sense of normality.

This research further supports the importance of the lifecycle when understanding patient responses in transition. It provides a useful context for considering adaptive coping, illness and treatment intrusion and identity integrity (Devins, Beanland, Mandin & Paul, 1997). Younger and older adulthood, while having differing mechanisms, demonstrated adaptive coping resources to integrate ESRD into their self-identity, thus attenuating distress. Whereas, distress was experienced more keenly in age groups in which illness is incongruent with their identity.

Participants reflected the importance of their relationship with HCPs, which is necessary for acceptance of medical advice (Harwood & Clark, 2013). Attachment theory (Bowlby, 1973) is a useful model of understanding the complex relationship between patients and HCPs. When patients feel under threat as a result of illness they are more likely to attach to HCPs in order to seek reassurance. HCPs are instrumental in guiding patients in their journey to dialysis, providing support, guidance and reassurance (Frederiksen, Kragstrup & Dehlholm-Lambertsen, 2010).

The ‘Technique’ extended the planning process providing a longer period of adjustment and opportunity to prepare psychologically for treatment (Kralik et al., 2006; Mahler & Kulik 2008; Rosenkoether & Garris, 2001). This was unique for these patients and one that has never been explored. In fact, no qualitative study has looked at the transition of patients to PD before. Therefore, this is the first indication of themes concerning not only transition to PD but transition following the ‘Moncrief-Popovich Technique’.

Future Research

To fully understand the participants’ experience of transition, future research may consider multiple interviews throughout the journey, including the embedded period. This would provide a more accurate in vivo account of their transition experience. A comparison

view of patients who have had the Moncrief-Popovich technique and standard transition to PD may illuminate any similarities or differences in these two experiences.

Further research to explore mechanisms of distress and coping in different age groups in relation to the Moncrief-Popovich technique would be useful for treatment planning and addressing risk factors.

A closer look at the renal Patient-Doctor attachment relationship in renal care would be of interest. As per the literature there is evidence of using information seeking, mastery and control to support transition to dialysis (Mitchell et al., 2009; Devins et al., 1997). Closer exploration of how health professionals were utilised and what patients found most useful may help inform future individualised care planning.

Limitations

Generalisability in qualitative research is difficult, and this research modality simply provides data which could be explored further. The sample was recruited from one renal unit; thus this research may reflect specific experiences of care in relation to the services participants received in the one unit.

Transition is not necessarily considered linear in chronic health conditions due to the fluctuating nature of health (Kralik et al., 2006). Time is an essential factor to be considered in transition research and these participants were recruited and interviewed only once after they had transitioned to PD.

Clinical Implications

Psychological theory of transitions helps inform clinicians of the internal subjective processes required to adjust to the multiple phases of ESRD. These internal phenomena are not typically considered by HCPs, despite them providing significant input for patients during

forced transitions (Harwood & Clark, 2013; Kralik, 2002). Clinical Psychologists have a role to play in educating and supporting HCPs to work with patients in a more psychologically informed way.

HCPs play a vital role in which to help patients build narratives of their condition and prognosis. Providing a *place of safety* in HCPs can foster expression of patients' distress, which is essential for supporting patients to regain identity integrity and wholeness in light of ESRD (Harwood & Clark, 2013). Other interventions including peer support may enable open discussions around procedures, losses and mortality and engaging in preparation and adaptive coping (Cormier-Daigle & Stewart, 1997; Harwood & Clark, 2013; Mitchell et al., 2009).

Conclusions

This paper provides a new insight into the experiences of patients who have received the 'Moncrief-Popovich Technique' and who have transitioned to PD. This procedure provides a stabilising period in which patients can retain a sense of normal. Transitions are in their nature difficult periods of personal fragmentation and rebuilding. Psychologically informed services from HCPs may ensure patients have validating and normalising support during their transition to PD.

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Appendix 2

Table 1. Sample characteristics.

| Participant number | Pseudonym | Life stage | Ethnicity | Time embedded (months) | Time on PD (months) | Current RRT |
|--------------------|-----------|------------------|---------------|------------------------|---------------------|-------------|
| P1 | David | Middle adulthood | White British | 7 | 5 | Transplant |
| P2 | John | Older adulthood | White British | 6 | 12 | PD |
| P3 | Jane | Middle adulthood | White British | 15 | 1.5 | Transplant |
| P4 | Nia | Young adulthood | White British | 3 | 9 | Transplant |

Table 2. Tabular representation of superordinate and ordinate themes.

| Superordinate theme | Themes |
|--|--|
| 1. End of part of your life | Beginning of the end The fragmented self I could die from this |
| 2. Control the direction not the outcome | (He said) it would be alright There really wasn't any choice to be made Control versus complete faith |
| 3. Protection of the self | I'll Carry on for as long as I can Lifeline Pursuit of normality It's there now, it's quite serious |
| 4. Moving onto the next step | A bit two sided really This is it |

Chapter 3

Contributions to theory and clinical practice.

The purpose of this paper is to draw together the two previous chapters and explore how their initially separate findings contribute together to further existing theory and clinical practice within the renal sector. This paper is split into four sections: (1) Overview of the previous chapters; (2) Theoretical Implications; (3) Clinical Implications; and (4) Personal reflections.

1. Overview of chapters

Systematic Review

The systematic review highlighted that a third to half of nurses fell into the moderate to severe range for emotional exhaustion. Prevalence of burnout in renal HCP's was shown to be similar to that of HCPs in other clinical settings (Kahmisa, Peltzer & Oldenburg, 2013; Kash et al., 2000). Renal HCP's are therefore not immune to burnout and the impact of organisational difficulties present in health services, such as high workloads and poor support for HCPs. Dissatisfaction with environmental factors including ambiguous leadership, workload and lack of resources reflects the current literature from other health specialisms. There is increased recognition of the organisation's impact on HCP's working and thus the effectiveness of health care services (Kings Fund, 2013; Rydon-Grange, 2015). Additionally, understanding the different organisational contributors to burnout and dissatisfaction in other renal HCPs would help inform tailored staff interventions and better informed organisational structure.

Empirical Paper

The findings from the empirical paper reflect those found in the literature for other renal groups (haemodialysis), whereby patients go through a process of fragmentation as a result of life disruption. This necessitates change, where participants may exert control, to

facilitate adaptive coping during transition to PD. Participants used the ‘Moncrief-Popovich Technique’ to assert control and organise their treatment plan. They used the embedded period before dialysis as a way of maintaining normality without the threat to mortality. It provided a restorative period in which participants continued with activities which maintained a stable sense of self, while feeling protected by the catheter. However, during this period the inevitability of starting dialysis was felt. This period did not ameliorate anxiety or dread associated with starting dialysis, despite the ambivalence held by participants that dialysis would bring about radical improvement in their health.

2. Theoretical Implications

Methodological limitations

Both papers reported on or utilised cross-sectional methods to explore renal health care professionals (HCPs) or patients’ experiences. The lack of longitudinal data offers no insight into how burnout experience changed for HCPs over time. This is relevant as the systematic review revealed risk of burnout appeared to reduce as HCPs (i.e. nurses) become older and more experienced. Future longitudinal research may help to ascertain what variables contribute to this change. This would be useful for service planning and HCP support.

The systematic review attempted to capture the relationship between features of the working environment and burnout and job satisfaction in all renal HCPs, but it was limited by the lack of papers investigating this beyond nurses. Other professional groups such as medics, dieticians, social workers, pharmacists and clinical psychologists were therefore underrepresented. Thus the review was unable to draw conclusions for other occupational groups, rendering recommendations about organisational change beyond renal nurses (particularly haemodialysis nurses) impossible. Many opportunities remain for building upon

the evidence base for these groups, as there is little indication of the relationship between the organisational mechanisms underpinning dissatisfaction and burnout in other renal HCPs. Qualitative research may have utility in identifying themes unique to these other HCP groups, which could be further explored using larger quantitative methods.

The empirical paper utilised retrospective reporting of patients' transition to peritoneal dialysis (PD). Kralik, Visentin and van Loon (2006) and Martin-McDonald and Beirnoff (2002) recommend multiple interviewing when exploring transitions. This would help to capture the process of fragmentation and change and (possible) resolution inherent in patients' journey to PD. Future studies addressing the aforementioned methodological issue may wish to begin interviewing patients before the embedded period, repeating until dialysis has commenced. This may be particularly interesting when further exploring the psychological utility of the embedded period for patients.

Participants in the empirical paper were recruited from a single source. While Interpretive Phenomenological Analysis (IPA) is ideographic in its methodology and does not purport to be generalisable (Smith, Flowers & Larkin, 2009); the findings may reflect a biased perspective of the experiences of patients from this one unit, who were all under the same Consultant. Further qualitative research may seek to recruit from other units who utilise the 'Moncrief-Popovich Technique' to add to the literature. Divergence and similarities in data may also identify themes with which quantitative analysis could be conducted on a larger scale, for instance life stage, attachments to HCPs, coping styles, attributions and resiliencies.

Three participants received transplants (two planned and one from a cadaver donor), before taking part in the study. This may have influenced their experience of reflecting back on their transition to PD, as these participants were experiencing a return to normal. They were exultant in the positive effects of the transplant; particularly when this was compared to the impact PD had on their lives. Whilst the participants' differing life stages brought up

interesting divergence in the data (as reflected upon in previous HD research), it also highlighted further features of the patients' experiences that could be considered in more depth. These features included adaptive coping and integration at different life stages and the importance of support systems during the embedded period.

Contribution to theory

The systematic review suggested that renal HCPs are subjected to the rigours of working in a highly demanding and competitive environment. The job demands-resources model (JD-R; Demerouti et al., 2001) illuminates the impact high demand and inadequate support has on HCP's wellbeing and emotional resilience. The systematic review provides useful information for mapping this model onto a renal context:

1. Job demands highlighted in this review included: long hours, high caseloads and working with a complex patient population with enduring health difficulties. When combined, these have a significant physical and psychological impact.
2. Job resources (or lack thereof) from this review included: poor leadership and supervision, dissatisfaction with role clarity, lack of professional progression and training or decision making and dissatisfaction with pay. As these resources were not present this placed significant physical and psychological burdens upon HCPs to address the demands placed on them.

Using this model, it is understandable that HCPs in the literature review were reporting high emotional exhaustion, cynicism in their role and lack of personal efficacy in light of high demand and poor support resources. This model has utility where areas of improvement may be for enhancing the working experiences of renal HCPs. Equally, future research could map onto this model with other renal HCPs not represented in this review to establish any

differences in the demands and resources. For instance, a huge component of a Clinical Psychologist's working practice is regular supervision (BPS, 2008). Therefore, this may highlight a difference in the resources made available compared to other HCPs.

Transitions in chronic health conditions are well documented and patients with end stage renal disease (ESRD) experience multiple transitions in light of the complexity of the disease and the treatments (Hutchinson, 2005; Kralik et al., 2006). There is evidence of identity distress and fragmentation in ESRD patients as a result of necessary changes borne from forced transitions (Kralik, 2002; Morton et al., 2010). Research investigating transitions to HD illuminated similar findings to this paper, where themes of choice taking, expectations with regard to adjustment, and divergence in the data due to age being a factor (Mitchell et al., 2009).

The unique aspect of the empirical study is the embedded period in which patients are being physically prepared for PD. This provides another step in planning and a further period in which to prepare for dialysis. It also provides another transition which patients must adapt to. While most patients found the period helpful in that it reduced apprehension related to the threat of acute decline, the embedded Tenkoff was also a reminder of their inevitable future and for one participant this was highly distressing. A deeper analysis of what mechanisms of reassurance and distress this embedded period provides for patients would be useful, not only for understanding individual differences in experiences, but to help make biopsychosocially informed recommendations for decision making and considering patient suitability.

Chapter two also found different coping styles with participants in different life stages, whereby younger adults were more likely to 'get on with it' and engage in active avoidance, yet older participants were more stoical and accepting of their context. Siegler (1989; cited in Devins, et al., 1997) suggests different stages of adult development are associated with differences in the emotional impact, illness appraisals and coping behaviours. This paper

demonstrated that when care decisions were made for patients, at the time of starting dialysis they were apprehensive regarding responsibility for their own care and 'looking after' the catheter. This apprehension at the sense of responsibility was not evident in participants in middle adulthood who had taken more responsibility for their care, from decision making and treatment planning, throughout their journey. When scanning the current literature this theme was not found for linking age and perceived responsibility. Further exploration of this may be useful, particularly when considering risk factors and vulnerabilities for added distress in patients of different ages at different stages of their transition.

A trusting relationship is considered essential for making informed decisions and patients' willingness to accept medical advice (Kulik et al., 2006). This was reflected in the empirical paper where patients described a relationship dynamic, which reflected trust and loyalty. Attachment relationships (Bowlby, 1973) have been discussed in the context of the patient-clinician dyad, and adherence and clinical outcomes in health care (Cassidy & Shaver, 2008; Ciechanowski, Katon, Russo & Walker, 2001; Tucker, Miltenberger, Pitts & Stringer, 2015). Attachment systems are triggered by a period of anxiety and a need to feel reassured by a secure figure.

The empirical paper noted that individuals who experienced an illness related threat sought reassurance and containment from HCPs who are perceived as expert. This was exemplified in the findings in which HCPs were considered very important figures, and there was even loss expressed when patients were transferred to other consultants. Equally, the review highlighted HCPs who are experiencing anxiety as a result of a stressful working environment and who have no access to a containing and supportive supervisor, may seek reassurance from patients. The review showed that although HCPs report dissatisfaction with organisational features of their work, they can also report satisfaction in providing care for patients. Here are two groups, patients and HCPs, who are experiencing distress from different

sources, but are bound together in a health care setting. They are seeking reassurance from each other, who are equally potentially unable to contain or support the other because of their own emotional demands, and lack of resources. Attachment theory captures the distress and coping of these two groups and how they are interrelated. While the empirical paper provided some insight into the importance of HCPs to patients, future research could explore renal HCPs experiences of working with, and the importance of their relationships to their patients.

When considering the implications of both papers combined, it is recognised that HCP's are unlikely to be able to provide high level care when working under conditions of persistent stress, poor working conditions and consequential poor health (Goodrich, Harrison & Cornwell, 2015). These issues have been shown to impact on patient satisfaction, outcomes and mortality (Argentero et al., 2008; Gardner et al., 2007). This is particularly pertinent as renal services provide long-term specialist care, where patients may be exposed to conditions of poor organisational working conditions and emotionally depleted HCPs repeatedly and over long periods of time. The empirical paper highlighted specific themes of distress and disappointment during transition to PD in relation to patients' ESRD and experience of dialysis being contrary to their expectations. Renal HCPs have a role in supporting patients during this journey as recommended in national guidance (NICE Guidelines, CG91, 2009; GS5, 2011; National Renal Workforce Planning Group 2002). However, while HCPs may be best place to provide this support, they can only support patients if they themselves are psychologically robust and not at risk of burnout.

With the theories mentioned above in mind and using them to consider how the experiences of HCPs and patients are interrelated a model has been proposed. The model presented in Figure 1 (Appendix 3, Page 115) below, not only considers the interrelated experience of renal care, but also identifies areas of intervention for both groups. The model

is informed by the aforementioned papers, as well as previous research and practice guidelines. It also considers areas in which psychological input would be best placed.

[INSERT FIGURE 1 HERE]

As illustrated in figure one above, poor HCP and patient wellbeing create a feedback loop in which HCP's are burnt out and unable to provide empathic care. This is problematic when we consider how attachment theory (Bowlby, 1973) explains the need for HCPs and patients to seemingly attach to each other in times of distress when no other reassurance is available. As noted above when, HCPs are unable to address patient distress, this impacts on patient satisfaction. If we consider here the JD-R model, when HCPs are unable to ameliorate patient distress this adds another demand for which they may not have adequate resources, such as emotional resilience or organisational support. Therefore, HCPs experience more pressure (without adequate resources) to ameliorate patient difficulties as they arise. This added workload demand and stress for HCPs, in turn impairs (attachment) relationships between them and their patients, which is important for treatment uptake in patients.

This feedback loop presented in the model exists in a climate of HCP's already feeling over-worked, lacking resources emotionally and via poor organisational support. No paper has attempted to provide a Psychological service provision model designed to support HCP's resilience through direct and indirect psychological input with improving patient outcomes during transitions to PD in mind. The interventions that could be implemented are discussed below.

3. Clinical Implications

The association between HCP's stress and low patient satisfaction is well established across many fields in health care (Aiken, 2012). This is pertinent as the empirical paper found distress to be associated with forced transitions in light of changed health status and new reliance upon technology for survival. It also highlighted didactic decision making and subsequent disappointment in treatment modality.

The model above suggests a pathway of service improvement starting with HCP's and then patients to create an improved feedback loop (see Figure 1) in which HCP's feel more supported, empowered and efficacious in their care. This improvement feeds into better multi-disciplinary, biopsychosocial provision of care for patients; which in turn reduces patient distress, improves satisfaction and outcomes. This then feeds back into HCPs feeling effective in their role.

The empirical paper recommended providing a space for patients to express their thoughts, fears and preconceptions in which renal HCPs can provide empathy and validation of these experiences and aid in informed decision making (Harwood & Clarke, 2013).

Disclosure of distress and communication

Evidence suggests patients do not disclose emotional difficulties as they do not see it as the clinician's role to listen (Ryan et al., 2005) or they report feeling discouraged to do so by non psycho-social HCPs, whose focus is on physical aspects of care (Maguire, 1985). However, where HCPs show validating and empathic behaviours and used psychologically informed approaches, patients were more likely to disclose difficulties (Taylor & Combes, 2014). One difficulty with encouraging HCPs to elicit emotional content from patients is HCPs' perceived competencies with managing such strong emotions. Combes, Allen and Sein

(2013) noted even empathic HCPs do not always respond fully and compassionately with patients and resort to a problem-solving style when distress in their patients is expressed. This may potentially invalidate the patients' emotional experience and hamper any future emotional disclosure. This lack of responding from clinicians is likely due to poor training in psychological distress, and (or) emotional exhaustion rendering clinicians unable to respond with validation, compassion and empathy.

Despite participants describing distress and skewed expectations during their interview, this was either hidden or not picked up by renal HCP's in a way that was reassuring to participants. Anecdotally, participants reflected not talking in as much length about their emotional experience before. This poses the question, were participants provided with an opportunity to express any difficulties they were experiencing? Or if they were, were they sufficiently validated? One participant expressed not feeling reassured when trying to discuss his fear of death. Therefore, are patients trying to talk about these issues but not finding a suitable level of validation or support currently?

HCP support

HCPs play a critical role in transitions (Meleis & Sawyer, 2000) and are best placed to spend time drawing out values and beliefs patients may hold about their prognosis and how they wish to lead their life. This would also illuminate how treatment modalities are conceptualised by patients, and offers an opportunity to right any misconceptions and help the patient make informed, collaborative choices (Harwood & Clarke, 2013; Kralik et al., 2006).

Chilcot, Wellsted and Farrington (2011) found perceptions of illness control and understanding predicted depressed symptoms in patients receiving HD. Treatment disruptiveness and depression was also associated with lower perceived control (Griva et al., 2009). The embedded period provided participants with the security of not needing emergency

care and they were actively planning and free from the shackles of some of their worries. Participants could continue with their lives and regain a sense of control. This may be an opportune period to continue to explore expectations about treatment effectiveness and continue to normalise feelings of apprehension related to starting dialysis. This would typically be provided by nurses who have the most frequent contact with patients. This time would facilitate the development of rapport and could serve to foster a '*place of safety*' for patients in the renal unit and their care team (Harwood & Clarke, 2013). It also serves to normalise psychological distress in the context of the patients' reality.

Other support

Peer support or expert patient programmes (EPP) provide opportunities to discuss experiences with other patients (Cormier-Daigle & Stewart, 1997; Winterbottom, Bekker, Conner & Mooney, 2011). Kulik et al. (1996) suggest pre- and post-operative friendships may also provide support for reducing misconceptions and procedures related distress. Patients report finding these groups helpful in finding validation through shared experiences and reassurances (Hughes, Wood & Smith, 2009). Although evidence of clinically significant change is limited (Foster et al., 2009) these interventions may form part of a catalogue of support for patients to address the complex needs of this group. These support systems also aid in planning, decision making and adaptive coping (Mitchell, 2009). This is pertinent as adequate preparation has shown to reduce psychological distress and promote personal resourcefulness during transitions (Mahler & Kulik, 1998; Mitchell et al., 2009; Rosenkoetter & Garris, 2001). Maintaining or re-engaging in meaningful activities is also recommended to reduce rumination, and regain some losses associated with illness intrusiveness experienced by patients; this could be encouraged by peers and HCPs (Taylor & Combes, 2014).

Clinical Psychology Support

Recommendations suggest patients receive psychological input up to a year before starting dialysis to ensure adequate preparation. Therefore, psychological support is considered an essential component of renal care (NICE GS5 2011; Department of Health, 2004; 2005); however, provision of clinical psychology or counselling is particularly low in the UK (Taylor & Combes, 2014). Despite this the evidence suggests renal HCPs and patients are experiencing distress. Clinical Psychologists are recommended as part of a renal multi-disciplinary team (MDT) to support patients and HCPs. Support could form part of a stepped care model of psychological provision (BPS, 2008; The National Renal Workforce Planning Group, 2002). Clinical Psychologist input could be in the form of direct support for patients or perhaps more usefully, training, supervision and consultation for renal staff in the importance of transitions and how best to work with patients during this period.

These clinical recommendations aim to reduce adverse distress during patients transition to PD. However, the recommendations depend on increased input from the whole renal MDT coming to recognise their responsibility in supporting the emotional needs of their patients. When considering the findings of the literature review, if renal professionals are already at risk of burnout, the expectation that they provide more emotional support for their patients is unfair and unrealistic without adequately supporting them to do so. Support from Clinical Psychology could be in the form of training, consultancy, supervision, facilitated reflective practice sessions or mentoring. However, one must consider that this would also create extra workload burden for psychologists and the MDT and possibly increase conflict in pulling nurses away from other 'pressing' tasks. As the model (Figure 1) above proposes, HCP's would need the support of their organisation to allow them time to engage in these newer, demanding activities. Organisational support would promote the message that it is a

key role to support patients, and also engage in self-care initiatives (reflective practice, supervision), and that these roles are of equal importance to physical care tasks. If this is not invested in, then the integrity of the model is compromised, and thus HCP and patient wellbeing is compromised. The literature already demonstrated when the above is not made available to staff, they are more at risk of stress and burnout.

Finally, in considering the implications of this research to policy, the role of the working environment on stress, burnout and job satisfaction in HCPs is well documented and has been described as a contributor to serious case reviews of institutional abuse and neglect (Francis Report (Francis, 2013); Winterbourne View (Department of Health, 2012); Tawel Fan (Ockenden, 2014)). This research serves to add more evidence of the key role the working environment and wider systemic difficulties play in HCP working experience and supports recommendations already made in policy to support HCPs in these environments. With regards the Empirical paper, as noted above policy recommends psychological input 12 months before patients start dialysis (The National Renal Workforce Planning Group, 2002). The psychological distress described by participants in this paper serves again to support policy in recommending better psychological provision of care in renal settings than there is currently (Department of Health, 2004; 2005; NICE GS5 2011; Taylor and Combes, 2014). The model outlined in the final chapter highlights existing recommendations of the role clinical psychology can play in supporting staff and patients in healthcare settings, and illustrates it in the context of preparation for PD. Therefore, these chapters serve to provide further evidence of the need for support for HCPs and patients in renal settings and supports recommendations laid out by policy.

4. Personal Reflections

A large component of qualitative research is reflexivity, in which the researcher considers themselves in the context of their research. I was aware of my particular interest in promoting psychological understanding of patients' experience in physical health settings. This is a long standing interest as I felt medicine does not allow patients to have a voice in the way other professions, like Clinical Psychologists do. Thus, I was aware of my passion regarding the promotion of patients' perspectives in their experience of medical treatment. This was particularly important in the empirical paper when patients expressed dissatisfaction or lack of autonomy in decision-making regarding their care.

I was apprehensive in embarking on a qualitative methodology as my background is in quantitative research. I felt nervous regarding being able to do the participants justice in my interviewing, in terms of eliciting rich enough data which ultimately shaped the analysis. I undertook two days training in IPA, which culminated in myself and four colleagues establishing an IPA group, meeting monthly to support members throughout the whole research process. Of particular importance support with the methodology, initial notations, further abstraction and peer support for developing super-ordinate themes. This group provided opportunities for triangulation, ensuring themes were still tied to the data and evidenced by transcript extracts.

My academic knowledge of renal care and PD was evident in early research proposals and supervision. I thought initially this was a disadvantage as I did not fully appreciate the psychological implications of renal disease. I wonder now whether this was an advantage as my preconceptions were limited due to this lack of knowledge. My analogy for understanding the embedded period was pregnancy, in which a woman has something inside of her for a prolonged period of time and she slowly adapts in preparation for the birth of her child, a major life transition. The difficulty with this analogy is it is typically considered a positive transition. Additionally, when this procedure was presented to me, it was again presented as

similarly positive, with favourable medical outcomes and patients being able to continue with important aspects of their life. It is possible this shaped my perception of the embedded period.

Thus, my initial expectations regarding the outcome of this research were that the embedded period would serve as an extended adaptation period in which patients would have more time to consider and prepare for dialysis, thus facilitating a smoother transition. However, this was not necessarily the case; the analysis revealed that whilst patients used this time to *just carry on* there was also evidence of increasing fear and apprehension with regard to starting dialysis. I had not really considered renal disease a terminal illness and thus I was not able to predict the fear of mortality nor appreciate just how scary renal disease was for participants.

Further insights into renal care were facilitated by my final year clinical placement in a renal psychology team during the data collection and analysis period. This was the same renal unit in which participants were recruited. Thus, the same HCP's mentioned in the interviews, were now my colleagues. I now had a personal insight into the ways HCP's worked with patients, including difficulties which arise from time to time. I also gained a clinical perspective as patients articulated their experience of renal decline and care during individual therapy sessions. Themes of invalidation from staff, isolation, fear and feeling overwhelmed were present during these sessions. This was in addition to adapting to the rigours of dialysis and the implications of this on quality of life and wellbeing for patients. This provided me with the clinical insights I had lacked during earlier periods of my research. Therefore, the reflexive process of diary keeping, research supervision, and peer support via the IPA group was imperative in remaining aware of my perceptions and further insights into the workings of the renal unit. This was particularly important when considering my perceptions of health professionals and their relationships with patients when working in the renal unit. I was able to see that under everything HCPs motivations were borne from a need to care, a need to care

for their patients. This new insight highlighted the tension for HCPs in providing expert medical care but being unaware of or unable to manage any psychological distress present in their patients.

Recruitment from such a small sample pool was a cause for concern for myself and supervisors and resulted in my developing a two-stage recruitment process. Patients utilising PD is relatively un-researched, and transition to PD has not been explored. If there were significant difficulties with recruitment, patients who utilised PD, but did not have the Moncrief-Popovich technique would be recruited. However, the data was considered sufficiently rich; therefore, it was deemed appropriate to not recruit from the main PD population.

During the interview phase, I was aware of how I was considered by participants, and how this may have shaped the interview process. It was known I was a trainee psychologist, all participants had met the local psychologist and one was seeing them regularly. Being viewed as a psychologist automatically placed me in the role of a HCP, which may have shaped their responses on certain topics. All participants had rote statements “the staff were great”, “I couldn’t praise them enough” and there may have been reluctance to speak ill of my fellow professionals. For some there was an assumption that I had knowledge about the procedure and their healthcare, this assumed knowledge may have prevented participants from elaborating on certain topics.

Rapport is essential for individuals to feel safe enough to disclose important information about themselves. The female participants elaborated much more freely and required much less prompting. It is possible as a fellow woman, disclosure of information felt easier and perhaps socially normal. Male participants were more guarded in their disclosure of emotive detail initially. During the analysis phase I noted a predilection in both men to present as strong or minimise the impact of the journey on them. As a young woman and a

stranger it is possible these male participants were uncomfortable or reluctant to disclose their vulnerabilities freely.

During the initial reading and re-reading I was unsure and fearful the data would not be sufficiently rich, this was particularly pertinent given the number of participants in the sample. I think, upon reflection this represents the analysis process and moving deeper to conceptual representations. As the analysis developed I was confronted with too much rich data, resulting in a need to prioritise themes most pertinent to transition and the embedded period. Consequently, I felt loss at having to discard vivid descriptions out of this narrative.

The importance of support featured for all participants and I had initial expectations that this would be a superordinate theme in the final findings. At times I was surprised when this became increasingly less present in the conceptualisation of the data and pulling together the narrative. I wondered about the social expectation to provide relational themes as they are a massive facet of our world, and indeed of transitions in ESRD (Hutchinson, 2005). Ultimately, I concluded the relational component, while rich, was not specifically linked to 'Moncrief-Popovich Technique' and did not add new information regarding transition in this population. My reflexive diary was crucial during this period and served to catalogue my thought processes during long days of analysis.

Regarding the clinical implications, I was unsure of the practical utility this thesis may have. Thus, I was surprised when supervisors read with engaged interest at the findings. It was from here useful conversations arose as to the implications of these papers for renal care and the circular connotations of making recommendations for one group: patients, and the impact this would have on the other group: HCPs. I felt strongly an ethical dilemma in that I could not make bold clinical recommendations for patients without considering what support HCPs would need to implement these.

This research process has not only strengthened my knowledge of transition in renal care, but also the stressors renal HCPs experience in their daily working lives. I found myself increasingly compassionate towards renal staff. Health care is relational, and viewing one group in isolation from the other would be futile as progress will only be found if both parties are considered. This is where I found myself excited about the utility of clinical psychology in supporting HCPs to support patients, and making a case for increased psychological provision in renal settings.

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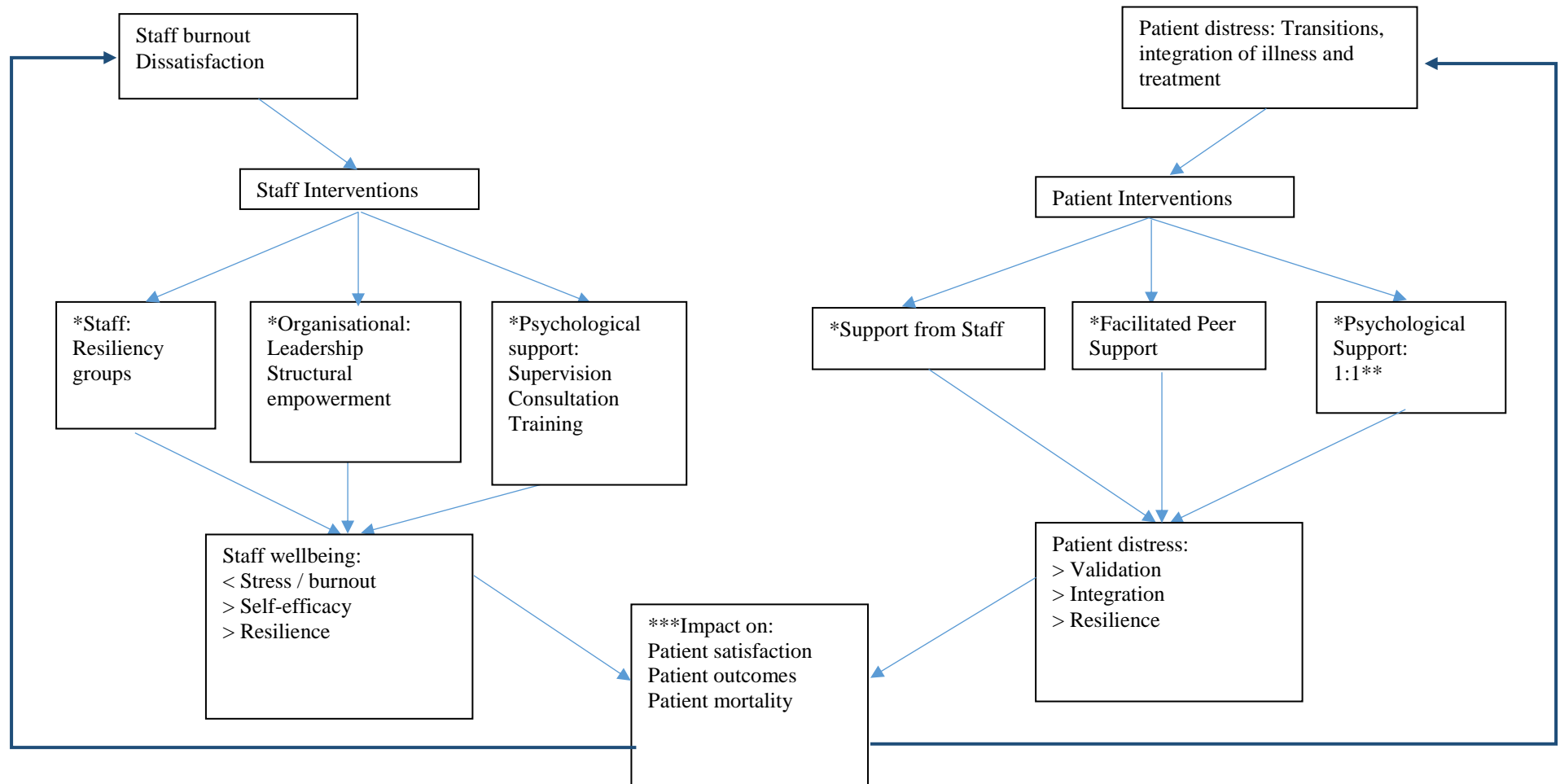
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Appendix 3

Figure 1. Model of staff and patient support facilitated by psychological input.



* Areas of Clinical Psychology input via direct or indirect support for staff and patients

** For more complex presentations which have not been ameliorated through staff support

*** Audit and evaluation via Clinical Psychology and fed back to into teams to demonstrate effectiveness.

Appendix 4

Data Extraction form

| | | |
|----------------------------|---|--|
| Author(s) Year | | |
| Title | | |
| Journal | | |
| Country | | |
| Sample size: | Profession: (n) <ul style="list-style-type: none"> ○ Nurses (HD / PD) ○ Nephrologists ○ Dietician ○ HCW ○ SW ○ Psychologist | Setting: <ul style="list-style-type: none"> ○ Renal Unit ○ In centre ○ Satellite Unit ○ Community |
| Mean age: SD: Range: | | Sex (M:F) |
| Methodology | | Years in nephrology |
| Measures | Burnout (m; SD): <ul style="list-style-type: none"> ○ Maslach ○ EE ○ DP ○ PE | Stress (m; SD): <ul style="list-style-type: none"> ○ NSS ○ GHQ ○ WoCQ ○ HCJSSQ |
| | Job Satisfaction (m; SD): <ul style="list-style-type: none"> ○ IWS ○ MSQ ○ HCJSSQ ○ CWEQ-II | Organisational/environmental (m; SD): <ul style="list-style-type: none"> ○ PMI ○ IWPS PES-NWI ○ COPSOQ B-PEM ○ PEIs |
| Other Measures | MOS - QoL Multiple Constructs - COPSOQ | |
| Statistics | | |
| Strengths | | |
| Limitations | | |

Based on Downs and Black 1998 – Intervention and RCT related questions removed.

Reporting

1. Hypothesis/aim/objective of study clearly described
Y 1/ N 0
2. Main outcomes measured clearly described in introduction and methods section
Y 1/ N 0
3. Characteristics of patients included in study clearly described
Y 1/ N 0
4. Main findings of study clearly described?
Y 1/ N 0
5. Random variability in data for main outcomes
Y 1/ N 0
6. Probability values reported
Y 1/ N 0

External validity

7. Subjects: asked to participant representative of entire population (must have reported potential population size)
Y 1/ N 0
Unable to determine 0
8. Staff, places and facilities representative of the treatment / working conditions of the majority of participants?
Y 1/ N 0
Unable to determine 0

Internal validity - bias

9. Inferential Statistics
Y 1/ N 0
10. Magnitude of effect reported (Effect size, odds ratio)
Y 1/ N 0
11. Main outcome measure valid and reliable (consider where reported)
Y 1/ N 0

Internal validity

12. Power discussed, reported?
Y 1/ N 0

Sample Transcript and analysis

| Clusters | Transcript | Comments |
|--|--|---|
| <p>normality. Acceptance of significance of procedure? Impressing others with resilience? Denial of impact? Alright? Keep moving to avoid what? Defeat vs keep moving Denial of limitations Needs psychologically driven – misguided Underlying drivers – values Beliefs – recovery, relationships Internal working models of self and others – contingencies Body image Physical reminder or illness Timescale – minimising impact of unwanted future Dampening outlook Positivity didn't save him from the inevitable</p> | <p>quite hard, um to the point where I was sometimes in quite a bit of pain because I was walking too far, after the surgery. k. do you know why that was? David. that I was walking too far? Coz I wanted to make sure I was alright (slightly defensive tone) you know I could lie there and let it just wait for it to heal itself or I could get up and move around and and push myself a bit which was what I was doing (p) I was trying to keep moving k. so you said too far David. yeah I mean, I was I was walking so I couldn't take the pain anymore, or it was getting to the point you know where the pain was quite bad bad, but then I had to walk back as well (smile); whereas, you know I could have walked so far and then come back, I was going as far as I possibly could and den I had to make my way back and that was when it was really hurting (smile) but to me that was a good thing because it meant I would have healed quicker k. ok (p) David. I needed to be up, as a again as I said as a single parent, although I have a partner we don't live together um so I had to be up and running quite quickly so that was my reason (defensive) k. ok, so you were up and running um immediately after, and I, I am wondering about that time then that the catheter was inside of you and before you'd started dialysis and what that was like for you David. it was quite strange because there was two sides of it, one was I've got this coil (emphasis) just under my skin which I could feel (emphasis) and I had a lump there k. ok</p> | <p>bed is important part of his display of him, he needs to be unaffected? He is still him? Not ill? I that why he didn't tell his partner? Need for illness not to defeat him? Why tell me this? Which part of him alright? Walking far is not a measure of recovery for this operation – why is that important to him? It should heal itself, control again? Facilitating his own recovery by pushing self, cant be passive agent? Did he think he ma not heal? What happens if he doesn't keep moving? Is this denial of the limitations imposed on him from the op? despite the short term? Pacing, psychologically driven to move and potentially hinder recovery. Misperception, moving, being strong are values which he may pit into this recovery. Partner only willing to look after children for fixed time? He always needs to demonstrate strength and resiliency? Is he using kids as reasoning/excuse is this just him, his internal drivers? Always keeping going? Being pro active? Tension. Body image, he could feel the coil, physiology. Constant reminder? Time scale, playing down? Scar, lump reminder of something more imminent that he doesn't want? Dialysis impacting on his mood? Reduced his positivity because this positivity hasn't avoided or changed his path. How relentless must it have felt to keep fighting to be positive, up out of bed quickly after op. Positivity is what kept him going, stopped him from being beaten. Uncertainty – out of his control. Embedded period, signified time to look toward what it represents – dialysis. Restrictions impacting on his life, more and more, soon he'd have to start shaping life around dialysis, does he want to do that? No</p> |

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| <p>Time Uncertainty Restrictions</p> | <p>David. um which was a little bit strange the scar healed after, well the pain receded after a couple of days, or three or four days so the pain was okay, um but I knew fairly soon I'd need another procedure to take this out and well I'd be awake so I was a bit nervous about that but also I think more significantly I was um it was a bit (p) how do I describe it now it was a bit like a dampening on, on my out you know my outlook because I knew at some point fairly soon I was gonna be told now's the time to start dialysis and I didn't know how that was gonna be, um I did know it was gonna take up a significant amount of my time because it would be four times a day um and dat (p) I would have to be ultra-sterile</p> | <p>Again trying to manage, control his environment, in this case for his better health. Consideration of his relationships impact on his broader life and systems not just him. Implicit in the sense, he may be impacting on their lives because of this, perhaps fuels that need to normal not just for him but his kids/partner.</p> |
| <p>Impact on relationships Normality uncertain</p> | <p>k. um (nodding)</p> | <p>Physical reminder, didn't need reminding of what's going to happen next.</p> |
| <p>Physical reminders</p> | <p>David. doing that with f f free kids in the house as well, trying to be sterile (shared smiling) I can't get them to clean up after themselves (laugh) so that was a, that was a concern um I was also concerned about the impact it would have on them, and on my partner and on on well on my on my way I of living my life I was confident and comm committed to living my life normally (p) but until I actually started dialysis I didn't know whether I would be able to (p) so. k. and did the coil serve as a reminder that that was going to happen?</p> | <p>Present tense, 'you' distanced send from comment, he feels different, looks different? Body image. Didn't want it there, taunting him? Conflict between want and need, knew it was a good thing but didn't feel like a good thing, entering into something against what he wanted really.</p> |
| <p>Feel different Sense of self Change There for my own good</p> | <p>David.um I didn't really need reminding, but I was conscious of the coil every day because I could see it, you know in the shower it was there It was just a little lump sticking out (gesturing to stomach area)</p> | <p>Good because of health, bad because of what it represents? Kidney failure, body failing him. Increased mortality risk, decreased strength.</p> |
| <p>Incongruence – presentation and context Protecting others</p> | <p>k. what was that like, tell me about that</p> | <p>Jumped to the hospital, surely they knew before. Kept it light, incongruent again with seriousness of the situation. Is there an avenue of conversation in his household to say if they're not fine? Avoidant too</p> |
| <p>Self as seen by others</p> | <p>David. uh, at first I felt, I didn't, I didn't like it being there because you you feel different don't you, you you look different um so it wasn't uh (p) it wasn't something I wanted to be there but it didn't bother me too much (p) you know it was there for my own benefit wasn't it really so, it was it was a good thing it just didn't feel a good thing k. ok, so at the time it didn't David. Hm, yeah, well you mean being on dialysis is not in its self a good thing is it, but what it does for you is, the benefits obviously are good, so it wasn't ideal but in my situation it was a good thing if that make sense?</p> | <p>Did he not do that with his sons? Didn't want to see Dad weak? Frail? Does dad represent strength? Make or let her see, minimising. Did she fear Dad would die? Did he think she feared this?</p> |

Superordinate themes

| Superordinate themes | Sub-theme | Example quotes |
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| End of part of your life | <i>The beginning of the end:</i> | <p>Nia: Pg 5, Ln 4-6I I even had to stay in hospital on my own, I thought mum can you stay with me and she's like <i>no I have to go you're 18 now</i> and I thought <i>oh my gosh I'm still a baby you know</i></p> <p>David: Page3, Ln25-29 - uh on a personal basis it was (p) I'd had ten years to to, get used to the fact it was gonna happen but it was still (T) quite mind blowing really</p> <p>David: Page29, Ln26-29 you know <i>I could die here</i> you know this could be the beginning of the end for me and dat was probably the worst part of it um (p)</p> <p>John: Pg 2, Ln 18-24 (shift in seat) um (p) well it's bit disappointing really when you realise it it's, it's, it's a major thing because um it an end of part of your life</p> <p>Jane : Pg 21, Ln 26-30 it is just like a grief reaction and I think from the beginning it has been because my lifestyle changed, my life, my future, my you know hopes and dreams and that kind of thing was was in jeopardy really was you know was was having to change.</p> |
| | <i>The fragmented self</i> | <p>Jane: Pg 3, Ln 15-16 um..so..um you know it all just awful I just had to be become the patient then if you know if difficult as well really</p> <p>David: Page23, Ln6-14 - It's quite sad really, um I always felt when I was younger I was invincible but I've I suddenly felt very vulnerable (p) um even though I knew it was gonna happen at some point. As a child I remember um telling people I was gonna live forever you know I was healthy, strong, I really did, I was convinced I was would live forever um so being diagnosed and told back in 2004 this would happen one day it was kind of something I knew about but didn't expect it to ever happen really and now we'd gotten to the point where it was happening it was quite sad, looking back on it, its um (pp) yeah</p> <p>Nia: Pg 5, Ln 4-6I I even had to stay in hospital on my own, I thought mum can you stay with me and she's like <i>no I have to go you're 18 now</i> and I thought <i>oh my gosh I'm still a baby you know.</i></p> |

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| <i>I could die from this</i> | <p>Nia Pg 6, Ln 22-29 I didn't cry until I needed the biopsy so over the weekend the first weekend I was first admitted I was fine I was just thing ooh I was just car carrying on and then they told me I have to have a biopsy and I thought wow this sounds, this sounds odd and this sounds really scary you know and I felt oh what going to ha what's going to happen to me afterwards wo wo was I going to be okay was I going to be able to finish my degree and just thinking</p> <p>Jane: Pg 9, Ln 10-11. well I suppose you feel for your life don't you or something really (tearful) sorry oh dear sorry</p> <p>John: Pg 16. Ln 19-23. John. I don't think it is no, um, (pp) life in general is slowing down um it's probably an age related thing as well um (p) I don't think things will, have improved or will improve as regards my general health I can only hope really for, um a continued on an even keel basis type of thing I don't think there's ever there's gonna be any real improvement in anything.</p> <p>David: Page29, Ln12-16 - it's still a shock knowing you've suddenly, dramatically dropped your function and without medical intervention you will die without a doubt, it's only a matter of when, so then not understanding the medi, the medical treatment, how it works or what does for you and how long you can continue the treatment</p> |
| Control the direction, not the outcome | <p><i>(He said) it would be alright</i></p> <p>John: Pg2, Ln 24-26 I don't really think I was depressed all that much because uh Dr was so keen on getting his job done and uh it just reassured me it would all be alright and I should be back to normal</p> <p>David: Page25, Ln21-22 you know I was never, I was never meant to go on dialysis, why, why am I gonna go on dialysis</p> <p>Nia: Pg 2, Ln 9-11 he was saying you're in early, early stages of kidney failure you don't have to worry about it now so I thought oh that's a good sign and um he said oh you'll be able to back and study your degree and don't worry about it</p> <p>Nia: Pg 2, Ln 28-31 / Pg 3, Ln I came home on my last year in university and I came home to the clinic here in (hospital) and Dr just looked at me and said <i>some things gone horribly wrong as in your, your, your health had deteriorated so badly in the last two years we haven't seen this before</i> and I thought <i>oh my gosh</i> cause he told me at first that I would be about 30-35 maybe even older having a transplant you know we didn't even think about a transplant before</p> |

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| <i>There really wasn't any choice to be made</i> | <p>David: Ln1-4 - I have a conversation uh well several conversations with my partner um and we discussed it quite in length um but although we were discussing it there really wasn't any choice to be made, it was PD, it had to be PD and I wanted to do it at home</p> <p>Jane: Pg 3, Ln 34 / Pg 4, Ln 1.I had then decided that you know, he had, that peritoneal would be more suitable for me</p> <p>John: Pg.1, Ln 33-35 / Pg. 2, Ln 1-2. um and he he highly recommended that I had a catheter rather than go in for the um three times a week uh hospital treatment uh um so I said I'd go along with that</p> <p>Nia: Pg 27, Ln 22-24 I can't even remember but I don't think that I made a decision to go on PD I think it was a decision that Doctor and the nurses thought it would be um better for me so that wasn't a decision that I made I don't think</p> |
| <i>No control vs complete faith</i> | <p>David: Pg 28, Ln 1-5 it start, started to hit me, and it was quite mind numbing in a sense and each stage is a little bit more mind numbing if you like just a little bit more like that, it was something I had no real control over, I could control the direction we went, but I couldn't control the outcome if you like, it was dialysis and or transplant there was no other option.</p> <p>Nia: Pg 5, Ln 14-16 when I met him at first I thought <i>oh my gosh I've got actually a personal consultant</i> d'you know that was quite bizarre and he's quite good he's always texting me saying <i>how are you today or how's it been</i> and he's very oh he's been amazing through it</p> <p>Jane: Pg 7, Ln 33-34.Dr had you know was there welcoming me like an old friend really and um and I think that helped you know</p> <p>John: Pg 9. Ln 14-16.so it had all healed up it was all working normally um (p) that was it really I mean Dr () seems quite happy with the situation and (p) he was the one that counted I suppose (laugh; P).</p> |
| Protection of self <i>Carry on for as long as I can</i> | <p>Nia: so anyway I just kept on going went back to university carried on with my course then I was coming home every month to see um Dr here in the clinics</p> <p>John: Pg 8. Ln 21-24. John. In al almost unaware of it actually, um (p) it's I suppose there must have been some soreness to start with but I can't remember it but uh I after it had healed over an I got back into my usual routine I don't think it had any effect on me at all</p> <p>David: Page7, Ln26-29 - But I think the biggest thing also is my belief that (P) if you're not positive den it will beat you (p) an dat alone was would've been enough but any combination of dose really I had no choice I had to just take it head on, just carry on the way I am.</p> <p>Jane: Pg 20, Ln 19-24 it was a year wasn't it since the Tenkoff was put in so I did have that time to adjust really um but I think I chose to just get on with it not think about it um and so d'you know just acce um deal with the situation as it arose really like having the Tenkoff that was it that's it forget that now dudududu go onto</p> |

the next thing and then when I became uhm needing dialysis again right deal with that and then that's that you know.

Lifeline

Nia: Pg 26, Ln 6-11 yeah um no, no cause it because it was hiding under my skin it didn't even and I wasn't able to feel it I didn't even think about it you know as I've said until I've gone to the shower or until I speak about it with my friends but probably if it was sticking out of my tummy straight away I would it would be a different story you know I would know the that it was there and I was depending on it to help me, help my health in a way cause that's how I felt about it when I came out I just felt its *oh its gonna happen now*

Jane: Pg 4, Ln 24-33 I went on another year then before dialysis started so uh but it did make me feel a lot safer. So it me feel if I become unwell then I'm not gonna have a worry coz my dread you know (...) but um so to me that was uh a lifeline I suppose really because I knew if I became unwell the access that was there for dialysis (...) so yeah I made me feel a lot safer really and um yeah yeah it did

John: Pg 21. Ln 35-36 – Pg 22. Ln 1-3 yes I could see the uh well wisdom of it or the forethought of it um because it's there when its needed then rather to start rushing around and having it all done at one go um (p) as he said at the *time it's preparation ready for when you do need it, you will need it in the future* and he's right I did so yes it went alright that did.

David: Page 31, Ln 5-8 Um but it was a comfort it was definitely a comfort because I knew if I suddenly I use I used the word crash sometimes at home (p) or when talking to people um in my op, in my mind my kidneys could crash any time an just stop functioning.

Pursuit of normality

John: Pg 9. Ln 18-25. The six months after I'd had it done and then uh? (Me nod) Um from what I can remember it was perfectly normal I just did everything as I'd done before, um cut the grass, cut the hedges, take the dogs for a walk whatever, uh do the shopping it wasn't till after I'd had the external part fitted that I started to realise more that it was um it was there because you're more conscious of the (p) external part than you are the internal part (p, talking quieter) but it isn't a great inconvenience at all it's just there

Nia: Pg 16, Ln 20-23 from uh March till June uh odd cause there was nothing sticking out so to think that this thing was inside me for three months and me actually not thinking about it every day I didn't actually think about it every day to be honest with you 'cause I just felt normal I felt just like me

Jane: Pg 5, Ln 8-12 I just like I say felt that it was a good option and that it was something that would make me able to get on with my life for a little bit really as well because that's important to me is to be able to to not be (pp) overwh well entrenched in this illness kind of thing really I wanted to get on with my life as much as I could really

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| | | <p>David: Page11, Ln6-9 - I was also concerned about the impact it would have on them, and on my partner and on - on well on my on my way I of living my life I was confident and comm committed to living my life normally (p) but until I actually started dialysis I didn't know whether I would be able to (p) so</p> |
| | <p><i>It's there now, it's quite serious</i></p> | <p>David: Page30, Ln29-33 once we had it embedded dat was (p) a definite step into you know moving onto the next step if you like whereas up until the point where it's done it's all something you're planning but now it's done it's done isn't it you know its there now its um (cough) it quite serious (p) yeah</p> <p>John: Pg 9. Ln 11-3 no it was just matter of thinking how long it would be before I actually start dialysis now I mean I was prepared for it I knew I'd got to start sometime but uh I think it was about six months before I decided that uh I needed to start it (p)</p> <p>Jane: Pg 11, Ln 14-18. I just felt obviously a little bit more in control I think and it made me feel safe and um I knew that if I did become unwell all I had to do was pick up the phone and there was no going you know collapsing and A&E and blaa you know all that (p) uch really long lines and things you know I wanted it done as simply as possible really and that and that really provided me with that that that feeling of safeness</p> <p>Nia: Pg 3, Ln 1-2 um that was on a Friday night and then by Monday morning I was on the operating table having a PD catheter fitted</p> |
| <p>Moving onto the Next Step</p> | <p><i>A bit two sided really</i></p> | <p>John: Pg 17. Ln 3-11. John. uuh it was a long time ago, um, I can remember (mumble) we used to see have appointments to see him at hospital um (p) he was always very positive, uh very thorough, always gave me a good medical examination and you were always convinced what he was going to do was the right thing for me, and I must confess up to a certain extent it certainly has been um (p)</p> <p>Nia: Pg 15, Ln 7-10 was horrible at first but afterwards it was fine it was just horrible because I had to learn so many things about dialysis about my health and my d'you know these medical terms and get used with um swallowing some tables and I'm taking them at the right time so the first two months was just yeah horrible but then it was just fine it came naturally then and just carried on.</p> <p>David: Page21, Ln23-23 - I think I expected in the near future to feel worse but then suddenly feel better once I did start dialysis, I was dreading the thought of having to start because I didn't want to be tied down, um but I was excited about the prospect of feeling better</p> <p>Jane: Pg 3, Ln 33-34. I didn't like the thought of um dialysis I didn't really want dialysis but I knew I would have to</p> |

This is it

Nia: Pg 24, Ln 28-30 and I thought this was very draining and I felt oh I've got to do this every day, every single day, every single week, for the next year

David: Page 21, Ln 14-16 - I think it took probably a couple of weeks for it to even start but once it started it was kind of constant if you know what I mean, it didn't, didn't get better and better and better it just stayed kinda at the level it was

Jane: Pg 16, Ln 14-19. your life just changes completely doesn't it because it's restrictive uh well restrictive mostly It's not painful or anything but its time consuming it's restrictive uhm you know you've you've just got no life basically to do anything extraordinary anywhere else you know so for me that was the worst part of it really yeah yeah

Nia: Pg 24, Ln 28-30 and I thought this was very draining and I felt oh I've got to do this every day, every single day, every single week,

John: Pg 14. Ln 22-25. I would like to do more I would like to see more I'd like to get out more probably but um I'm tied down A. with doing dialysis and B. because uh I don't think I can cope with going too far doing too much at any one time, is it any help? (Looking right at me)

Ethical Submission