An investigation into body image disturbances in adult end-stage renal failure patients undergoing dialysis.

Thesis submitted for the degree of Doctor of Clinical Psychology at the University of Leicester.

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30<sup>th</sup> June 2008

### **Statement of originality**

I confirm that this is an original piece of work. The literature review and research report contained within this thesis have not been submitted for any other degree, or to any other institution.

## **Target Journals**

## Literature Review: Journal of Advanced Nursing

(See Appendix A for author guidelines).

### **Research Report: Kidney International**

(See Appendix D for author guidelines).

**N.B.** Following discussion with my research supervisor, it was considered most appropriate to follow BPS referencing standards rather than those specified in the guidelines to authors listed above.

### **Summary**

### Literature review

Increased use of medical-technology has led to the creation of a group of individuals who are dependent on, but not cured by technology and who report high levels of iatrogenic side-effects, morbidity and mortality. The experiences of such individuals were explored using a transparent and systematic literature search. Studies were appraised for quality and narrative synthesis used to describe common themes identified by thematic analysis. Themes identified were: coming to terms with the need for medical-technology, issues of power and control, reactions to medicaltechnology, accepting the impacts of medical-technology and continuing to live with technology. Denial and ambivalence prevailed across all themes and individuals struggled to express the conflicting feelings they experienced. The clinical implications of the findings are discussed and possible areas for research identified.

## **Research Report**

Individuals with end-stage renal failure rely on dialysis to replicate the function of the kidneys to stay alive. Dialysis-users report high levels of psychological morbidity, significant detrimental impacts in all areas of life and there is evidence to suggest they experience body-image changes. Psychological morbidity is associated with poorer quality of life and increased mortality and body-image changes are associated with elevated psychological morbidity in other chronically-ill populations. The Selfregulatory Executive Function (S-REF) model offers an explanation for these findings with specific reference to cognitive-schemas and self-focus. Mixed methodology was used to identify the prevalence of body-image disturbance in 97 adult haemodialysis and peritoneal dialysis patients and investigate any association between body-image and psychological morbidity. Aspects of appearance-schemas and self-consciousness were also investigated with regard possible influence on both psychological morbidity and body-image disturbance. Participants described wide-ranging impacts of dialysisrelated body changes and high levels of psychological morbidity and body-image disturbance were reported which were significantly associated. Facets of appearanceschematisation and self-focus were significantly associated with psychological morbidity and body-image disturbance. Implications for clinical practice are discussed and future areas for research identified.

## **Critical Appraisal**

Reflections are made on the research process with particular consideration of the impact of participant narratives on the Researcher and of the Researcher's impact on the project. Barriers and facilitating factors are discussed and learning outcomes described.

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## Word count

Section 1. Literature Review	7988 (References 898)
Section 2. Research Report	11942 (References 2038)
Section 3. Critical Appraisal	2707
<b>TOTAL</b> (excluding references and appendices)	24357 words

(with references and appendices)	31093 words

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Section 1

Literature Review

The psychological impact of life-maintaining medical-technology on adult

patients – a narrative synthesis of qualitative research.

#### Abstract

Background: In recent years increased use of medical-technology has led to the creation of a novel group of individuals who are dependent on, but not cured by such technologies and who report high levels of iatrogenic side-effects, morbidity and mortality. Whilst health professionals and families of patients report negative reactions to medical-technology, studies with patients are largely neglected.

Aims: The current literature review aimed to explore the experiences of patients using life-sustaining medical technologies.

Method: A transparent, systematic approach to literature searching and analysis was used. Studies were appraised for quality and thematic analysis deployed to identify common themes.

Results: Although some participants reported improvements in health and quality of life, significant negative impacts were also reported. The following themes were commonly described: coming to terms with the need for medical-technology, issues of power and control, reactions to medical-technology, accepting the impacts of medical-technology and continuing to live with technology. Denial and ambivalence prevailed across all other themes and individuals struggled to express the conflicting feelings they experienced.

Conclusions: Health professionals may be able to support individuals using medicaltechnology by acknowledging the psychosocial impacts, offering appropriate information and promoting person-centred care which focuses attention on the individual rather than technology.

#### 1. Introduction

'Health technology' describes a range of methods used to promote health, prevent and treat disease and improve rehabilitation and long term care and includes drugs, devices, procedures, settings of care and screening (HTA, 2008). This review concerns two types of medical *devices*; *prosthetic* which simulate body functions or replace organs, for example renal dialysis and mechanical ventilation and *therapeutic* which interrupt, stimulate, alter, and/or regulate body processes, for example insulin injections and implantable cardioverter defibrillators (Sandelowski, 1993). Whilst medical-technology can prolong life, it has also been found to be associated with morbidity, iatrogenic side-effects and mortality (Sandelowski, 1993). The use of medical-technology has created new chronic illnesses, most notably end stage renal failure (ESRF) (Keller, 1992; Plough, 1981). Once a stage patients passed through before dying, people with ESRF can now live for decades using dialysis. This dependence on, rather than cure by, medical-technology is an interesting and relatively new phenomenon that will comprise the focus of this review.

Studies suggest that people commonly anthropomorphise technological objects they use by talking to, touching and ascribing them with purposive decisions and attitudes (Epley et al., 2007; Luczak et al., 2003). Anthropomorphism is thought to reduce uncertainty and increase effective interaction with technology and is observed more in individuals who are socially isolated, desire more control or are likely to repeatedly interact with the technology in the future.

Physically disabled individuals report that using assistive technology can increase autonomy, independence, communication, mobility and socialisation, yet respondents

felt that the same technologies marked them out as different and created barriers to their self-presentation (Lupton & Seymour, 2000). Particularly concerning were others' negative assumptions about them on seeing the technology and their interactions with the technology rather than the individual.

In health-care settings, large amounts of medical-technology are often equated with high-quality care (Stroud, 1997). Such environments have also been described as controlling, dehumanising and dignity-destroying to patients, resulting in health professionals focusing on the technology rather than the patients (Wikstrom, et al., 2007; Walters, 1995; Wichowski, 1994; Keller, 1992) Staff working in intensive care units (ICUs) report ambivalence towards technology, recognising the facilitated health benefits whilst being distrustful of it (Wikstrom et al., 2007; Wichowski, 1994).

Families of ICU patients initially respond to technology with fear, ambivalence and curiosity, describing technology as inhuman, controlling and potentially dangerous (Stroud, 1997; McConnell & Murphy, 1990). Families assess the severity of an individual's illness by the number of machines involved in their care and over time the machines become synonymous with the person's illness eliciting negative attitudes and emotions towards them (Stroud, 1997).

The incidence of PTSD in patients leaving ICUs is thought to be high and these individuals report that the wires and machines of the ICU compromised their bodyboundary and distorted their body-image and self-concept (Bennun, 2003; Mello & Batista, 2001). Individuals using home-care technology report low self-esteem stemming from using the technology (Arras & Dubler, 1994) and implantable

cardioverter-defibrillator (ICD) patients report high levels of psychological distress, negative body-image and reduced quality of life subsequent to implantation (Ladwig et al., 2005; Duru et al., 2001; Herrmann et al., 1997).

A number of theories have been advanced related to this field of enquiry. *Embodiment* theory argues that one's view of the body is important when threatened by illness. Whilst the *ideal body* is healthy, allowing independence and control over physiological functioning, a dysfunctional body implicates a deficiency in the person and must be separated from the self in order to protect one's identity (Gallagher & MacLachlan, 2001; Krakauer, 1998). Theories of chronic illness suggest that whilst physical discomfort may be a natural primary focus for health practitioners, illness destroys an individual's self-image and they must develop compensatory valued self-images to avoid losing self-esteem and hope (Charmaz, 1983). The Components of User Experience (CUE) model of human-technological interaction suggests that a user's knowledge and skills of an object combine with its functionality and design to create a representation of technology-use (Thuring & Mahilke, 2008). At the same time, an emotional reaction is formed from the aesthetic, ease of use and efficacy. The two aspects combine into an overall appraisal of the technology which influences whether an individual continues to use it.

To date, responses of health professionals and patients' families to medicaltechnology have been explored, yet recipients far less so. Previous studies have found that staff and families fear and mistrust technology and that machine-dependency is associated with difficulties in body-image and self-representation. This review seeks to examine the experiences of patients using medical-technology. As the field of

medical-technology is wide, the scope of this review was narrowed to the following life-sustaining medical-technology; artificial pacemakers, ICDs, dialysis, insulin pumps and mechanical ventilation (see Appendix B for descriptions).

### 2. Aims

This review aims to systematically review studies investigating the use of lifesustaining medical-technology to:

- Provide an overview of the research quality
- Synthesise research findings of the psychological impacts on individuals
- Discuss the relevance and impact of findings on clinical care
- Consider further research needs in this area

### 3 Methodology

#### 3.1 Selection of Studies for Inclusion

Using the MeSH keywords 'psychosocial' and 'technology' the following databases were searched in October 2007 and March 2008; MEDLINE, EMBASE, PsycINFO, ISI Web of Science, AMED, World Cat Dissertations, National Library for Health, Kings Fund, CINAHL(R), The Cochrane Library and the Healthcare Commission (Appendix C details timeframes of databases). As the topic was inadequately covered by the available MeSH terms, additional terms relating to specific illnesses and medical treatments were also used to ensure comprehensive initial paper retrieval (kidney/renal failure, cancer, diabetes, heart failure, dialysis, pacemaker, radiotherapy, insulin pump, ventilator and life support). Only English language documents were retrieved. Key and current researchers (from the National Research Register) were contacted for information and unpublished materials, Grey literature and conference proceedings were explored using Open SIGLE.

#### 3.2 Search Selection

The initial search yielded 2078 papers of which 342 were duplicates. The remaining 1736 abstracts were examined using the following inclusion criteria:

- Population Studies with adults (over 18 years) who were using medicaltechnology without which they would die or which prevented life-threatening events. Technology was excluded if designed to be curative e.g. chemotherapy.
- Aims Studies addressing the psychosocial impacts or experiences of using medical-technology.

#### 3.3 Paper Retrieval

77 potentially relevant abstracts were identified and full papers retrieved. These were assessed against the inclusion criteria and the following excluded: 14 studies addressing medical-technology ethics; one studying non-medical-technology; seven concerning medical-technology not addressed in this review; twelve studies failing to consider psychosocial factors and 34 studies not addressing the specific impact of medical-technology on participants. The Social Science Citation Index was searched for papers referencing the nine studies and the papers' reference lists were examined for further relevant studies. This yielded two additional papers resulting in eleven papers appropriate for the review. Of these ten used qualitative and one quantitative methodologies. The sole quantitative study identified was excluded as whilst it compared two types of medical-technology, the study did not provide sufficient

information regarding participants' experiences and the psychosocial impacts (Duru et al., 2001). The review subsequently focussed solely on qualitative studies.

#### 3.4 <u>Review Methodology</u>

The emphasis on evidence-based practice in health and clinical practice in recent years has relied heavily on the use of systematic reviews, almost exclusively examining quantitative research. However, there has been increasing recognition that data from qualitative studies offers additional important information. A range of methods for reviewing or synthesising such evidence has been identified but not yet as extensively applied. Reviews of qualitative research have been criticised for lacking rigour, transparency and replicability and being prone to bias (Higgins & Green, 2005), however weighty recommendations for disciplined, systematic approaches have been advanced (Bradbury-Jones, 2007; Dixon-Woods et al., 2006; Popay et al., 2006).

As the current review addresses a research question incorporating a wide range of clinical populations, a narrative synthesis using a systematic approach to data searching and analysis was used. Narrative synthesis is an "approach to that part of a systematic review process concerned with combining findings of multiple studies" (Popay et al., 2006, p. 5) which presents evidence in the form of a story. In order to increase rigour and replicability, detailed explanations of methodology, analysis and reflection have been included (Bradbury-Jones, 2007; Dixon-Woods et al., 2006; Popay et al., 2006).

#### 3.5 Quality Issues

Quality appraisal is arguably an integral part of narrative synthesis (Popay et al., 2006) and was considered important in the current review to contextualise findings. Studies were quality-critiqued using standards described by Meyrick (2006) addressing methodology, epistemological and theoretical position, reflexivity and transferability (shown in Table 1).

#### 3.6 Data Extraction and Synthesis

For each paper a brief summary was written comprising methodological information, findings and clinical implications or recommendations (shown in Table 2). Thematic analysis was used to 'translate data', an important process to assimilate information from different studies that have existing identified themes and concepts as "apparently similar concepts in different studies may actually be referring to different phenomena" (Popay et al., 2006, pp77). Themes were checked for consistency by NR (supervisor) before being collated and organised into higher-order themes.

This review used an inductive approach to provide a descriptive account of the experience of living with medical-technology rather than attempting to prove a particular theoretical model (Dixon-Woods et al., 2006; Popay et al., 2006).

#### 4 Findings

#### 4.1 Overview of Studies

Three studies related to cardiac technology (pacemakers or ICDs), five to haemodialysis, one to implantable insulin pumps and one studied various technologies comprising ventilators, oxygen pumps, intravenous antibiotics and parenteral

nutrition. One study comprised only female participants, two all male participants, whilst all other populations were mixed.

#### 4.2 Quality Issues

The methodological critical appraisal is summarised in Table 1 and detailed below.

#### 4.2.1 Sampling and Recruitment

Two studies selected their samples from specific populations; male veterans or female pacemaker recipients (Anderson, 2004; Beery et al., 2002). Many used purposive sampling which can be problematic because the resulting sample is unlikely to be representative of the relevant population (Giles, 2005; Lehoux et al., 2004; Beery et al., 2002; Rittman et al., 1993). Furthermore, selecting participants perceived as especially forthcoming or to recommend others to participate may skew the data towards extreme or homogenous viewpoints (Beery et al., 2002; Curtin et al., 2002; Nagle, 1998). Three studies failed to detail how participant recruitment occurred (Anderson, 2004; Lehoux et al., 2004; Burke, 1996) and only four specifically described inclusion and exclusion criteria making study replication difficult (Ritholz et al., 2007; Anderson, 2004; Beery et al., 2002; Gregory et al., 1998).

#### 4.3 Data Collection

Six studies used semi-structured interviews (Giles, 2005; Beery et al., 2002; Curtin et al., 2002; Gregory et al., 1998; Burke, 1996; Rittman et al., 1993) and three carried out unstructured interviews (Anderson, 2004; Lehoux et al., 2004; Nagle, 1998). Most interview studies involved only one interview with participants, however some conducted second and successive interviews either to gain information at different

time points (Giles, 2005; Burke, 1996) or validation of interpretations by respondents (Beery et al., 2002; Curtin et al., 2002; Gregory et al., 1998; Nagle, 1998; Burke, 1996).

#### 4.3.1 Data Analysis

The following types of analysis were used; content (Ritholz et al., 2007; Curtin et al., 2002), content and thematic (Anderson, 2004), constant comparative (Lehoux et al., 2004; Gregory et al., 1998; Burke, 1996), hermeneutic (Nagle, 1998; Rittman et al., 1993) and interpretive phenomenological (Giles, 2005) with all aiming to identify common themes between participants. Beery (2002) failed to describe or reference the type of analysis used.

Attempts were made by several authors to increase the validity of the analysis by using several or independent coders or consultants (Ritholz et al., 2007; Beery et al., 2002; Gregory et al., 1998; Rittman et al., 1993) or by confirming interpretations with participants or other technology-users not involved in the study (Beery et al., 2002; Curtin et al., 2002; Gregory et al., 1998; Nagle, 1998; Burke, 1996; Rittman et al., 1993).

#### 4.3.2 <u>Transparency</u>

Papers reviewed often lacked methodological transparency, calling into question replicability and systematicity and the extent to which reported findings represented data collected.

#### 4.3.3 Epistemological and Theoretical Standpoints and Reflexivity

Seven authors described their epistemological standpoint (Giles, 2005; Anderson, 2004; Beery et al., 2002; Gregory et al., 1998; Burke, 1996; Rittman et al., 1993) however, how this influenced the focus and methodology of the research was rarely described explicitly. However, three authors reflected on how their position as a researcher or the research process may have affected the study focus and findings (Giles, 2005; Lehoux et al., 2004; Gregory et al., 1998).

Most studies conducted exploratory research with no predetermined theoretical stance with only embodiment and chronic illness (Curtin et al., 2002) and the sociology of technology and illness (Lehoux, 2004) investigated. Gregory (1998) aimed to develop a model from the findings.

### 4.3.4 <u>Ethical Issues</u>

Anderson (2004) alone considered ethical issues; ensuring participants were informed of their rights regarding the research process and confidentiality of findings. Other issues it may have been important to consider were the researchers' position of power and the possible impacts of research on participants who are ill.

### 4.3.5 <u>Transferability</u>

Of the minority of studies that explored issues of transferability, some were limited by their sample whilst others suggested findings would be relevant to other patient groups (Giles, 2005; Ritholtz et al., 2001; Burke, 1996; Rittman et al., 1993). However, the review identified some commonality of themes across the samples.

# Table 1. Summary grid of papers reviewed: Process issues

# Key

		Sample		Ouali	tv Issues		Transferabi	lity	
		R = Recruit n	nent issues	$\widetilde{C} = C$	Credibility ignored		I = Transfe	rability igr	iored
		not identified	d	T = T	ransparency lacking	in presentation	of	5 0	
		E = Ethnicit	у	analys	sis		Č .		
		unreported		U = E	Ethical issues not add	ressed			
Author, year, country and technology studied	Sample	Method of data collection	Method of analys	f data is	Coherent epistemological position	Theoretical perspective	Reflexivity (re: self as a researcher and research as a process)	Quality Issues	Transferability
Anderson (2004) (Australia) Pacemakers	n=8 (8M) War veterans. Purposive sampling from veteran unit E, R	Unstructured individual interviews	Thematic ar content anal as specified Interactive Interactionia	nd lysis by sm	Interpretive Interactionism	None given	Neither	С	Ι
Beery et al. (2002) (N. America) Pacemakers	n=11 (11F) Purposive sampling Participants enrolled until	3 semi- structured interviews; 1 primary interview, 1	Unspecified coding usin NUD*IST. Participant verification	l g to	Hall's 'Focused life stories'	None given	Neither	U	Ι

	theoretical saturation achieved	clarification interview, 1 to feedback interpretation and elicit participants feedback	support data dependability					
Burke (1996) (N. America) Implantable cardioverter defibrillators	n=24 (14M 10F) Sample from all patients admitted to 2 medical centres R	4 Interviews using interview guide; 1-8 days, 10-15 weeks, 6-7 months after implantation. 4th interview with 3 participants to confirm interpretations	Constant comparative analysis Nurse-researchers reviewed coding and challenged interpretations	Grounded theory	None given	Neither	U	Possible relevance to other technology users
Curtin et al. (2002) (Location unclear) Haemodialysis	n=18 (10M 8F) 'Information- rich' long- term dialysis-users	Semi- structured interviews	Content analysis. Codes verified by independent researcher. Theme verification with 3 study participants and 4 non-study	None given	Embodiment Chronic illness model	Neither	U	Ι

	selected who suggested other participants		haemodialysers.					
Giles (2005) (Canada) Home Haemodialysis	n=3 (3M) Purposive sampling	Two semi- structured interviews over 1-2 weeks. Qualitative exploratory descriptive design.	Interpretive phenomenological analysis.	Qualitative phenomenological framework Participants clarified interpretation.	None given	Researcher may have influenced interpretations	U	Study scope limits transferability
Gregory et al. (1998) (N. America) Haemodialysis	n=36 (18M 18F) From dialysis unit	1 semi- structured interview, 2 <sup>nd</sup> interview at 6-8 weeks to confirm interpretive summaries	Constant comparative method. Transcription accuracy and classification system examined by independent consultants	Grounded theory	None given	Impact of interviewer's presence and style on responses.	U	I
Lehoux et al. (2004) (Canada)	n=16 patients, 6 caregivers, 16 home-	Open-ended biographical interviews, direct	Constant comparative analysis using NUD*IST	None given	Sociology of technology Sociology of	Researcher's possible bias in research focus.	T, U	Ι

Mechanical ventilation, portable oxygen tanks, parenteral nutrition, intravenous antibiotic therapy	care nurses Purposive sampling from primary care organisations R	observation			illness			
Nagle (1998) (Canada) Haemodialysis	n=11 (6M 5F) Purposive sampling from out- patients.	Open-ended interviews	Hermeneutic interpretive analysis. Participant validation of themes.	Gadamer's philosophical hermeneutics	None given	Neither	C, U	Ι
Ritholz et al. (2007) (N. America) Implanted insulin pumps	n=30 Type-I diabetics. Purposive sampling from diabetes unit	5 focus groups split by individuals' level of blood glucose control. Questions derived from researchers' clinical experiences.	Content analysis using NVivo2. Coded independently to achieve triangulation	None given	None given	Neither	U	Transferable to similar populations but not to different ethnic and socioeconomic groups.

Rittman et al.	n=6 (5M 1F)	Semi-	Hermeneutical	Heideggerian	None given	Neither	U	Transferability
(1993)	Purposive	structured	analysis	phenomenology	_			limited as
(N. America)	sampling	interviews	interpreted by 5					sample not
			researchers.					demographically
Haemodialysis			Validated by					representative of
			participants.					wider illness
								population

Author	Stated aim	Themes	Outcomes
Anderson (2004)	War veterans experience of their bodies in relation to invasive cardiac technology	<ul> <li>Ambivalence, powerlessness, suffering and inner conflict across themes of the body interacting with:</li> <li>1. Emotional knowing – physical abilities limited, face mortality</li> <li>2. Belief of biotech as a miracle – technology postpones health decline</li> <li>3. Medical encounter - powerlessness</li> <li>4. Technological constraints – realise technology may fail</li> <li>5. Altered heart – increased awareness of body</li> </ul>	<ol> <li>Nurses not an extension of technology but a source of education and counselling and should focus on humanistic not technological aspects.</li> <li>Tailoring technology to the individual.</li> </ol>
Beery et al. (2002)	Exploring women's experiences of living with permanent cardiac pacemakers	<ol> <li>Relinquishing care – losing control over one's care</li> <li>Owning the device – describing the device</li> <li>Experiencing fears – worries pacemaker will fail</li> <li>Imaging the body – seeing one's body differently</li> <li>Normalising – attempts to be seen as normal, adjusting to changed life</li> <li>Positioning as caregivers – responsibilities limited time available to worry</li> <li>Finding innate resilience – coping with setbacks</li> <li>Sensing omnipotence – pacemaker providing sense of personal power</li> <li>Cross-thematic aspect of internal contradictions in accepting/rejecting pacemaker</li> </ol>	<ol> <li>Enabling women to familiarise themselves with technology to reduce distress of initial exposure</li> <li>Promote control by offering realistic options for healthcare.</li> <li>Facilitate support from other women with pacemakers.</li> <li>Psychosocial interventions available for adjustment problems.</li> </ol>

# Table 2. Summary grid of papers reviewed: Content issues

Burke (1996)	Exploring the experience of living with an ICD during 6 months post- implantation.	<ol> <li>Choosing life with technology – ensure survival, recognise vulnerability, plan resources</li> <li>Integrating technology into life – negative and positive aspects and feelings</li> <li>Living life through technology – accept the need for ICD, focus away from ICD, accept as normal life</li> </ol>	<ol> <li>Three new aspects of chronic illness identified – the use and change of support networks, uncertainty becoming normal, long-term focus is resumption of normal life not problem management.</li> <li>Introduce individualised assessment and counselling, adequate information to prepare patients and families for emergencies and health professionals available in crises</li> </ol>
Curtin et al. (2002)	Exploring the processes involved in living long-term on dialysis.	<ol> <li>Transformation: comprehensive, active self- management</li> <li>Adapting to changed self: self-affirmations         <ul> <li>a) Self-preservation</li> <li>b) Self-identification</li> <li>c) Self-worth</li> <li>d) Self-efficacy</li> </ul> </li> <li>Adapting to changed circumstances: coming to terms with permanent kidney failure         <ul> <li>a) Risk of death/uncertainties</li> <li>b) Life constraints</li> <li>c) Dialysis itself</li> <li>d) Repeated setbacks</li> </ul> </li> </ol>	<ol> <li>Transformation phenomena of adapting/adjusting to kidney failure.</li> <li>Process of acceptance of change is not passive and requires many activities.</li> <li>Possible identification of predictors for successful transformation</li> </ol>
Giles (2005)	To understand the lived-body in relation to haemodialysis.	<ul> <li>Three cases described separately:</li> <li>1. I don't worship the machine</li> <li>2. Hooked up – a solitary act of attaching to machine</li> <li>3. Getting close to the machine</li> <li>Overarching central theme of individual's struggles</li> </ul>	<ol> <li>Paradox of lived-body and dialysis machine.</li> <li>Emotional support to acknowledge machine's dehumanising tendencies.</li> <li>Individual social assessment to address who will work with machine at home.</li> <li>Empower to recover sense of independence.</li> </ol>

		between the body and the machine	
Gregory et al. (1998)	To explore patients' experiences of ESRD and haemodialysis.	<ol> <li>Redefining the self         <ol> <li>Health</li> <li>Adapting to new normal</li> <li>Quality of supports                 <ol> <li>Informal support roles</li> <li>Nursing care effectiveness</li> <li>Medical care effectiveness</li> <li>Meanings of illness and treatment                     <ol></ol></li></ol></li></ol></li></ol>	<ol> <li>Battle between illness uncertainty and effects of treatment whilst hope for improved health and return to normal life</li> <li>Quality of support is redefined following illness and treatment</li> <li>Critical events impact on the meanings of illness and treatment</li> </ol>
Lehoux et al. (2004)	Why and how people use health technology at home and in society.	<ul> <li>Similarities and differences considered in the following features:</li> <li>1. Ability to use technology</li> <li>2. Skills and knowledge</li> <li>3. Safety measures</li> <li>4. Perceived autonomy</li> <li>5. Nature of responsibilities</li> <li>6. Fit with home environment</li> <li>7. Maintenance of professional and social life</li> <li>Technology forced people to become more knowledgeable about illness - seen as beneficial.</li> <li>Technology provided spatially-defined autonomy which was partially dependent upon others' participation.</li> </ul>	<ol> <li>People are ambivalent about benefits and drawbacks of technology. This was shaped by where technology used.</li> <li>There is a contrast between idealised technology use shown in manuals and actual use</li> <li>People are either passive recipients or active-users of technology</li> <li>Professionals should provide thorough information on alternative options so patients make informed choices about technology-use.</li> </ol>

Nagle (1998)	To understand the meaning of the healthcare experience in chronic renal failure	<ol> <li>Coming to terms with loss and limitations</li> <li>Realising the realities of lost renal function</li> <li>Resigning to a different life</li> <li>Abiding with technology</li> <li>Being transformed by the need for dialysis</li> <li>Watching one's body deteriorate</li> <li>Vigilance about oneself and one's care</li> <li>Surviving amid uncertainty</li> <li>Enduring the treatment environment</li> <li>Wanting to have a say</li> <li>Being part of a community</li> </ol>	<ol> <li>Continuing struggle against objectification in the context of illness care - dialysis sustains life but fractures wholeness.</li> <li>Patients' views should be incorporated into the technological environment</li> <li>Dialysis environment should facilitate patient socialisation</li> <li>Nurses must seek to understand meaning of technology and maintain humanism</li> </ol>
Ritholz et al. (2007)	To identify psychosocial issues related to diabetes and self- care in type 1 diabetics using insulin pumps	<ol> <li>Passive-recipient or active engagement</li> <li>Emotional reactions to the insulin pump - allowing freedom or frightening and problematic</li> <li>Body-image and social acceptance</li> </ol>	<ol> <li>Different experiences of those with higher and lower blood glucose control.</li> <li>Active-users view pump as a tool and have good glucose control. Passive recipients were initially unrealistic and have poorer glucose control</li> <li>Before technology-use address any misconceptions or concerns, give realistic information on instructions, the limits of treatment and their required interaction.</li> </ol>
Rittman et al. (1993)	Exploration of lived experiences of patients with chronic renal failure.	<ol> <li>Taking on a new understanding of being</li> <li>Maintaining hope</li> <li>Dwelling in dialysis</li> <li>Constitutive pattern of control</li> </ol>	Nurses must use caring relationships to counterbalance problems with technology, maintain human connection and focus on lived experiences not technology.

## **Themes**

A number of themes were identified using thematic analysis which clustered into four higher-order themes (shown in Figure 1). These are described below and illustrated using participants' quotes where possible.





## DENIAL AND AMBIVALENCE

### A. Accepting the need for medical-technology

Participants discussed experiences culminating in recognising and coming to terms

with their need for life-maintaining medical-technology.

#### A.1. Becoming ill

Respondents described realising that their body was no longer functioning as previously, with associated limitations on their capabilities and activities (Gregory et al., 1998). The trajectory of this differed with varying health problems, some acute and some longer-term onset (Nagle, 1998).

The diagnosis was very quick. It was just like being hit in the face with a wet sponge. That was a bit of a shock. (Anderson, 2004, p.256)

Some participants had been warned that without certain health-behaviour changes they would require technical intervention, expressing regret if they had been unable to make such changes.

*I would have done some things differently that I'm paying the price for now* (Curtin et al., 2002, p.619).

#### A.2. Facing mortality

As individuals recognised the deterioration in physical health, they began to face their mortality.

I am close to death. I just take the wrong step one way or the other off that line and I could be going the wrong direction (Curtin et al., 2002,

p.618).

This was often dependent on the onset of the individual's condition, such that cardiac participants felt close to death having had a cardiac event, whilst renal patients generally experienced a slower process. Participants awaiting availability of technology experienced a period of time of increasing insecurity and vulnerability, especially if symptoms increased (Gregory et al., 1998; Burke, 1996). Once they had considered their mortality, some individuals no longer thought about it.

Having.....met that enemy, to have thought about it ...and then it's done .....now you don't have to deal with it. (Curtin et al., 2002, p.618).

#### A.3. Making the decision to live

After facing imminent death, participants became aware that their lifestyle must change if they were to live (Anderson, 2004; Curtin et al., 2002; Gregory et al., 1998). Whilst a tenuous hold on life made people anxious it also appeared to initiate a decision either to accept death or to make the necessary changes. Descriptions of the decision-making process were varied: some reflected on their life and likely future with or without technology (Anderson, 2004; Burke, 1996), some refused to let the illness beat them (Lehoux et al., 2004; Curtin et al., 2002), some were scared of dying (Anderson, 2004; Gregory et al., 1998) and others made a list of reasons to live (Anderson, 2004; Curtin et al., 2002; Burke, 1996; Rittman et al., 1993).

#### B. Barriers to accepting technology

#### B.1. Power and control

Participants' experiences of power and control were extremely significant in accepting and coping with their need for technology as they often felt disempowered, using a number of ways to try and regain control.

Control? Well, it's too late for that now. (Anderson, 2004, p.257).

### B.1.1. Loss of control to the illness

Initially people felt their health problem had robbed them of power over their bodies leaving them with unreliable bodies (Nagle, 1998; Burke, 1996).
#### B.1.2. Loss of control to health professionals

Participants often described being forced to relinquish power and decisions about medical treatment to medical professionals (Anderson, 2004; Nagle, 1998).

As a patient..... you have no rights or say so, you just pretty well put yourself in their hands (Beery et al., 2002, p.14)

This disempowerment was augmented by participants' lack of knowledge, having their knowledge overlooked or experiences of professionals withholding information (Curtin et al., 2002; Gregory et al., 1998; Nagle, 1998). Participants who physically interacted with the technology, for example dialysis-users, stated that health professionals expected them to be passive and allow staff to control such interactions (Giles, 2005). As individuals became experienced using the technology, or for those with their own equipment at home encountering this attitude in hospital, this was especially difficult and frustrating (Lehoux et al., 2004).

Whilst most people disliked lacking control, others felt more comfortable and actively discouraged professionals from giving them information or involving them in decision-making (Lehoux et al., 2004).

# B.1.3. Loss of control to the technology

Most participants described that technology had power over them as using it determined their movements (needing to maintain proximity to the technology), the timing and type of their activities and resulted in side-effects (Ritholz et al., 2007; Lehoux et al., 2004).

You don't control it. You can't control it, it controls you (Anderson, 2004, p.258)

Some participants described the technology as omnipotent.

*I've heard of pacemakers that could .....just kill you all at once* (Beery et al., 2002, p.18).

Some individuals were unaware of the influence of their behaviour on the technology efficacy, for example, insulin pump users ignorant of dietary monitoring felt disempowered and suffered deleterious health impacts (Ritholz et al., 2007; Lehoux et al., 2004).

# B.1.4. <u>Regaining control</u>

Most people described that regaining even small amounts of control was very important. Information was often seen as key with participants informing themselves about their condition and the technology to facilitate decisions about health and treatment and monitor the activity and effects of the technology (Ritholz et al., 2007; Curtin et al., 2002; Gregory et al., 1998; Nagle, 1998).

Control was also articulated by territoriality over the area of technology-use, for example by insisting on the same dialysis bed every session (Ritholz et al., 2007; Nagle, 1998).

At times participants offered staff advice about their normal reaction to treatment, or did small tasks related to the technology, although staff did not always react positively to this (Giles, 2005). Some negotiated compromises with staff, for example, a woman who needed a replacement ICD asked that the ICD charge be lowered to postpone the operation until she could attend an important family function (Giles, 2005; Beery et al., 2002). Alternatively, others exerted control by avoiding information and insisting that professionals take responsibility for all technology-related activities (Lehoux et al., 2004).

#### B.2. Reacting to medical-technology

#### B.2.1. Emotional reactions

Emotional reactions to technology were uniformly negative with few exceptions. Some participants articulated relief and gratitude for a maintained life or resumption of activities (Ritholz et al., 2007; Nagle, 1998), however more typically technology engendered feelings of intimidation, sadness, anxiety and fear (Ritholz et al., 2007; Giles, 2005; Lehoux et al., 2004; Gregory et al., 1998; Nagle, 1998; Burke, 1996). Negative feelings did not diminish with familiarity; rather they evolved into frustration, irritation, degradation and humiliation (Anderson, 2004; Lehoux et al., 2004; Nagle, 1998). Some participants talked of being tired of the technology but that they must continue with the "necessary evil" (Ritholz et al., 2007).

It's just something I live with every day. I'm never going to get rid of it. It's always going to be there. (Beery et al., 2002, p.16).

#### B.2.2. <u>Reactions to a machine</u>

Participants described initial concerns over the appearance of medical-technology and their constructions of technology as mechanical created barriers to acceptance (Nagle, 1998).

*I was wondering if they were going to ship me out to outer space* (Gregory et al., 1998, p.775).

It's just like a pile driver (Anderson, 2004 257)

The sense of the 'alien', to have a machine inside one's body was difficult to overcome and technology worn on the outside of the body was also problematic (Ritholz et al., 2007).

I fought it off for a long time. The thought of having some kind of mechanical thing in my body turned me off (Beery et al., 2002, p.16). At times, technology interacted with other devices and reminded individuals of the machinery inside them, for example, an ICD discharges when close to an electric microphone (Anderson, 2004). Some respondents were able to accept this as intrinsic to the technology.

You're going to have setbacks in this thing. The thing is.... getting on your feet and keep going (Curtin et al., 2002, p.622)

However, the mechanical nature of technology also encouraged the hope that new and better (and perhaps even curative) technology might be developed in the future (Anderson, 2004; Beery et al., 2002).

# B.2.3. Technology as fallible

Many respondents considered that medical-technology would ultimately wear out or fail them because it was a machine (Anderson, 2004; Beery et al., 2002) and cardiactechnology users lived with a high likelihood of the device misfiring thereby reinforcing these concerns (Burke, 1996). By using mechanical language, individuals were able to describe the unthinkable possibility of technology failure or malfunction without relating this to themselves or the likely fatal result (Anderson, 2004).

*I guess, sometimes like cars, they get called back in* (Beery et al., 2002, p.19)

Interestingly, the actual occurrence of technological problems in ICD participants did not increase their mistrust of the technology over time but decreased their uncertainty (Beery et al., 2002).

# B.2.4. Technology as a miracle

Some individuals framed the technology as miraculous, considering it to have miracle properties bestowing them with special protection to do tasks they couldn't do before (including behaviours which risked their health) (Anderson, 2004; Lehoux et al., 2004; Beery et al., 2002).

(it's a) *miracle* ... you can do anything you want now (Ritholz et al., 2007, p.550)

# B.3. Accepting the impacts of technology

B.3.1. Treatment effects and medical regimen

As well as their illness an individual's treatment often had detrimental health impacts (Gregory et al., 1998; Nagle, 1998; Burke, 1996).

The things that go along with (the treatment).... makes it really bad

(Curtin et al., 2002, p.622).

Where individuals felt that the technology was delivering health benefits, they found the impacts easier to accept and vice versa.

I was so sick.... and (dialysis) brought me around 100% ...... I feel like a brand new woman (Gregory et al., 1998, p.774).

... I don't feel that ... dialysis has improved my health. ... If anything it has made me a lot worse (Gregory et al., 1998, p.769).

Many people were expected to adhere to dietary, fluid and activity restrictions to facilitate technology efficacy and described as time-consuming and effortful learning about and adhering to these limitations (Lehoux et al., 2004; Rittman et al., 1993)

You must be alert... you can't just be careless and not watch things (Gregory et al., 1998, p.776)

Some people actively ignored the suggested regime, relying on technology to rectify their overindulgence despite the resulting pain and side-effects or that the technology may not be able to compensate (Ritholz et al., 2007; Rittman et al., 1993).

Negative impacts pushed individuals to the limits of their coping abilities and led to reflections on life with technology.

Some days I don't feel like coming in... but I know that if I do that too often it will kill me... so that is why I just keep doing it, coming here and doing it all the time...I don't want to die yet.(Nagle, 1998, p.7)

# B.3.2. Role changes

Participants often described that their roles had dramatically changed leaving them dependent on others to fulfil these roles or for practical or emotional support (Lehoux et al., 2004; Gregory et al., 1998; Nagle, 1998; Rittman et al., 1993). Socially participants were often excluded due to the ignorance or fear of others.

*Friends and family.... leave me out....Yes I don't eat but I'm not a leper.* (Lehoux et al., 2004, p.634)

These changes impacted detrimentally on participants' self-esteem and maintaining and feeling valued within important relationships was extremely important (Gregory et al., 1998; Burke, 1996).

#### B.3.3. <u>Self-esteem and body-image</u>

Many participants felt that society viewed them as an 'ill-person' rather than a 'person who was ill'. They resisted this wanting to be valued for being themselves (Gregory et al., 1998; Nagle, 1998).

(I'm like) a bestseller.... my dust jacket is really tattered and torn, but the book is still a book that has value (Curtin et al., 2002, p.616)

Public and intimate relationships suffered as a consequence of changes in appearance or when others saw the technology (Ritholz et al., 2007; Lehoux et al., 2004; Beery et al., 2002).

People started looking at me differently and reacting to me differently and it wasn't pleasant (Nagle, 1998, p.5)

Women particularly disclosed a sense of difference and disfigurement; however, both women and men described negative feelings about themselves as a result of body changes (Ritholz et al., 2007; Anderson, 2004; Lehoux et al., 2004; Burke, 1996).

*I really felt less than a woman* (Beery et al., 2002, p.17)

### B.3.4. Dependence on technology

The slow and unpredictable nature of an illness sometimes exposed unpreparedness for drastic intervention and the realisation that intervention would be life-long was a shock (Gregory et al., 1998; Nagle, 1998). Being dependent on medical-technology was particularly difficult with even those describing positive outcomes feeling humiliated, worthless, helpless, inadequate and infantilised (Curtin et al., 2002; Gregory et al., 1998; Nagle, 1998).

# C. Continuing to live with technology

Participants expressed a variety of viewpoints which enabled them to continue living with technology. Some saw technology as a buffer delaying death (Lehoux et al., 2004), others as a way of coping itself (Gregory et al., 1998) whilst some felt it represented a stark choice (Anderson, 2004; Curtin et al., 2002).

If you were sick, dialysis is the most comforting thing that you could ever

do (Gregory et al., 1998, p.769)

It's either this or the boneyard, one of the two (Gregory et al., 1998,

p.775)

A key challenge was incorporating technology into their life and view of themselves without being subsumed by it.

#### C.1. Living with mortality

Participants continued to live with a sense of mortality.

*I just take the wrong step one way or the other off that line and I could be going the wrong direction* (Curtin et al., 2002, p.618)

Feelings of vulnerability intensified when other people in the same 'illness community' died.

my life flashed before my eyes ..... (Gregory et al., 1998, p.772)

# C.2. Integrating technology into the self

Often participants anthropomorphised technology in their attempts to integrate it into their lives and bodies. Medical-technology was described as having its own needs and wants which took priority over the participant's (Giles, 2005). Whilst some individuals felt they had a relationship with the technology;

... it becomes like a I would say more or less like a family member (Giles,

2005, p.25)

or that using it was just another task,

Just like breathing (Nagle, 1998, p.5)

some felt it had become part of their self

as my kidney ... a part of me (Ritholz et al., 2007, p.330)

and others described the technology as part of their body but not part of their self.

It's a part of my body because it's something I need (Beery et al., 2002

16).

Commonly, respondents struggled with integration of the technology as it was also important that the failed body part or technology didn't define them as a person (Giles, 2005).

I don't even think of it as separate. I don't want to say it's part of me, but it is. (Ritholz et al., 2007, p.552).

#### C.3. Integrating technology into a new 'normal life'

Participants described that their illness or technology-use meant they were socially excluded, couldn't work, travel or plan long-term (Lehoux et al., 2004; Curtin et al., 2002; Nagle, 1998; Burke, 1996; Rittman et al., 1993). They described adjusting to the illness and the technology and often talked of starting a new life which had different roles and priorities (Ritholz et al., 2007; Burke, 1996; Rittman et al., 1993). Adjustment was aided by a perceived continuity with the person they previously were (Curtin et al., 2002; Nagle, 1998).

I cannot go back to the way it used to be....It's like I have – I've lived two lives. One life when I was healthy and then this life with this illness (Curtin et al., 2002, p.620)

Over time some participants described that the 'new life' became 'normal' but others either never adjusted or felt their 'new life' wasn't worth living (Curtin et al., 2002; Gregory et al., 1998; Burke, 1996; Rittman et al., 1993).

It's keeping me alive, but I'm not living (Lehoux et al., 2004, p.635)

# C.4. Sources of support

Family and friends were important in offering support but respondents worried about burdening them (Giles, 2005; Gregory et al., 1998).

They helped me survive! There was no way I could have managed alone (Burke, 1996, p.369)

Whilst the technical competence of professionals was important, of highest priority was their availability and whether they listened (Gregory et al., 1998; Nagle, 1998). There was a tension between the support participants gained from others with similar health problems and their need for individuality within the 'illness group' (Curtin et al., 2002; Nagle, 1998; Burke, 1996).

### D. Denial and ambivalence

Cutting across all of the themes was participants' ambivalence and denial about using medical-technology and its impacts. When participants described worries, fears or distaste at medical-technology they concurrently denied they existed (Beery et al.,

2002). This was achieved by distancing; describing problems as those other people experience or by using mechanical language allowing them to describe unthinkable events as technological rather than human events (Beery et al., 2002) or by denial; describing negative emotions or life changes yet simultaneously denying the occurrence or importance of these (Beery et al., 2002).

(Describing life initially) *It's like being a pianist and having your hands cut off at the wrists.* (Describing life after 5 years of dialysis) *My life is not much different* (Rittman et al., 1993, p.329)

Participants often used negative and positive terms together in the same sentence to describe medical-technology, illustrating their ambivalence over their need for and acceptance of the technology, with their distrust of it as a machine (Ritholz et al., 2007; Beery et al., 2002; Nagle, 1998; Rittman et al., 1993).

# 5 Conclusion

Despite different clinical populations examined, common themes were elicited from the papers reviewed describing the experience of users of life-sustaining medicaltechnology. These technologies do not cure, rather they keep individuals alive but with irrevocably altered, and often significantly reduced, quality of life.

Respondents described accepting the need for technology; coming to terms with being ill, facing mortality and deciding to live. They lost power over their bodies, to technology and health professionals and described diverse attempts to regain control. Participants' initial reactions to the technology tended to be one of distress and mistrust and whilst it's mechanical nature suggested a miracle cure (or the future prospect of one), it also engendered worries of failure and was a particular barrier to

acceptance. The substantial changes in roles, body-image, activities, employment and relationships significantly reduced individuals' self-esteem with dependence on technology being considered negatively. Over time individuals described integrating technology into their life or accepting that it would be an ongoing need.

During these changes individuals tried to maintain a sense of individuality and ensure that their need for technology did not define them. These processes appear similar to the task described by Charmaz (1983) of preserving valued self-images or developing compensatory ones to maintain self-esteem and reduce distress.

Individuals' negative emotions regarding technology and worries of failure were coped with either by minimising or distancing themselves from the difficulties. Telford et al. (2006) discuss that this use of defences (as described by psychodynamic theory) appears to be functional rather than pathological in chronically-ill individuals.

As predicted, many individuals anthropomorphised the technology as they were often experiencing all three of the risk factors for anthropomorphism; social isolation, desire for control and need to interact with technology in the future. This may have tempered an individual's concerns over the relationship they had developed with the technology by humanising or demechanising it. Anthropomorphism may have helped people to regain control and certainty but it did not indicate adjustment to technologyuse or integration of technology into the self. Respondents used both negative and positive language concurrently which illustrated their ambivalence and denial of acceptance of medical-technology.

Difficulties accepting medical-technology can be viewed in the context of the CUEmodel (Thuring & Mahilke, 2008). Originally the aesthetic aspect (mechanicity) of the technology and users' limited knowledge were barriers and resulted in negative appraisals. As an individual's knowledge and skills increased, their appraisal might become positive were health benefits were apparent, or remain negative where sideeffects compromised the technology functionality or health benefits. Whilst the CUEmodel predicts that individuals developing negative appraisals would choose not to use the technology in the future, as participants' options were so limited they felt they must simply cope with the negative feelings during repeated use.

Living with life-sustaining medical-technology is not an easy task with iatrogenic complications potentially compounding underlying physical problems. People live with mortality and a drastically altered life whilst trying not to become a 'different person'. For most people their new life became normal after some time as they adjusted to its limitations and opportunities, however, others described never adjusting and wished that they had not started using technology in the first place. Participants did not always appear able to accept and express the conflicting feelings and reactions they experienced which often resulted in denial and an ambivalent attitude that may be hard for others to understand, especially if they expect patients to be grateful for being alive.

#### **6** Implications for Clinical Practice

Although many individuals expressed gratitude for their continuing life, they also described a substantial number of detrimental impacts to their lives. Whilst health professionals are naturally primarily concerned with health problems, the

psychosocial impacts of depending on medical-technology should not be overlooked. Most patients disliked feeling disempowered and were often keen to have technological information. Health professionals could aid this by giving appropriate information, encouraging patients to be involved in their health decisions (if they wish to) and utilise other individuals with the same condition for information and support. The Expert Patient Programme is a Department of Health initiative offering generic courses to help individuals cope with chronic-illnesses and these findings suggest programmes may be improved by making them illness-specific (DOH, 2006).

Individuals also wanted to preserve their individualism so any assessments must be individualised ensuring that the focus of their attention is on the person rather than the technology. As part of such person-centred care, consideration should be made of how the technology can fit into their existing life and how to enable individuals to maintain valued activities, roles and relationships. Individuals struggled with ambivalent responses to technology which may make it difficult to talk about adjustment difficulties or result in certain health-related behaviours, for example, not adhering to required diets. If health professionals are aware of this they can subsequently offer support rather than censure.

Future research addressing the impacts of medical-technology use on body-image, psychological morbidity and quality of life is warranted, along with exploration into the influence of patients' experiences on their adjustment and adherence to medical regimen as well as possible biomedical markers.

#### 7 Critique of the Literature Review

A difficulty prevalent to qualitative literature reviews is that searches identify too few or too many studies, thus either overlooking important studies or requiring exclusion of large swathes of studies (Dixon-woods et al., 2006). The current review search terms were expanded due to wide variety of terminology used by previous studies, resulting in a high number of potentially relevant abstracts but ultimately relatively few relevant papers.

The Researcher's background is in psychology with a particular interest in renal failure. Although every effort was made to ensure that this did not influence toward theme identification or interpretation, this may have contributed bias to the review.

Because of the paucity of research in this area, this review includes a small number of papers investigating patients' experiences of a range of technologies. The Researcher could describe only themes reported by the study authors and it is possible that if the raw data from all studies were amassed, a number of additional themes may emerge that were not expressed by sufficient participants to be reported in individual studies but were common to participants across the studies. Despite this, common themes with significant clinical implications were identified.

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Section 2

**Research Report** 

An investigation into body-image disturbance in adult end-stage renal failure

patients undergoing dialysis.

# Abstract

Background: An increasing number of individuals in the UK develop end-stage renal failure and receive dialysis which replicates the function of the kidneys thereby maintaining their lives. Dialysis-users report high levels of psychological morbidity and significant detrimental impacts in all areas of life and elevated psychological morbidity is associated with poorer quality of life, adherence to medical regimen, adjustment to illness and increased mortality. More circumscribed evidence has identified body-image changes occurring in dialysis-users and such changes are known to be associated with psychological morbidity in other chronically-ill populations. The Self-regulatory Executive Function (S-REF) model offers an explanation for these findings with specific reference to cognitive-schemas and self-focus (focus on one's thoughts and emotions).

Method: The association between appearance-schemas and self-consciousness with psychological morbidity and body-image disturbance were investigated in 97 adult haemodialysis and peritoneal dialysis patients using mixed methods.

Results: Dialysis-users reported levels of psychological morbidity and body-image disturbance above those found in community and other chronically-ill populations and psychological morbidity and body-image disturbance were significantly positively associated. Participants also described wide-ranging impacts of dialysis-related body changes. Facets of appearance-schematisation and self-focus were significantly associated with psychological morbidity and body-image disturbance.

Conclusions: Results supported the S-REF model, providing a tentative explanation for the levels of psychological morbidity in dialysis-users and suggesting possible markers in identifying individuals likely to struggle to adjust to dialysis with possible clinical relevance.

#### **1. Introduction**

#### 1.1. Renal Failure and Dialysis

There are approximately 43 901 adult patients with end-stage renal failure (ESRF) receiving dialysis in the UK (The Renal Association, 2007) and these individuals will die unless they receive a transplanted kidney or undergo dialysis. Dialysis replaces the function of the kidney by using diffusion and ultrafiltration to remove body wastes and water from the blood, and comprises two types: haemodialysis (HD) and peritoneal dialysis (PD).

In PD a catheter is permanently inserted into the abdomen and fluid from a bag is drained through a catheter into the peritoneal cavity where the abdominal lining acts as a membrane for dialysis. The fluid is left in situ until dialysis has taken place and is then drained out. Patients usually carry this out themselves approximately three times a day. Patients often gain weight due to the levels of glucose in the dialysis fluid, the additional fluid can make an individual appear bloated and some people have concerns over the appearance of the catheter used (Higgins, 2005; Beer, 1995).

In HD blood is removed from the body and cleansed in a dialysis machine before being returned to the body. This is usually done three times a week in sessions lasting between three and five hours with most patients attending a hospital to use the machine. Access to the blood stream is either by a dialysis catheter inserted into a large vein or by a fistula which is made by joining a vein to an artery. Patients sometimes find the fistula or catheter unsightly or may have scars from previous attempts at creating fistulas (Higgins, 2005).

Both types of dialysis require patients to monitor their fluid and dietary intake as well as being vigilant to prevent infection and other problems at the site of dialysis. This often limits their activities, as lifting heavy objects can damage a fistula and participating part in certain sports may lead to a catheter being dislodged.

#### 1.2. Psychosocial Impacts of Dialysis

Several research studies indicate that people with ESRF experience higher levels of depression and anxiety than community and other chronically-ill samples. Up to 40% of individuals with ESRF report mild anxiety and 23% mild depression (Christensen & Ehlers, 2002; Finkelstein & Finkelstein, 1993) with a notably high suicide rate (McGee & Bradley, 1994). Individuals also report impaired quality of life, social, vocational and sexual difficulties (Beer, 1995; Kaplan de-Nour, 1994; Finkelstein & Finkelstein, 1993) and dialysis itself can cause pain and pruritus (Higgins, 2005; Wight et al., 1998).

Such distress is associated with poorer adjustment to illness, adherence to dialysis regime and quality of life in both the short and long-term (McKee et al., 2005; Franke et al., 2003; Vasquez et al., 2003) as well as higher mortality (Valdes et al., 2006; Mapes et al., 2004; Lopes et al., 2003; Mapes et al., 2003; Christensen & Ehlers, 2002). Non-adherence to diet and fluid regimens has adverse consequences for the trajectory of ESRF.

Several qualitative studies have also identified difficulties relating to body-image in dialysis patients. Body-image is '*the combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and* 

*desirability of one's body'* (Taleporos & McCabe, 2002, p. 971). Societal, cultural and individual expectations of an 'ideal body' influence whether an individual's bodyimage is negative or positive and the extent to which this affects their view of themselves. Physical changes following injury or illness result in body-image changes which can challenge an individual's beliefs about body-image and impact on their feelings of self-worth and self-esteem.

Dialysis-users have described a number difficulties related to body-image including poor self-esteem and sexual difficulties, disliking being attached to a machine, feeling changes in their appearance made them less attractive and increased body awareness and individual body part dissatisfaction which influenced their choice of dress and activities (Beer, 1995; Sorter et al., 1994; Finkelstein & Finkelstein, 1993; Severino, 1980). Body-image changes also appear to act as high stressors in female dialysisusers (Aoki & Muraoka, 1993). Individuals given a choice of dialysis modality partially based their decision on their expectation of the subsequent body changes, choosing which was most acceptable given their own body-image and self-concept (Tweed & Ceaser, 2005; Whittaker & Aibee, 1996). Importantly, although a large proportion of dialysis-users reported body-image concerns, the majority of health professionals working with these patients did not consider this to be an issue (Bass et al., 1999).

Body-image changes in dialysis-users have been found to be associated with metabolic imbalance (Foster et al., 1973) and decreased body satisfaction associated with poorer social support and increased depression (Gusman, 1998). Studies with nonclinical and chronically-ill populations have found increased body-image dissatisfaction predictive of elevated anxiety and depression levels (Sinton & Birch, 2006; Cash & Fleming 2002; Beer, 1995; Noles et al., 1985) and in chronically-ill individuals, body-image negatively influenced psychosocial recovery, adaptation to illness and quality of life (Beer, 1995). Given the previous findings and the number of physiological and overt anatomical changes resulting from dialysis, it is likely that body-image is influenced by dialysis and that this contributes to levels of distress experienced. However, no systematic evaluation of body-image status, changes and impacts have been undertaken with this population as previous research has been limited by inadequate sample size or incidental focus on body-image.

# 1.3. Factors that Exasperate or Ameliorate the Impact of Dialysis

The effects of dialysis are profound, affecting almost every aspect of an individual's life from confronting mortality, adjusting to chronic illness to lifestyle choices and iatrogenic effects. Adverse psychological reactions are therefore understandable and studies have investigated how religious beliefs (Ko et al., 2007), coping style (Mok & Tam, 2001), locus of control (Christensen & Ehlers, 2002; Martin & Thompson, 2000; Poll & Kaplan de-Nour, 1990), health status (Martin & Thompson, 2000; Steele et al., 1996), lifestyle disruption (Devins et al., 2001), physiological stressors (Gurklis & Menke, 1998) and social support (Cukor et al., 2007) influence psychological distress in dialysis-users. Some of these factors were found to exacerbate or ameliorate psychological well-being but none adequately and comprehensively account for the high levels of psychological distress experienced by dialysis-users. Notably absent from previous investigations have been studies of cognitive schema. Cognitive schemas facilitate, and can distort, perception, cognition, inference drawing or interpretation of new information in relation to existing knowledge and memories.

Schemas are modified and adapted by the incorporation of new experiences. Each person has several self-schemas which represent their beliefs and views of their personality, appearance and role. These enable an individual to cognitively evaluate self-related information arising from personal and social experiences. Schemas become dysfunctional and result in distress if they are rigid or extreme and cannot be modified to incorporate recent experiences. Any major life-event will impact upon and be influenced by one's schema, thus becoming dependent on dialysis and the accompanying lifestyle and physical changes are likely to challenge patients' currently-held schemas and require significant adaptation in order to incorporate these experiences. An individual's illness self-schema are the positive or negative meanings they hold about being ill and have been found to partially predict levels of depression in haemodialysis patients (Gusman, 1998). However, little attention has been paid to the potentially profound impacts of altered body-image changes consequent to dialysis nor to body-distortion from invasive interventions and the impact of machine dependence. These are prominent factors for psychological morbidity which are worthy of study.

Given the previous findings of body-image changes in chronically-ill populations and dialysis-users, appearance-schemas are implicated in this population. Appearance-schemas are activated and influenced by appearance-related interactions with others. Negative appearance-schemas have been found to be associated with body-dissatisfaction and depression (Sinton & Birch, 2006) and are believed to influence body-image dissatisfaction by heightening focus on, recall of, and incorporation of appearance-relevant messages. If a person is appearance-schematic, they place a high value on their appearance determining their worth as a person and are more likely to

be disturbed if their appearance does not match up to the images approved of by themselves or society.

#### 1.4 The Self-Regulatory Executive Function model

Wells and Mathews (1994) combine information processing and schema theory in the Self-Regulatory Executive Function model (S-REF model), arguing that emotional dysfunction and the subsequent distress arise from chronic and intense self-focus. Self-focus has two main components: private and public. Private self-focus relates to aspects of one's self that are hidden from the view of others such as thoughts, feelings, attitudes and wishes. Public self-focus is the general awareness of aspects of one's self that are observable by others such as physical appearance, speech, behaviour and expression of emotions (Fenigstein et al., 1975). During self-focus an individual compares their current state against their ideal state for a specific aspect that is important to them, for example physical appearance, and then tries to reduce any negative discrepancy between these. If they feel that they have little success in achieving this they become distressed. Some people have a tendency to engage in self-focus frequently and therefore have a heightened awareness of possible discrepancies. If an individual is also appearance-schematic, identifying unalterable discrepancies will lead to more distress as more of their self-worth is associated with their appearance. Wells and Mathews (1994) propose that chronic and intense selffocus further promotes distress because it limits attentional resources, preventing the information-processing necessary to modify dysfunctional schema. Consequently, people who are highly self-focused can experience difficulties in changing their value system with resultant distress.

Applying the S-REF model to dialysis-users suggests that an individual prone to selffocus is more likely to evaluate their physical appearance adversely compared with the ideal they hold and therefore more likely to report body-image disturbance (BID). Equally, an individual who is more invested in their appearance is also more likely to report BID as any discrepancy regarding this is highly salient for them. As dialysisrelated physical changes are unalterable and the discrepancy between idealised and actual appearance cannot be reduced, an individual is likely to become distressed. If they are able to incorporate the experience by adapting schema this distress will reduce, however this will be more difficult if they are prone to self-focus due to limits on their attentional capacity. This is illustrated in Figure 2.

# 1.5 Clinical Relevance of the Research

Increased levels of psychological morbidity found in dialysis-users are associated with decreased adherence to medical regimen and increased levels of mortality. Qualitative studies have found evidence for body-image related difficulties in dialysis-users and many studies with other chronically-ill populations have linked such difficulties with increased levels of psychological morbidity. Given the pervasive impacts of the physical changes resulting from dialysis and the iatrogenic side-effects this appears to be a likely cause of distress in this population. Despite this, body-image in dialysis-users has largely been ignored by both researchers and health professionals. Investigating the prevalence and impacts of body-image change is valuable to identify the extent of this problem, educate clinicians and help identify possible interventions or support that may be of benefit to dialysis-users.



#### Figure B. Chain of events following dialysis proposed by S-REF model.

The S-REF model offers an explanation of how body-image changes might influence distress in dialysis-users and other individuals. BID and negative appearance-schemas have previously been found to be associated with elevated levels of distress in other populations (Sinton & Birch, 2006; Cash & Fleming 2002; Beer, 1995; Gusman, 1998; Noles et al., 1985). Whilst previous studies have attempted to explain the causes of elevated distress levels in dialysis-users, despite being implicated in other

chronically-ill populations, there is a paucity of research examining the influence of cognitive schemas on dialysis-users. Further investigation of these factors may allow identification of any relationships between body-image changes, schema and psychological morbidity in addition to testing the S-REF model.

Should appearance-related schema contribute to elevated psychological morbidity, its identification may enable preventative or strategic interventions thereby potentially enhancing the quality of life and mortality rates amongst dialysis patients.

#### 1.6 Research Questions and Hypotheses

Despite evidence that body-image difficulties are commonly reported by dialysis patients, there have been no previous studies exploring these phenomena within a relevant theoretical framework. The present study investigated the levels of psychological morbidity and BID reported in adult dialysis patients with reference to the S-REF model. The following four research questions and resulting hypotheses were addressed.

# 1.6.1 <u>Hypothesis</u>:

Levels of psychological morbidity will be higher than those reported by healthy individuals and by individuals with other chronic illnesses.

# 1.6.2 What levels of body-image disturbance are reported by dialysis patients?

# **1.6.2.1 <u>Hypothesis</u>:**

Body-image disturbance levels reported by dialysis patients will be higher than those reported by healthy populations.

# 1.6.3 <u>Is there a relationship between an individual's level of body-image</u> <u>disturbance and their reported levels of psychological morbidity?</u>

# **1.6.3.1 <u>Hypothesis</u>:**

As an individual's reported level of body-image disturbance increases, their level of psychological morbidity will also significantly increase.

# 1.6.4 <u>Is there a relationship between a person's level of self-focus and extent to</u> <u>which they are appearance-schematic and their reported levels of</u> psychological distress and body-image disturbance?

# **1.6.4.1 Hypothesis (a):**

As an individual's level of self-focus and extent to which they are appearanceschematic increases, the levels of psychological morbidity they report will also significantly increase.

# **1.6.4.2 Hypothesis (b):**

As an individual's level of self-focus and extent to which they are appearanceschematic increases, the levels of body-image disturbance they report will also significantly increase.

#### 2 Methodology

#### 2.1 Design

This study firstly addressed levels of morbidity and BID in the entire sample and subsequently used a between-subjects design to investigate the impact of a number of different variables on this sample. Self-completion questionnaires collecting quantitative and qualitative data were utilised over a period of four months. Whilst it could be argued that individuals awaiting dialysis could have been used as controls, the present study did not use a control group. This was because obtaining access to these individuals between identification of their dialysis need and commencing dialysis would have been difficult and would not yield a sufficient sample-size to allow appropriate statistical comparison. In addition, the levels of psychological morbidity reported by such individuals might be distorted by their adjustment reaction to ESRF thus preventing a true comparison.

Demographic information and data on psychological morbidity, BID and cognitive schemas associated with appearance and self-focus were collected using questionnaires completed by participants. Questionnaires were selected as the most appropriate research method for this study as they could be completed at the participant's convenience and enabled a large amount of data to be collected with minimal distress, time and effort from participants. These factors were thought to increase the likelihood of participants completing the questionnaires.

Following study completion, results were disseminated to dialysis patients and staff at the renal units where the research was undertaken.

# 2.2 Participants

The present study obtained its sample from the population of patients receiving dialysis services from a regional specialist centre in the Midlands. A power analysis was completed prior to the study to determine the necessary sample size required using tabulated values for multiple regressions calculated by Cohen (1992). A power value of 0.8 was used as this has been identified as a suitable power for psychological studies in order to reduce Type II errors (Cohen, 1992). A significance criterion of 0.05 was used as this is the conventional significance level at which it is agreed to reject a null hypothesis (Coolican, 2004). Using these assumptions, the number of required participants identified for small, medium and large effect sizes was 34, 76 and 547 respectively. As there had been no previous studies with this or a similar population that could be used to predict the likely effect size, a medium effect was adopted as this corresponds to the average size of observed effects in a variety of fields investigated (Cohen, 1992). The intended sample size was thus 76 participants.

#### 2.3 Inclusion and Exclusion Criteria

Participants were excluded if they had been undergoing dialysis for less than six months.

This was to allow time for normal adjustment reactions to dialysis to take place which might otherwise influence the data collected. The timeframe of six months was chosen in accordance with previous studies with this population (Polaschek, 2007; Mok & Tam, 2001).

#### Participants were excluded if they were unable to comprehend English.

Some of the measures used in the study have not been standardised in non-English languages therefore it was not possible to use translated measures.

#### Participants with severe visual problems were excluded.

The dialysis population is an aging one with high levels of co-morbid diabetes, thus a high level of visual problems was anticipated amongst the population sampled. Therefore all questionnaires, invitation letters and information sheets were printed in large print to enable participation of as many individuals with limited vision as possible. Those unable to read and complete the questionnaire pack were excluded from the study.

# 2.4 <u>Research Procedure</u>

#### 2.4.1 Ethical Approval

Ethical approval was sought and obtained from the relevant local ethics committee (Appendix E) and NHS Trust (Appendix F). Although it was not anticipated that completion of the questionnaires would cause distress to participants, if required, provision was made for consenting participants to be referred to local Health Psychology services by the renal staff or Researcher.

#### 2.4.2 Obtaining the Sample

All patients over the age of 18 who were receiving any type of dialysis under the care of the regional specialist centre were invited to take part in the study. Questionnaires were distributed to individuals either at out-patient appointments or haemodialysis sessions and individuals identified as not meeting the inclusion criteria did not receive
questionnaire packs at this juncture. To maximise participant uptake in the limited time available, each participant was given the opportunity to enter into a prize draw for a nominal amount of vouchers. The procedure for obtaining the sample is shown in Figure 3 below.

# 2.4.3 Data Collection

Home-haemodialysis and peritoneal dialysis participants were given packs comprising an Invitation letter, Information Sheet, Demographic Sheet, Questionnaires and Prize draw sheet (Appendices G, H, K to P) by the clinic administrator at out-patient appointments over the course of four months. Hospital haemodialysis participants were given the study packs by an administrator at haemodialysis sessions (Appendices I to P). Once issued with a pack, participants could address any questions they had about the research to the Consultant or Specialist Registrar at their appointment or by the Researcher over the telephone. If they opted to participate, individuals completed and returned the questionnaires to the Researcher in pre-paid envelopes. Consent to take part was implicit in participants' completion of the questionnaire.

The sampling frame comprised the summer period of May to August 2007 to reduce the influence of seasonal variance on participants' mood.



# 2.4.4 Measures

# 2.4.4.1 Demographic information

The Researcher created a structured data collection sheet (Appendix K) to record relevant demographic data comprising participant age, gender, ethnicity and type and duration of dialysis.

# 2.4.4.2 Psychological morbidity

### Hospital Anxiety and Depression Scale (HADS; Snaith, & Zigmond, 1994)

The HADS (Appendix L) was used in the present study as it has been widely used to measure psychological morbidity in non-clinical, renal and chronic illness populations and is designed to measure psychological distress without being influenced by health factors which are likely to be present in the study population.

The HADS is a 14-item self-report questionnaire measuring levels of anxiety and depression (Zigmond & Snaith, 1983). The HADS has two subscales, Anxiety and Depression, each consisting of seven items. Questions are rated on a Likert scale from 0-3, and scores for each subscale summed with a maximum of 21. The higher the subscale score, the greater the level of morbidity and the authors recommend a cut-off score of 8 to indicate clinical levels of anxiety or depression (Bjelland et al., 2002).

The HADS has been reported to have satisfactory internal consistency, test-retest reliability (Crawford et al., 2001; Snaith & Zigmond, 1994; Clark & Fallowfield, 1986) and face, construct and concurrent validity (Snaith & Zigmond, 1994; Zigmond & Snaith, 1983). In recent investigations using the HADS with ESRF patients, the HADS showed satisfactory internal reliability (Martin & Thompson, 1999).

#### 2.4.4.3 <u>Body-image disturbance</u>

# Body Image Disturbance Questionnaire (BIDQ; Cash, Melnyk, & Hrabosky, 2004)

The BIDQ (Appendix M) was selected for the present study as it has been widely used with adults of both gender and offers norms for comparison with the study sample. It also enables specific qualitative information to be collected regarding the experiences of participants which was considered extremely beneficial in this exploratory study.

The BIDQ is a seven-item scale measuring the extent to which an individual is preoccupied with appearance-related concerns and the resultant emotional, social, occupational and behavioural impacts of this. Questions are rated on a Likert scale from 1-5, responses for all items are summed and a mean obtained with a maximum mean of 5. Higher scores on the BIDQ indicate higher levels of BID. Five items also ask for open-ended clarification of some of the responses

The BIDQ has been reported to be internally consistent and free from impressionmanagement response bias (Cash, Phillips et al., 2004). It has a test-retest reliability of .80 to .92 and converges with other body-image indices (Cash & Grasso, 2005).

#### 2.4.4.4 Measures of cognitive schemas and self-focus

To allow investigation of the S-REF model, measures of appearance-related cognitive schemas and self-consciousness were included in the data collection.

# a) Appearance Schemas Inventory – Revised (ASI-R; Cash, 2003)

The ASI-R (Appendix N) was selected for the present study as it allows investigation into an individual's psychological investment in their physical appearance and provides norms for levels of such investment.

The ASI-R is a 20-item self-report measuring an individual's beliefs or assumptions about the importance, meaning, and influence of appearance on one's life (Cash,

2003). The scale comprises of two subscales: Self-evaluative Salience (twelve questions) measuring the extent to which individuals' beliefs about their physical appearance influence their personal or social sense of self and Motivational Salience (eight questions) measuring the extent to which individuals attend to their appearance and engage in appearance-management behaviours. Items are rated on a five-point Likert scale which are summed and mean scores obtained for individual subscales and for both together.

The ASI-R has been found to have high internal consistency (Cash, Melnyk et al., 2004) and be internally reliable (Cash et al., 2005; Rusticus & Hubley, 2005).

# b) Self-consciousness Scale (SCS; Fenigstein, Scheier, & Buss, 1975)

The SCS (Appendix O) was selected for the present study as it allows further exploration of the S-REF model by measuring an individual's level of self-focus and has norms for adults.

The SCS is a 23-item scale measuring three components of self-consciousness: Private Self-Consciousness (ten items) assesses an individual's tendency to attend to their inner thoughts and feelings; Public Self-Consciousness (seven items) assesses an individual's awareness of themselves as a social object having an influence over others; and Social Anxiety (six items) assesses the degree of discomfort experienced in the presence of other people (Fenigstein et al., 1975). Questions are rated on a Likert scale from 1 to 4 and items are summed to provide scores for each subscale and a total score. The SCS has been reported to have satisfactory levels of internal reliability (Nystedt & Ljungberg, 2002; Turner et al., 1978; Fenigstein, Scheier & Buss, 1975), the concurrent and discriminant validity have been demonstrated by Carver & Glass (1976) and the construct validity and discriminate validity of subscales are also supported (Turner et al., 1978).

#### **3** Results

#### 3.1 Data Analysis

Thematic analysis was used to identify themes from the qualitative data. Quantitative data were analysed using the Statistics for the Social Sciences (SPSS) version 14.0. Data was first interrogated to investigate the demographic characteristics of the population and then to address specific research hypotheses.

## 3.2 Procedures for Statistical Analysis

The distribution of the data was checked for skewness and kurtosis and the findings satisfied criteria for parametric tests. Cronbach's alpha was completed for the BIDQ, ASI-R and SCS and all had satisfactory internal reliability for this data set (0.944, 0.873 and 0.840 respectively). The level of p<0.05 was used throughout to identify whether a result was statistically significant.

Levels of psychological morbidity were identified using scores obtained on the HADS and independent sample t-tests used to compare the scores for HD and PD participants. Linear and multiple regressions were carried out to identify whether the following variables were associated with the levels of psychological distress reported; BID, levels of self-focus (scores on the SCS) and importance of appearance-schema (scores on the ASI-R).

Levels of BID were identified using the BIDQ scores and one-sample t-tests used to compare against community norms. Independent-samples t-test used to compare scores for females and males both using entire samples and splitting by dialysismodality. Linear and multiple regressions were carried out to identify whether levels of self-focus (scores on the SCS) and importance of appearance-schema (scores on the ASI-R) were associated with the levels of BID reported.

These statistical methods were selected as they were appropriate for the number of participants and it was felt that they would allow the maximum possible information to be obtained from the data without increasing the likelihood of Type 1 and Type 2 errors. As this is an under-studied subject, it was important to capitalise on the data collected and support future research possibilities.

#### 3.3 Missing Data

Study methodology precluded participant attrition; however, a small number of participants submitted questionnaires with missing data. When planning the study it was predicted that any data would be 'missing at random' therefore multiple imputation could be used to allow analysis of any incomplete data (Carpenter & Kenward, 2005; Raghnuthan, 2004). However, when the study was undertaken one questionnaire in particular was returned with fewer completions whilst other data was missing at random rendering multiple imputation inappropriate. To ensure that

if they were missing the data for a specific analysis (cases excluded pairwise) and included for analyses for which they had the necessary information.

#### 3.4 <u>Research Findings</u>

#### 3.4.1 Description of Participants

204 people on haemodialysis were approached and 151 packs were issued. Fiftyseven potential respondents either did not meet the inclusion criteria or declined to participate. Fifty-three individuals meeting inclusion criteria completed and returned the questionnaire, giving a response rate for useable questionnaires of 35.1%.

101 packs were issued to patients going through the peritoneal dialysis out-patient clinics. Forty-four individuals meeting inclusion criteria completed and returned the questionnaire, giving a response rate for useable questionnaires of 43.6%.

Table 3 shows the demographic characteristics for the study sample. The sample of PD participants was older and had a higher proportion of individuals from a White ethnic background than HD participants.

Table 4 shows the demographic characteristics of the sample population compared with the dialysis populations recorded by the Renal Registry (2007) for the area in which the research was carried out, England and the UK (Renal Registry, 2007). The study sample contained a higher proportion of peritoneal dialysis patients than the general dialysis population with the gender mix and ages of individuals similar to that of the wider dialysis populations. PD participants in the study had a higher median treatment time than HD individuals contrary to the trend in the UK's dialysis population. The proportion of patients from an Asian/Asian British background in the

study is representative of the city the research was conducted in, but is higher than seen in English and UK populations whilst the proportion of people from a Black/Black British background was higher than found in the general population of the city but similar to that found in the wider dialysis population. The study sample had no individuals from Chinese or Other Ethnic backgrounds, differing from the comparison dialysis populations.

Variable	Haemodialysis	Peritoneal	Total sample
	sample	dialysis sample	
	(n=53)	(n=44)	(n=97)
Age (years)			
Mean	57.57	62.29	59.72
Standard deviation	17.016	12.956	15.401
Median	59	64	63
Range	19-87 (68)	24-83 (59)	19-87 (68)
Gender (%)			
Male	50.9	61.4	55.7
Female	37.7	34.1	36.1
Missing data	11.4	4.5	8.2
Ethnicity (%)			
White British	60.4	97.7	77.3
White any other background	1.9	0	1
White and Black Caribbean	1.9	0	1
White and Asian	3.8	0	2.1
Asian or Asian British	22.5	2.3	13.5
Black or Black British - Caribbean	5.7	0	3.1
Black or Black British - African	1.9	0	1
Black or Black British – any other	1.9	0	1
Chinese	0	0	0
Any other background	0	0	0
Time on dialysis (months)			
Mean	31.76	37.05	34.23
Standard deviation	26.389	27.250	26.782
Median	23	26.5	24
Range	6-99 (93)	6-96 (90)	6-99 (93)
Type of dialysis (%)			
HD	100	-	54.6
PD	-	100	45.4

 Table 3. Demographic characteristics of participants.

Variable		Study sample	Area where	England	UK
			research		
			carried out		
Dialysis type (%)					
Haemodialysis		55	75	81	80
Peritoneal dialysis		45	25	19	19
Median time trea	ted (yrs)				
Haemodialysis		2	-	-	2.8
Peritoneal dialysis		2.2	-	-	2
Median Age (year	rs)				
Haemodialysis		59	62.2	64.9	60.1
Peritoneal dialysis		64	63.1	65	59.9
Gender (%)					
Haemodialysis	Male	51	68	63	63
	Female	38	32	37	37
Peritoneal	Male	61	64	62	62
dialysis	Female	34	36	38	38
ALL	Male	56	-	63	62
	Female	36	-	37	38
Ethnicity (%)					
White		78.3	80	80.1	82.2
Black		6.1	2.6	6.1	5.5
Asian		15.6	16.3	10.1	9.1
Chinese		0	0.1	0.7	0.7
Other		0	0.9	2.9	2.6

Table 4. Comparison of study population with dialysis populations in UK.

# 3.4.2 **Qualitative Data**

Qualitative data describing participants' experiences of the body changes resulting from dialysis was collected from the following five open-ended questions on the BIDQ:

- What specifically bothers you about the appearance of body parts which you consider especially unattractive?
- What effect has your preoccupation with your appearance had on your life?

- Has your physical "defect" significantly interfered with your social life? If so, how?
- How has your physical "defect" significantly interfered with your schoolwork, job, or ability to function in your role?
- What do you avoid because of your physical "defect"?

The responses were collated and thematic analysis used to identify common themes which are described below and illustrated, where possible, with anonymised quotes.

# 3.4.2.1 General characteristics

75% of the total sample (37 peritoneal dialysis and 36 haemodialysis participants) answered at least one open-ended question and all but one respondent described feeling distressed by the changes. Haemodialysis and peritoneal dialysis patients reported many of the same problematic aspects of appearance, although a small number were specific to one type of dialysis. All problematic aspects of appearance reported are shown in Table 5. The problems resulting from aspects of appearance reported were common to both groups of dialysis-users therefore the themes are described together.

Peritoneal dialysis	Haemodialysis	Both dialysis types
<ul> <li>Protruding stomach (from presence of the PD fluid)</li> <li>Catheter attached to the peritoneum for inserting the fluid.</li> </ul>	<ul> <li>Fistula and/or catheters (to connect person's blood supply to the dialysis machine)</li> <li>Scars of failed fistulas/catheter sites.</li> </ul>	<ul> <li>Weight loss or gain.</li> <li>Swollen ankles</li> <li>Scars</li> <li>Skin problems</li> <li>Stomach</li> <li>Hair loss</li> <li>Muscle loss</li> <li>Facial differences due to weight changes</li> <li>Itching</li> </ul>

Table 5. Problematic aspects of appearance described by dialysis types.

## 3.4.2.2 Body-image

Participants described feeling that they looked different to other people. They were self-conscious or embarrassed about their bodies and doubted their physical and sexual attractiveness to others. These feelings were present when they were with strangers, family, friends and both potential and established partners. Many participants reported that they avoided undressing or being partially undressed when others were around and subsequently avoided certain activities where this was required, e.g. swimming, other sports, saunas and visiting the beach.

"... as a single man, I am concerned about potential sexual partners' reactions"

Participants stated that they changed the type of clothes they wore to hide certain aspects of their bodies or had been forced to make practical changes for example, wearing loose fitting tops and wearing braces instead of belts as the latter compromised the dialysis access site. Clothes-shopping was often described as a distressing activity to be avoided where possible.

"I think that I look pregnant when going out"

# 3.4.2.3 Social impacts

Participants often stated that they felt more self-conscious and embarrassed in social situations. This impact was not limited to strangers but affected them with friends, family and partners. Participants tried to avoid other people knowing that they were using dialysis and many described being treated differently by other people.

"When people know/find out about "defect" they tend to treat me differently (more tentatively etc)" "I have met with fearful and/or rejecting responses from others"

Participants' low self-esteem meant that they actively avoided meeting new people as well as socialising with familiar people. Some described that they were no longer invited to socialise by certain friends. Even if participants wanted to socialise, the physical effects of dialysis meant they were tired or their dialysis schedule limited their available time. As a result of these problems many participants described feeling isolated.

"(I) don't go out unless necessary.... don't feel normal"

# 3.4.2.4 Impacts on roles

Many participants described difficulties in employment or education resulting from the dialysis-related body changes. Some described actively hiding their illness at work for fear of losing their job, others that the impacts of dialysis had led to them changing roles with their employer, for example being unable to lift, experiencing attention or concentration problems, tiredness and reduced confidence. Many others had been forced to give up work or felt unable to get a job because of their difficulties.

"Had to give up a job which I loved"

"I thought my life was over so I dropped out (of college). I haven't felt well enough or confident enough to find work"

Physical limitations also meant that participants were unable to carry out their usual roles. Commonly people described no longer being able to take part in DIY, gardening, sports, cooking, cleaning and care-giving activities.

"(I can no longer do) anything over physical which I wouldn't have thought twice about prior to 'defect'"

These changes impacted on a person's view of themselves and on the people around them.

"My husband couldn't cope with my illness and left"

# 3.4.2.5 Coping

Reduced confidence, social isolation, physical impacts and the enforced changes in participants' roles impacted on their self-esteem and they described varied coping mechanisms to try and manage these issues. Some tried not to think about their difficulties, others distracted themselves using other activities, whilst some stated that their age meant they no longer cared about their appearance.

"I don't let these thoughts interfere with my daily routine" "I try and get on with other important things such as my children." "At my age (83)....who cares?"

# 3.4.3 Addressing Research Questions

# 3.4.3.1 <u>What levels of psychological morbidity are reported by dialysis</u> patients?

Previous studies have consistently reported elevated psychological morbidity in individuals with ESRF compared to community samples and those with other chronic illnesses (Martin et al., 2004; Christensen & Ehlers, 2002; Crawford et al., 2001; Martin & Thompson, 1999; Clark et al., 1998; Herrmann, 1997; Spinhoven et al., 1997; Finkelstein & Finkelstein, 1993) giving rise to the hypothesis that Levels of psychological morbidity (defined by indices of anxiety and depression) will be higher than those reported by healthy individuals and individuals with other chronic illnesses.

To address this hypothesis, HADS anxiety and depression scores were examined to

look at the proportion of study participants who scored above the cut-off points for

mild, moderate and severe levels of for anxiety or depression (8, 11 and 15

respectively). These are reported in Tables 6 and 7.

Table 6. Sample characteristics of anxiety scores and proportion of individuals meeting criteria for varying anxiety levels.

	SAMPLE								
HADS-An	xiety	Total study sample	HD	PD	Community 1	Renal <sup>2</sup>	Chronically ill <sup>3</sup>		
Characteristics	Mean	7.06	6.81	7.55	3.84-6.14	6.9	4.08-8.47		
	s.d.	5.179	5.001	5.398	-	-	-		
	Median	7	6	7	-	-	-		
	Range	0-21	0-21	0-20	-	-	-		
Percentage of	Mild	41.2	36	47	21.6-40	39	-		
individuals meeting cut-off	Moderate	24.7	22.6	27.2	7–12.6	-	10-39		
point for levels of anxiety	Severe	5.2	6	9	2.6	-	-		

Dialysis patients in the current study reported higher mean levels of anxiety and depression than all community and renal samples and levels in the higher end of the range reported by chronically-ill individuals.

Whilst the proportion of individuals in the current study reporting mild anxiety was slightly higher than the community samples, the proportion reporting moderate or

 <sup>&</sup>lt;sup>1</sup> Crawford et al., 2001; Clark et al., 1998; Spinhoven et al., 1997.
 <sup>2</sup> Martin et al., 2004; Martin & Thompson, 1999.
 <sup>3</sup> Clark et al., 1998; Herrmann, 1997.

severe anxiety was double that found in community samples but similar to those found previously in renal and other chronically-ill samples. The proportion of individuals reporting all levels of depression were higher than community, renal and chronically-ill populations.

	SAMPLE								
HADS-Depression		Total study sample	HD	PD	Community 1	Renal <sup>2</sup>	Chronically ill <sup>3</sup>		
Characteristics	Mean	6.5	7.15	5.8	1.68-4.6	5.2	3.16-8.26		
	Standard	4.094	4.448	3.587	-	-	-		
	deviation								
	Median	6	7	5	-	-	-		
	Range	0-20	0-20	0-13	-	-	-		
Percentage of	Mild	38.1	41.5	34	5-7.8	23	-		
individuals meeting cut-off	Moderate	18.6	22.6	14	2.9	-	17.34		
point for levels of depression	Severe	2.1	6	0	0.7	-	-		

Table 7. Sample characteristics of depression scores and proportion ofindividuals meeting criteria for varying levels of depression.

When the study sample was split by dialysis type, PD participants reported higher mean levels of anxiety and a higher proportion met the criteria for mild, moderate and severe levels of anxiety. HD participants reported higher mean levels of depression and a higher proportion met the criteria for mild, moderate and severe levels of depression. An independent samples t-test carried out showed that the differences between mean levels of anxiety and depression reported by HD and PD participants were not significant (see Table 8).

These findings give partial support to the hypothesis.

Variable	t	df	Sig.	Mean Difference	Std. Error Difference
HADS-Anxiety	.732	89	.466	.801	1.093
HADS-Depression	-1.594	90	.114	-1.350	.847

 Table 8. Independent samples t-test comparing anxiety and depression levels

 reported by HD and PD participants.

# 3.4.3.2 <u>What levels of body-image disturbance are reported by dialysis</u> patients?

Previous studies have found that ESRF patients report increased body awareness and dissatisfaction with individual body parts which may influence their choices of dialysis, dress and activities (Tweed & Ceaser, 2005; Beer, 1995; Sorter et al., 1994) and limited anecdotal evidence describes body-image changes in patients on dialysis (Beer, 1995; Severino, 1980). This led to the hypothesis that *Body-image disturbance rates (defined by scores on the BIDQ) reported by dialysis patients will be higher than those reported by healthy populations.* 

To address this hypothesis, mean total BIDQ scores reported by individuals in the study were examined, one-sample t-tests used to compare them with norms for community samples and then independent-samples t-tests used to compare dialysis modalities within gender groups. These analyses are shown in Tables 9 to 11.

Norms for the BIDQ are 1.57 (*SD* 0.6) for males and 1.81 (*SD* 0.67) for females. The mean levels of BID reported by dialysis patients in this study were higher than those reported in community samples (Cash & Grasso, 2005).

	HD		Р	D	Total study sample		
	Males	Females	Males	Females	Males	Females	
Mean	2.19	2.12	2.15	2.34	2.17	2.22	
SD	1.07	1.09	0.96	1.18	1.01	1.12	
Median	2.14	2.00	2.07	1.86	2.14	1.93	
Range	1-5	1-5	1-5	1-5	1-5	1-5	

Table 9. Descriptive statistics for scores obtained on the BIDQ.

The one-sample t-tests identified that male dialysis participants reported significantly higher levels of BID than community populations both as a group and when divided by dialysis type. Only when all female dialysis participants were considered do their elevated levels of BID reach a significant level, when divided by dialysis type these differences were not significant.

norms. Mean Differen Std error of df mean t Sig. ce Males 4.329 **Total sample** 52 .000 .599811 0.197 3.010 .006 .620476 .206 Haemodialysis 26 3.072 **Peritoneal dialysis** 25 .005 .578352 1.88 **Females Total sample** 2.090 31 .045 .413214 0.138 Haemodialysis .261 .307647 .264 1.166 16

1.752

14

.102

.532857

0.304

Table 10. One-sample t-tests comparing mean BIDQ scores with community

When dialysis modalities were compared using independent-samples t-tests, female PD participants reported marginally higher BID than HD participants whilst male HD participants reported marginally higher than PD participants; however, these differences were not statistically significant.

These findings support the hypothesis.

**Peritoneal dialysis** 

	t	df	Sig.	Mean Difference	Std. Error Difference
MALES	151	51	.525	042125	.279780
FEMALES	.562	30	.289	.225210	.400621

Table 11. Independent samples t-test comparing BIDQ scores between dialysismodality by gender.

# 3.4.3.3 <u>Is there a relationship between an individual's level of body-image</u> disturbance and their reported levels of psychological morbidity?

Studies with nonclinical and chronically-ill populations have found that increased body dissatisfaction predicts higher levels of anxiety and depression (Sinton & Birch, 2006; Cash & Fleming 2002; Beer, 1995; Noles et al., 1985). The dialysis population has not been studied with this factor in mind but consideration of previous findings resulted in the hypothesis that

As an individual's reported level of body-image disturbance increases, their level of psychological morbidity will also significantly increase.

To address this hypothesis, linear regressions were carried out to investigate whether there were significant relationships between BIDQ scores and HADS subscale and total scores. The results of these analyses are shown in Table 12.

This analysis found that for anxiety and depression subscales and for total HADS scores, as the BID of a dialysis patient increases the levels of psychological morbidity they report also increases significantly.

As an individual's score on the BIDQ increases by 1 point, their total anxiety score increases by 2.875 points. Levels of BID reported were responsible for 34.4% of the variance in anxiety reported.

As an individual's score on the BIDQ increases by 1 point, their total depression score increases by 2.242 points. BID was responsible for 33.8% of the variance in depression reported.

As an individual's score on the BIDQ increases by 1 point, their total HADS score increases by 5.169 points. BID was responsible for 40.4% of the variance in total psychological morbidity reported.

These findings support the hypothesis.

Dependent variable	Unstandardised coefficients		Standardised coefficients			
	В	Standard	Beta			
		error		r <sup>2</sup>	t	Significance
Total Anxiety	2.875	.431	.586	.344	6.676	<0.000
<b>Total Depression</b>	2.242	.336	.582	.338	6.671	<0.000
Total HADS	5.169	.685	.635	.404	7.543	<0.000

Table 12. Linear regression of HADS scores against BIDQ scores.

# 3.4.3.4 <u>Is there a relationship between a person's level of self-focus and</u> <u>extent to which they are appearance-schematic and their reported levels</u> of psychological distress and body-image disturbance?

#### (a) Psychological morbidity

The S-REF model suggests that during self-focus an individual compares their current state with regard important specific aspects, such as appearance, against their idealised state. An individual tries to reduce any negative discrepancy between these and becomes distressed if they feel that they have little success in doing so. Since individuals on dialysis incur unalterable physical changes those individuals more prone to self-focus are more likely to notice discrepancies between their body and the ideal and experience subsequent distress. An individual whose sense of self is more invested in their appearance is also more likely to be distressed by these physical changes as the differences they perceive impact more greatly on their sense of self and self-worth. Therefore the hypothesis was that

As an individual's level of self-focus and extent to which they are appearanceschematic increases, the levels of psychological morbidity they report will also significantly increase.

To address this hypothesis, linear regressions were carried out to investigate the extent to which anxiety, depression and total HADS scores were influenced by aspects of self-focus and appearance-schematisation (using subscale and total scores on the ASI-R and SCS). The results of the linear regressions are shown in Tables 13, 16 and 18. All variables found to significantly influence psychological morbidity from the linear regressions were entered into a stepwise multiple regression to investigate

which best predicted levels of psychological distress when the impact of other variables were accounted for. Due to the relationship between subscales and total scores for individual measures, regressions were carried out either with subscale or total scores only. Results of these secondary analyses are shown in Tables 14,15,17,19 and 20.

## (i) Anxiety

Participants' levels of anxiety were significantly influenced by all aspects of selffocus (subscales of the SCS) but only self-evaluative salience and total appearanceschematisation from the ASI-R.

Subscale		Unstan coeffic	ndardised cients	Standardised coefficients			
		B	Standard	Beta			
			error		$r^2$	t	Sig.
	Private self-consciousness	.467	.090	.512	.262	5.193	.000
SCS	Public self-consciousness	.280	.097	.306	.094	2.873	.005
505	Social Anxiety	.274	.131	.239	.057	2.086	.041
	TOTAL	.199	.043	.498	.248	4.661	.000
ACT	Self-evaluative salience	3.381	.713	.471	.222	4.745	.000
A51- P	Motivational salience	.132	.780	.019	.000	.169	.866
IN IN	TOTAL	3.047	.902	.355	.126	3.376	.001

Table 13. Linear regression comparing self-focus and appearance-schematisation with HADS anxiety scores.

When all significant predictors were considered, self-evaluative salience and private self-consciousness accounted for 41% of the variance of anxiety reported. When scores on self-evaluative salience and private-self-consciousness increased by 1, anxiety scores increased by 2.790 and .294 respectively.

	Unstandardised Coefficients		Standardized Coefficients	t	Sig.
Subscale	В	Std. Error	Beta		
Self-evaluative salience Private self-consciousness	2.790 .294	.779 .103	.410 .327	3.581 2.858	.001 .006

Table 14. Multiple regression of anxiety and relevant ASI-R and SCS subscales.

With regard to total measure scores, only self-consciousness significantly predicted the levels of anxiety reported and accounted for 25% of the variance seen in anxiety scores. For every one-point increase on the total SCS score, an individual's anxiety score increased by 0.199 points.

 Table 15. Multiple regression of anxiety and ASI-R and SCS totals.

	Unstanda Coefficier	rdised nts	Standardize d Coefficients	t	Sig.
	В	Std. Error	Beta		
SCS total	.199	.043	.504	4.628	.000

# (ii) Depression

Participants' reported levels of depression were significantly influenced by two facets of self-consciousness (private- and public- self-consciousness) as well as total levels of self-consciousness but only one facet of appearance-schematisation, that of selfevaluative salience.

Subscale		Unstandardised coefficients		Standardised coefficients			
		В	Standard	Beta			
			error		$r^2$	t	Sig.
	Private self-consciousness	.261	.071	.398	.152	3.685	.000
SCS	Public self-consciousness	.167	.074	.247	.061	2.264	.026
505	Social Anxiety	.143	.105	.160	.025	1.362	.178
	TOTAL	.100	.036	.324	.105	2.781	.007
ASI- R	Self-evaluative salience	2.112	.560	.393	.154	3.771	.000
	Motivational salience	959	.597	177	.031	-1.607	.112
	TOTAL	1.367	.711	.213	.045	1.922	.058

Table 16. Linear regressions comparing self-focus and appearance-schematisation with HADS depression scores.

When all significant predictors were added to the regression, self-evaluative salience and private self-consciousness accounted for 26.5% of the variance of depression reported. When scores on self-evaluative salience and private-self-consciousness increase by 1, depression scores increase by 1.762 and .165 respectively. No total measure scores were significant when other variable impacts were accounted for.

Table 17. Multiple regression of depression and relevant ASI-R and SCSsubscales.

	Unstanda Coefficier	rdised nts	Standardized Coefficients	t	Sig.
	В	Std. Error	Beta		
Self-evaluative salience	1.762	.602	.340	2.926	.005
Private SC	.165	.075	.256	2.207	.031

# (iii) Total psychological distress

Psychological morbidity was significantly influenced by private-, public- and total-

self-consciousness along with self-evaluative salience and total appearance-

schematisation.

Dependent variable		Unstandardised coefficients		Standardised coefficients			
		В	Standard	Beta			
			error		r <sup>2</sup>	t	Sig.
	Private self-consciousness	.728	.146	.497	.247	4.990	.000
SCS	Public self-consciousness	.450	.158	.304	.093	2.838	.006
505	Social Anxiety	.417	.218	.221	.049	1.913	.060
	TOTAL	.298	.071	.458	.210	4.189	.000
ASI- R	Self-evaluative salience	5.493	1.133	.471	.221	4.710	.000
	Motivational salience	825	1.289	071	.005	640	.524
	TOTAL	4.416	1.499	.317	.100	2.947	.004

Table 18. Linear regression comparing self-focus and appearance-schematisation
with Total HADS scores.

When all significant predictors were added to the regression, private selfconsciousness and self-evaluative salience accounted for 34% of the variance of total psychological distress reported. When scores on private self-consciousness and selfevaluative salience increased by 1, total psychological distress scores increased by .493 and 3.975 respectively.

Table 19. Multiple regression of HADS total and relevant ASI-R and SCSsubscales.

Uns Coo		lardised Standardised ents Coefficients		t	Sig.
	В	Std. Error	Beta		
Private Self-consciousness	.493	.160	.339	3.081	.003
Self-evaluative salience 3.975		1.291	.339	3.080	.003

With regard total measure scores, only self-consciousness significantly predicted the levels of total psychological distress reported, accounting for 22% of the variance seen in anxiety scores. For every one-point increase on the total SCS score, an individual's anxiety score increased by 0.304 points.

	Unstandardised Coefficients		Standardized Coefficients	t	Sig.
	В	Std. Error	Beta		
SCS total	.304	.071	.477	4.305	.000

Table 20. Multiple regression of HADS total and ASI-R and SCS totals.

The findings for HADS Anxiety, Depression and Total scores give partial evidence in support for the hypothesis as almost all subsections of self-focus and appearance-schematisation influenced the levels of anxiety, depression and overall psychological distress reported. Only motivational salience and social anxiety did not significantly influence levels of anxiety, depression and psychological distress. These subscales measure the extent to which individuals engage in appearance-management behaviours and the degree of discomfort experienced in the presence of other people.

Self-evaluative salience (SES) and private self-consciousness (PrSC) were the most significant predictors and remained so when all other variables were accounted for. SES is the extent that an individual's beliefs about their looks influence their personal or social sense of self and PrSC is one's tendency to attend to one's inner thoughts and feelings.

When comparing total levels of self-consciousness and appearance-schematisation the former was the biggest predictor of anxiety and psychological distress, however neither were significant predictors for depression once the impacts of other variables were accounted for.

The hypothesis was partially supported.

#### (b) Body-image disturbance

The S-REF model suggests that during self-focus an individual compares their current state for a specific physical attribute. An individual on dialysis more prone to self-focus is more likely to report BID as they are more likely to have evaluated their physical appearance compared with the ideal they hold. Equally, an individual who invests more in their appearance is also more likely to report BID as due to the salience of any discrepancy for this domain. The hypothesis was therefore that *As an individual's level of self-focus and extent to which they are appearance-schematic increases, the levels of body-image disturbance they report will also significantly increase.* 

To address this hypothesis, linear regressions were carried out to investigate the extent to which total BIDQ scores were influenced by aspects of self-focus and appearance-schematisation (using the ASI-R and SCS subscale and total scores). These results are shown in Table 19. Following this, any aspects found to significantly influence BID were entered into a stepwise multiple regression to investigate which variables best predicted levels of BID when the impact of other variables were accounted for. Due to the relation between subscales and the total

scores for an individual measure, regressions were carried out either with subscale

scores or total scores only. The results of these secondary analyses are shown in

Tables 22 and 23.

In the current study all aspects of self-consciousness and all aspects of appearanceschematisation except motivational salience significantly influenced the levels of BID an individual reported.

Table 21. Results of linear regressions comparing self-focus and appearance-schematisation with BIDQ scores.

Subscales		Unstandardised coefficients		Standardised coefficients			
		В	Standard	Beta			
			error		r <sup>2</sup>	t	Sig.
	Private self-consciousness	.083	.020	.441	.195	4.259	.000
SCS	Public self-consciousness	.067	.020	.359	.129	3.413	.001
565	Social Anxiety	.077	.028	.316	.100	2.785	.007
	TOTAL	.043	.009	.505	.255	4.713	.000
ASI- R	Self-evaluative salience	.821	.136	.567	.322	6.046	.000
	Motivational salience	.084	.161	.059	.003	.525	.601
	TOTAL	.771	.177	.444	.197	4.343	.000

When the impact of all other variables were considered, self-evaluative salience and private self-consciousness accounted for 25% of the variance in BID reported. When scores on self-evaluative salience and private-self-consciousness increased by 1, BID scores increased by 0.683 and .046 respectively.

	Unstanda Coefficier	rdised nts	Standardize d Coefficients	t	Sig.
	В	Std. Error	Beta		
Total self-evaluative salience	.683	.161	.487	4.244	.000
Private Self-consciousness	.046	.021	.252	2.195	.032

Table 22. Multiple regression of BIDQ scores with relevant ASI-R and SCSsubscales.

Only total self-consciousness predicted levels of BID when other variables were accounted for and accounted for 29% of the variance in BID reported. When scores on total self-consciousness increased by 1, BID scores increased by 0.044.

Table 23. Regression of BIDQ scores and total ASI-R and SCS scores.

	Unstandardised Coefficients		Standardize d Coefficients	t	Sig.
	В	Std. Error	Beta		
SCS total	.044	.009	.539	5.034	.000

When all factors were considered, only self-evaluative salience and private selfconsciousness significantly predicted levels of BID. For totals, self-focus was more important than appearance-schematisation in predicting BID.

These findings provide partial support for the hypothesis.

# 4 Discussion

# 4.1 Study Aims

The current study was designed to identify the levels of psychological morbidity and BID experienced by adult haemodialysis and peritoneal dialysis patients. Data was

interrogated to identify whether BID and psychological morbidity were associated, and then to determine whether an individual's levels of self-focus and schemas relating to appearance were associated with either of the investigated factors. Additional data enabled identification of the impacts of dialysis-induced physical changes.

## 4.2 <u>Research Questions</u>

#### 4.2.1 Impacts of Body Changes

A large proportion of participants completed questions specifying the physical impacts of dialysis and subsequent consequences on their lives. This group was demographically representative of the study sample and wider dialysis populations. Whilst some body changes were specific to dialysis-type, succeeding effects were the same. Participants felt they looked different, were embarrassed or self-conscious about their bodies and felt unattractive to intimates and strangers alike. As a result many altered the clothes they wore and avoided being undressed in the presence of other people. Often respondents hid their dialysis-use and resulting body changes as these were considered stigmatising. Individuals felt forced to give up work or education and all described lifestyle change such as relinquishing activities, physical limitations and social isolation. A few described their coping mechanisms which included distraction, avoidance of reflecting on changes and denial that changes were important to them.

It is clear from the responses that the physical consequences of dialysis impact greatly on individuals' self-esteem, activities, socialisation and relationships and there are farreaching consequences for them and their wider networks. The descriptions illustrate

common issues that are likely to contribute to the high levels of BID and psychological distress reported in dialysis patients.

## 4.2.2 <u>Psychological Morbidity</u>

Consistent with previous findings, mean levels of anxiety and depression and the proportion of individuals in the study meeting criteria for mild, moderate and severe levels of anxiety and depression were higher than found in community populations and within the ranges found in other chronically-ill populations. However, whilst levels of anxiety and number of individuals meeting cut-off levels for anxiety were similar to those previously found in dialysis participants, corresponding results for depression were higher.

Whilst previous studies have been equivocal regarding the influence of dialysis modality on levels of anxiety and depression, in the current study there was a trend for PD-users to report higher levels of anxiety and HD-users to report higher levels of depression. Devins et al., (1983) found that PD-users experienced higher levels of anxiety and depression than HD-users whilst Martin et al., (2004) report the opposite. Zimmermann et al. (2001) found that HD patients experienced greater depression than PD patients but there were no differences in anxiety levels, whilst Killingworth & Van den Akker (1996) and Morris & Jones, (1989) reported no difference between individuals using different types of dialysis. The current study does not therefore fully replicate any of the previous studies and of particular note is that the study sample as a whole reported elevated levels of depression than found previously. The reasons for the trend observed in this study are unclear and further investigation into this would be warranted if these results are replicated in future. Elevated levels of psychological distress experienced by dialysis-users may be explained by the social, vocational and sexual impacts of dialysis. Anxiety and depression levels have been previously found to negatively affect adherence to dialysis regimes (Brownbridge & Fielding, 1994) and depression to be significantly associated with reduced quality of life (Steele et al., 1996). Despite the evidence available for the significant number of individuals affected and the efficacy of psychological interventions on psychological morbidity, such distress is often neglected and unremedied by health professionals working with this population.

#### 4.2.3 <u>Body-image Disturbance</u>

Levels of BID experienced by both males and females in the study were significantly higher than reported in community populations, confirming previous anecdotal evidence. This was true for males on haemodialysis, peritoneal dialysis and the entire sample of male participants but only true for the entire sample of female participants. When grouped by dialysis modality, female PD-users reported marginally higher BID than HD-users whilst the opposite was true for males. However, these differences were not statistically significant. Body-image has been found to negatively influence psychosocial recovery, adaptation to illness and quality of life in other chronically ill populations, therefore the increased levels seen across this sample are concerning.

All individuals in the study reported elevated BID levels, which is perhaps unsurprising given the body changes that occur following dialysis and the subsequent effects on physical abilities, roles, work, education and relationships. As these findings cannot be compared with those from other chronically-ill populations, the possible impact of illness itself on BID levels cannot be discounted. The impact on males found in this study is particularly striking and may be explained by the impact of dialysis-related changes on the roles that are important to them, for example, working or being physically able. It is also possible that traditionally masculine roles reduce acceptability of male concern with body-image. Adherence to masculine convention may also inhibit discussion of such difficulties with others, interfering with adjustment.

It is possible that the small differences in BID between individuals using different dialysis types are influenced by cultural expectations of gender; as the impacts of PD often concern the bulky appearance of the catheter and an increase in weight which may concern females more, whilst effects of HD often relate to the sensitivity of the fistula and decreased physical abilities which may concern males more. Another explanation is that since individuals choose their dialysis modality partly on their prediction of the likely body-image changes (Tweed & Ceaser, 2005) it may be that individuals selecting of a specific treatment type did not anticipate the physical or subsequent impacts with consequent BID. However, not all participants would have actively chosen their dialysis modality.

# 4.2.4 Body-Image Disturbance and Psychological Morbidity

Consistent with previous studies with nonclinical and other chronically-ill individuals, BID was significantly associated with levels of anxiety, depression and overall psychological distress. This link may result from the life-altering impacts of dialysis which are likely to negatively alter an individual's view of themselves. The rejecting and distancing reactions of other people are also likely to make dialysis-users feel different to other people and to their pre-dialysis selves, and to magnify their distress

over physical changes. The study findings support the S-REF model which suggests that BID occurs when an individual identifies irreversible discrepancies between their actual body and ideal body and distress results as they either cannot reduce the discrepancy or reconcile this with their existing schemas relating to the world.

The negative impacts associated with increased levels of psychological distress in renal patients have been described previously and do not require reiteration here but it is important to recognise that any successful intervention addressing BID with individuals would also reduce psychological morbidity and the associated problems of quality of life and mortality.

# 4.2.5 <u>The relationships between Self-Focus and Appearance-Schematisation</u> and Psychological Morbidity and Body-image Disturbance

When considering participants' total scale scores, only Total Self-Consciousness (TSC) significantly predicted levels of anxiety and total psychological morbidity suggesting that self-consciousness and self-focus are more influential than appearance-schemas on the development of psychological distress in dialysis patients.

Placing this in context of the S-REF model, high TSC not only increases the likelihood of identification of discrepancies between ideal and actual physical states, but also limits an individual's attentional capacity to adapt to these changes by amending schema. Subsequently, an individual's inability to reduce discrepancies results in distress. Findings suggest that salience of appearance is not as influential as self-focus and it may be that dialysis-users identify discrepancies in other more salient aspects which are compromised, for example work or social roles, and that high selffocus exacerbates the subsequent distress relating to these factors more than appearance-related factors.

When focusing on subscales of ASI-R and SCS, most significantly predicted anxiety, depression and total psychological morbidity. However, when all variables were considered, only Self-evaluative Salience (SES) and Private Self-consciousness (PrSC) remained significant. SES (an aspect of appearance-schematisation) is the extent that beliefs about a person's physical appearance influence their personal or social sense of self and PrSC (an aspect of self-focus) is the tendency to which an individual focuses on inner thoughts and feelings. In the context of S-REF, individuals high in SES are more likely to compare physical aspects of themselves against their ideal and deficiencies identified are more likely to negatively impact on their sense of self and worth. Inability to reduce discrepancies results in distress. People reporting high PrSC scores are more likely to attend to their own emotions and thoughts related to physical changes (and other lifestyle impacts) and to the resulting distress and their limited attentional capacity to adapt augments their distress.

Public Self-consciousness and Social Anxiety (aspects of self-focus) were not as significant predictors of psychological morbidity contradicting the S-REF model which predicts that an individual's difficulties will be especially activated by social cues. Despite participants reporting social stigma and isolation, what an individual thought of themselves was more important than others' thoughts and actions. Although participants often described hiding changed aspects of their appearance, Motivational Salience (attending to appearance and engaging in appearancemanagement behaviours) did not significantly predict psychological morbidity. It is

possible that Motivational Salience has less influence because, as supported by the qualitative data, an individual's appearance is so obviously altered that all individuals notice the impacts, the repetitive dialysis routine reconfirm these changes and the impact of individual differences in this trait are negated.

PrSC and SES were more weakly associated with depression compared with anxiety and total psychological morbidity and neither total ASI-R or SCS scores were significantly associated with depression when all other variables were accounted for. The S-REF model suggests that depression is related to the appraisal of loss and failure, providing an explanation for the high depression levels reported. However, the model would also predict a stronger association between depression and levels of SES and PrSC. This may be explained by losses unrelated to appearance being more influential, but one would still expect an influence of self-focus on these difficulties to be present. In this way the findings give only partial support for the S-REF model.

When all predicting variables were considered, only SES, PrSC and TSC were significantly associated with levels of BID. Individuals with higher levels of SES are more likely to identify body changes and subsequently report BID as these impact more on their sense of self. Increased levels of emotional reflection in those reporting high levels of PrSC are again likely to increase reports of BID. Previous studies have found that individuals using medical-technology begin to view the technology rather than the illness as their main difficulty to be overcome (Curtin et al., 2002; Burke, 1996). This may heighten body-image dissatisfaction and disturbance in dialysis-users by focussing dissatisfaction on the physical impacts of dialysis rather than ESRF.
## 4.3 <u>Clinical Implications</u>

The levels of anxiety and depression reported in the current study were higher than reported previously in community and other renal samples. In addition, the high levels of BID experienced and the significant impacts described by the participants offer new insight into the experience of dialysis-users. The study identified that levels of BID and psychological morbidity were significantly associated.

The results suggest that a large number of dialysis-users experience significant difficulties which are often neglected by health professionals. This may be because health professionals feel image is a secondary concern whilst patients should feel grateful to be alive. Alternatively, as previous studies report, technology rather than the individual often becomes the focus of health professionals' attention which may result in neglect of the wider issues impacting the dialysis-user (Walters, 1995; Wichowski, 1994).

The study findings should be noted by physical and mental health professionals alike due to the negative implications for the disease, patients' quality of life and levels of mortality. Screening for distress and body-image problems might be incorporated into routine medical follow-ups. As some of the risk factors predicting adjustment difficulties were identified, pre-dialysis screening for these might identify those most likely to develop difficulties. For this to be effective, suitable support must be available, possibly by creating dedicated psychologist or therapist posts.

There is good evidence that cognitive-behavioural interventions are effective in addressing anxiety, depression, dysfunctional schema and BID (NIHCE, 2007a;

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NIHCE, 2007b; Cash & Lavallee, 1997; Butters & Cash, 1987) and any such interventions would have subsequent positive impacts on psychological morbidity and associated effects. As the dialysis population is predicted to rise in the future, successful interventions would impact an increasing number of individuals and families as well as resulting in benefits for wider society, for example, enabling individuals to work for longer. Knowledge of the specific difficulties that individuals may face could be incorporated when educating individuals regarding their choice of dialysis and subsequently preparing them for commencing dialysis.

## 4.4 Theoretical and Research Implications

The current study extends previous research into psychological morbidity in renal populations and addresses under-researched cognitive-schemas in this population. It identifies the relatively high levels of BID in the population and the qualitative data illustrates the significant impacts of dialysis and BID which have previously been unexplored. Corroboration of the current study findings with a larger population would be extremely valuable and replication with other chronically-ill populations warranted. Studies addressing BID and the possible impacts of an individual's gender, ethnic origin and dialysis-modality and a longitudinal study addressing the impact of dialysis on BID would further inform the evidence base.

The study findings provide support for the S-REF model, offering an explanation for the high levels of BID and psychological morbidity in the dialysis population and some of the associated factors. Since certain interventions and risk factors of developing difficulties are implicated, controlled trials examining whether such interventions result in reduced levels of distress and BID in this population as well as investigation into the impact of BID and schema on biomedical outcomes.

## 4.5 Methodological Critique

#### 4.5.1 <u>Design</u>

A pilot study, which was not used, may have identified the increased levels of missing data returned on the SCS measure enabling earlier rectification. The lack of a control group for comparison with individuals with the same chronic illness to identify the impacts of each dialysis type is also a weakness, but this was deemed inappropriate for the reasons outlined previously.

## 4.5.2 <u>Sample</u>

The questionnaire response rates were 35.1% and 43.6% for HD and PD participants respectively. This was slightly below the average of previous questionnaire studies with UK renal patients who achieved between 33 and 78.8% (Murtagh et al., 2007; Lee et al., 2005; Wight et al., 1998) by sending reminders or additional questionnaires to those who failed to respond. NHS ethical constraints prohibited such methods in the current study. However, the large proportion of individuals completing the open-ended questions shows a high level of engagement with the topic. A large number of Asian or Asian-British individuals who were unable to read English were excluded from the study sample but despite this, the demographic profile of the study sample was generally representative of the city the research was carried out in as well as the wider English and UK dialysis populations. It was therefore appropriate to compare current study findings with those from previous studies.

There are additional vulnerabilities that as questionnaires were completed away from the research site it cannot be guaranteed who completed them. Due to the aetiology of ESRF, many individuals develop cognitive decline and whilst individuals issued with packs were informally screened for this by those distributing them, it is possible that some individuals with mild cognitive decline affecting their understanding of the questions may have completed the questionnaire, introducing inconsistencies into the data set. There may also have been a number of participants whose first language was not English who also completed the questionnaires with poor understanding which again may have influenced the results. However, it is anticipated that most individuals who did not understand the questionnaire would not spend time completing it.

## 4.5.3 Measurement

Any missing data from the questionnaires was missing at random for all scales except the SCS which was returned with an increased level of missing data. Whilst this was accommodated in the analysis this remains a weakness as the sample size for calculations using this data were subsequently lower.

One question in the depression subscale of the HADS directly addresses an individual's interest in their appearance which may also have introduced skew into the reported levels given by individuals who are more invested in their appearance.

## 5 Conclusion

The participants in the current study had been dialysis-users for an average of three years but despite this significant length of time, they reported high levels of BID, psychological morbidity and a wide range of subsequent difficulties which have been

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largely neglected by health professionals. Since few of these individuals are likely to receive a kidney transplant, they will be dialysis-users for the remainder of their lives experiencing reduced a quality of life but importantly many will die earlier than they otherwise would either as a result of non-adherence to the dialysis regime or through suicide. The study gives support for the S-REF model as an explanation for psychological distress, identifying traits that may put an individual at risk of developing problems once commencing dialysis and identifying possible areas for intervention. Further study is warranted to corroborate and extend the findings of the current study however this study illustrates to health professionals that whilst individuals' lives are being maintained by dialysis, this intervention is not entirely benign and results in individuals struggling to cope with changed bodies and altered lives.

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Section 3

**Critical Appraisal** 

## 1. Origins of the Study

As an undergraduate student of Neuroscience, I was fascinated by the interface between mind and body and the long-standing debate over dualism. Subsequently I became interested in body-image and especially the phenomena of phantom limbs and phantom pain and investigated them as a dissertation project. When I began working in Clinical Psychology, I was naturally drawn to the area of health psychology, especially the impact of health and illness on one's sense of self. I was intrigued by how individuals externalise illnesses as 'other' and not part of themselves as a coping mechanism and the common refusal to accept the impact of illness on their lives as unimportant. However, since an individual's reaction to illness is also influenced by the impact on their body, if the body is separate and 'other', how does this impact upon an individual's sense of self? As a woman and a feminist the cultural expectations of certain 'desired' body types which are expected of women and increasingly men, is of interest to me and I felt that surely this must impact an individual when the body fails or is altered through illness. These interests converged toward the experiences of end-stage renal failure patients and it seemed intuitive that they may experience difficulties as a result of the physical changes resulting from dialysis. A range of health professionals working with ESRF patients supplied anecdotes that supported this prediction and whilst the published informative literature for patients and the staff concurred, I could find no direct evidence that backed up this 'perceived wisdom'. The same professionals were dumbfounded when I informed them that this area was understudied and unproven. However, as studies with other populations had found these to be important aspects, I therefore felt that such evidence could provide the foundations for future research in this area and this augmented my enthusiasm. Identification of the scale of such difficulties would also

add to the evidence-base for renal staff, and once identified, perhaps suitable support or intervention might be available for patients.

Many health services across the country have Health Psychology departments working solely with individuals with health problems and there are also specific posts for working with renal patients, however, body-image problems are underrepresented in such work. I wondered if this was because the prevalent medical model is one of 'fixing' problems as the focus of the clinicians' work with individuals, consequently, the sense of a person often becomes lost. It is as if individuals should be grateful that they are alive, and that their reduced quality of life or radically changed lifestyles should not be of concern to them or those working with them.

## 2. The Research Process

## 2.1. Planning the Study

My previous research experience had been such that I had previously never required ethical approval through the COREC. I found the combination of meeting the requirements for approval by COREC, the NHS and the University bewildering at times. Since commencement of the current study, these systems have been altered and improved but at the time that I progressed through the system the various tasks involved appeared endless and incomprehensible. Each organisation had its own set of rules, regulations, paperwork and ethical standards meaning that processes of peer review were replicated, a myriad of individuals were required to read and sign paperwork as well as requesting additional tasks. To my frustration, each organisation had different timescales and all perceived that their requirements took precedence over the others. Most exasperating and perplexing was the pervading sense that I was the first person to go through this process (because I was expected to identify the required sequence often without advice and when I sought information it was often difficult to obtain), although this was clearly not the case. It was time-consuming and effortful enough to identify the 'known unknowns' let alone ascertaining the 'unknown unknowns'. I chose to overcome these challenges by acquiring a full and comprehensive knowledge of my proposal and by carrying everything of relevance to the project around with me in anticipation of unexpected eventualities.

Researching in a team and department in which I did not work brought practical difficulties and I was reliant on nursing staff to help me iron out these details, for example, the numbers of patients available, when and where to distribute questionnaires and other aspects whilst ensuring that I remained within the constraints of the NHS Research and Development protocols. I found the clinical members of staff to be very accommodating during the planning process and I was buoyed by their enthusiasm for the subject as this reiterated the clinical relevance and need for the research.

## 2.2. Execution of the Study and Data Analysis

Although I considered the study to be extremely important to the evidence base and clinical work with ESRF patients, I had initial concerns about asking individuals to take part in the study when I was aware of the daily difficulties they were facing but I feel now that I also forgot that these were adults who could make informed choices and just as easily throw a pack away as complete it. However, once the study was underway I was heartened by their reactions to the study and many individuals

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appeared to be pleased with the opportunity to describe their experiences of an aspect of their lives that had never or very rarely been addressed with them.

#### **Maintaining Motivation**

Planning, carrying out and writing-up the research and literature review required me to take the long-view of the project as a whole and to maintain motivation over an extended period of time. Whilst I consider time-management and organisation to be amongst my strengths, it was difficult at times to sustain momentum when the final deadline was many months away. At times it was possible, and indeed essential, to impose smaller deadlines on the work by splitting the work into sections. However, once these were achieved, the bulk of the remaining work required me to complete the report and the deadline for this was distant enough to stifle my impetus to complete it.

I identified a number of periods where I felt lost in a 'fog' of data or literature and could not see in which direction the work was going or needed to go. It felt difficult to see the meaning and structure of the information at my fingertips and I became anxious that no meaning would emerge or that I would never finish the work. After a period of time of wading through the information, it was possible to see the meaning and the 'fog' lifted to reveal the 'path' on which I needed to travel. This was both a positive and a negative experience as I could see where I was going and how I would get there but I was also suddenly able to recognise the large amount of work that would be required to get to that point. When nearing completion of writing-up I began to see a light at the end of the tunnel and found I wanted to concentrate on the thesis at all times. Despite recognising that this was not feasible or desirable, the pull to finish the work during every waking moment was very strong. Following this came recognition that I would have to identify a point to stop or I would simply continue amending the document forever. Knowing when the document was 'good enough' was extremely difficult.

## 2.4 Managing Research and Clinical Commitments

Whilst carrying out the research I was neither geographically close to where the research was occurring nor working in the field of Health Psychology. This had subsequent practical implications but also meant that mentally I had to shift from one mindset to another when research days followed clinical workdays and vice versa. This was a task in itself and proved more difficult than I had predicted as well as partly limiting the productivity of my research days due to the initial time it took to recognise what point in the process I was at and what tasks I should work on next. In order to overcome this I made detailed lists and flowcharts of my progress through the research tasks.

## 2.5 Use of Supervision

Research supervision was offered regularly and I found that I used it to address practical issues whilst capturing reflections and emotional responses in my research diary. I consider this to have been the most appropriate use of the supervision, perhaps because the work was mainly quantitative I did not feel at any time that the emotional impacts were impacting enough to require discussion in this forum. I received positive comments as well as constructive criticism from my research supervisor and was interested to find that in the final stages of the research that although my supervisor had a great deal of expertise on writing reports, publications, research methods and analysis, that I had become the expert on my research and that ultimately I had to trust my own judgement regarding the focus of writing-up and knowing when to stop.

## 2.6 Issues of Control

I found being reliant on other people who could delay or expedite the study to be a particularly difficult aspect of the research process. Whilst I encountered few actual delays and obstructions, the process of handing over my work was a challenge and it felt uncomfortable to leave your project in the 'care' of another person who had no vested interest in its success. I found that this feeling was evoked even when considering participants of the study and found myself feeling personally affronted when people did not fully complete the questionnaires or made comments in the margins or on the open-ended questions that they had no difficulties with dialysis. I began looking to see if they had contradicted themselves by the responses on the rest of the questionnaire (and often they had) but this appeared on reflection to be a defensive response to a project I was extremely invested in and which I felt was worthwhile. I felt that these individuals were questioning the merits of my study and this reflected on my merits too. In this way, the project had become more than an experiment but was something I felt I needed to protect and guide. On reflection of these feelings, I attempted to take a step back and put some distance between the project and me as a person or researcher.

## 2.7 The Impact of Contact with Participants

During the planning process, a large number of individuals using dialysis were kind enough to describe their experiences of ESRF and dialysis to me. Through these individuals I saw the significant impacts that dialysis has on individuals' sense of self, lifestyle and support networks. These human stories shocked me more than I had anticipated it would and I reflected that perhaps I had previously ascribed to the medical view that people would (or should?) be grateful for being alive and subsequently tolerate any of the iatrogenic effects of dialysis. As I came to realise, dialysis itself was often a considerable and underestimated ordeal that took a great deal of energy and commitment to overcome before one could even think about living a 'normal' life.

I had very little contact with participants during the execution of the study as the questionnaires were completed and returned anonymously. Subsequently felt that there was a large amount of distance between the participants and myself, as they became just a number on a spreadsheet. However, this feeling of distance declined as I compiled the qualitative data and read about the personal impacts of dialysis. This data gave a richness to the study, as if the quantitative data formed a skeleton and the comments put flesh on this to form a human being with a human existence. This reminded me that these were real people, struggling with real and important experiences and I felt I had a responsibility to tell their stories but also to do my utmost to publish the study findings and show health professionals what was being missed.

## 2.8 The Impact of Myself as a Researcher on the Research

Although I had little contact with participants during the actual study, my interest meant that I had focussed on the aspect of body-image. My personal style was infused throughout the participant invitation and information sheets but it will not be possible to identify what impact this had on the individuals. A structured methodology was

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used to analyse the qualitative data to limit any bias being introduced, however, it must be considered that my personal judgement and opinions may have influenced the interpretations made of the respondents' comments and the importance placed on these.

## **3** Learning Outcomes

I have learnt a great deal about managing a research project, the barriers posed by the systems one researches and about my own strengths and weaknesses regarding research. Perhaps the biggest learning curve for me was carrying out a truly systematic literature review, which I feel not only gave me a thorough grasp of the methodology but also taught me how to identify and overcome the inherent difficulties. Qualitative literature reviews were relatively novel to me, and narrative reviews even more so, but I found that placing participants' stories at the heart of the review was extremely interesting and fleshed out the theories and research in a way that made the field easier to understand as well as being more engaging. Critiquing the quality of research was a revelation as through this I identified how much I have learnt since doing similar exercises as an undergraduate. With an enhanced ability to recognise good-quality research came recognition of poor quality research and I was at times disillusioned with some of the work published in the field. This also brought its own anxieties as I became aware that others may be critiquing my work in a similar manner in the future and I was keen not to be found wanting.

Before embarking on the research I was already aware that I approach work in an organised manner and do not like to complete things at the last-minute and these factors helped during the process. I was also aware that I am a relatively untidy person

and work with a number of piles of documents in addition to a more organised filing system. Whilst initially attempting to change these latter methods, I learnt that doing so hindered rather than helped my work and I now fully accept that I will likely be an individual who always works amongst 'organised chaos' and that embracing this resulted in more time spent working and less time spent tidying.

## **4** General Reflections

At times I became distracted by the wealth of information available and whilst I should have been concentrating on one thing, something else interesting and yet not entirely (or at all) relevant would catch my interest and send me off on a tangent. I learnt to put research 'blinkers' on in order to curb this curiosity and maintain focus during literature reviewing and doing background research. However, I again began to slip back into this habit when analysing the study findings and was tempted to be over-inclusive despite the weakly powered conclusions that would inevitably emerge if I were to 'trawl' the data. Once I identified these temptations, I was able not to succumb to them and to address solely the defined hypotheses. I feel that this process offered me a glimpse of the obsession that individuals develop for a subject as I fleetingly felt that whilst this research was valuable, the small insights it offered were not sufficient and that more would be needed.

I experienced a constant fear throughout the research process, but especially when writing-up, that someone would embark on a similar study before I could complete mine; therefore rendering it pointless. Despite this, it was extremely motivating to be undertaking 'real research' with 'real people' and building on existing evidence with strong clinical relevance. This was especially so when analyses identified the high

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levels of difficulties reported by the sample. I was pleased to be part of something that clinicians might use one day, with other people building on the work, and more importantly, may make a significant difference to someone's life. Appendix A. Guidelines for authors: Journal of Advanced Nursing

# JOURNAL OF ADVANCED NURSING

# **Guidelines for Authors**

# **Review Papers**

Journal of Advanced Nursing publishes high quality traditional literature reviews, aggregative and interpretive reviews, qualitative, quantitative and mixed method systematic reviews, meta-analyses, metasummaries and meta-syntheses. Review papers should not exceed 5000 words for the main text, excluding the abstract, summary

statement, tables and references. The following headings should be used:

Title .

> Should end with a descriptor that best describes the type of review, such as: literature review, qualitative, quantitative or mixed method systematic review, meta-summary, meta-synthesis or meta-analysis.

Abstract

The 250 word abstract should use the following headings: Aims (of the paper), Background, Data Sources, Review Methods, Results, Conclusion.

**Summary Statement** . Please see the Summary Statement guidelines for further information.

# **Summary Statements**

# What do I need to include in my summary statement?

For all summary statements, please use the following guidelines:

## Format

To be headed SUMMARY STATEMENT and put on a separate, but numbered, page after the abstract. The two headings should be in bold:

- What is already known about this topic .
- What this paper adds .
- Under each of the two headings, there should be 2-3 bullet points. ٠
- Each bullet point should be concise, with between 20 and 30 words in each point. ٠
- Each bullet point should stand alone as a meaningful statement (i.e. not rely on preceding . statements).
- All bullet points should be derived from the content of the paper and be supported by the evidence . presented in the paper.
- The summary statement should not contain abbreviations or references. ٠
- Colloquial terms and local details should not be included, and nor should the paper's country of . origin (unless that is essential, pertinent information). Instead the statements should be framed globally.

## For example Summary Statements, please see below:

## What is already known about this topic

Severe visual impairment caused by macular degeneration is a health-related experience common ٠ to many older adults worldwide.

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- Most existing guidelines for the ethical conduct of health research are for biomedical research and cannot easily be applied to qualitative studies.
- The Roy Adaptation Model has been tested in various settings and with various populations but its
  validity in the context of chronic pain has not been investigated.
- Agoraphobia is a common and disabling mental health disorder.
- The over-75 years age group, with its complex health needs, is likely to make up an increasing
  proportion of the workload of accident and emergency staff in the coming years.
- Immigrants and refugees with diabetes are frequently described as at risk of poor metabolic control.
- The terms care and caring are often used in the nursing literature as if the core attributes were already known, but the terms remain ambiguous.
- Poststroke depression is potentially treatable, but is often missed.

# What this paper adds

- Nurses can facilitate client self-management in mental health care for agoraphobia.
- Debriefing is a structured psychological intervention for which a clear and consistent framework or model should be used to enhance the rigor of future research and evaluation of routine postnatal debriefing.
- The literature reflects widespread interest in understanding the psycho-spiritual needs and experiences of individuals with advanced cancer, as evidenced by investigations around the world and across disciplines.
- Minimum standards for applying an instrument developed in another language should include backtranslation and monolingual testing
- An alcohol-based surgical hand rub is more effective than a 6-minute surgical ahnd scrub using 4% chlorhexidine gluconate in terms of microbial counts immediately after scrubbing.
- Pressure ulcers cause much pain, discomfort and distress that is not always recognised or adequately treated by nursing staff.
- The proportion of nurses dissatisfied with shift handovers varies considerably across Europe.
- Close relatives experience chaotic suffering when confronted with contradictory signs of life and brain death is seen as a 'living death'.

## • Keywords

Should include 'literature review' and other MeSH headings appropriate for the specific review, such as 'systematic review', as well as subject-specific keywords.

# Introduction

As for empirical papers – should include rationale, conceptual or theoretical context, international relevance of topic.

# The Review

# Aim/s

- Of the review
- Include research topic/ objectives / questions / hypothesis(es)
   For example, "The aim of the (type) review was to..."

# Design

Should identify type of review, methods used and sources of reference, such as the Cochrane Handbook, Centre for Reviews and Dissemination Handbook, EPPI approach, Joanna Briggs Institute approach, or other rigorous systematic review methodological approach. Should identify and adhere to relevant gold standards for the reporting and conduct of systematic reviews such as the QUOROM statement for meta-analyses of RCTs (see <u>http://www.consort-</u> <u>statement.org/?o=1065</u>) or, for example, ESRC guidance on Narrative Synthesis.

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**Search methods** 

Should include: search strategy, inclusion/exclusion criteria, databases searched, keywords, languages and inclusive dates of the literature searched.

# Search outcome

Search outcome and audit trail if appropriate - application of inclusion/exclusion criteria, retrieval and selection of references and handling. Summarise included and, if appropriate, excluded studies in separate tables.

# Quality appraisal

Should include approaches used and audit of discarded studies. For qualitative and traditional reviews, include a statement as to whether included studies were quality appraised or not and a supporting rationale.

## **Data abstraction**

Systematic reviews should include a description of the process(es).

# **Synthesis**

Should include description of process(es) used.

# Results

With appropriate subheadings and should adhere to the relevant standard(s) of reporting (eg QUOROM statement for systematic review of RCTs). Where appropriate, identify the conceptual or theoretical context of each definition or discussion of the concept found in the literature.

# Discussion

Start with limitations and strength of the evidence. Draw out the applicability, theoretical and practical implications of the findings.

# Conclusion

Real conclusions, not just a summary/repetition of the findings.

Recommendations for practice/research/education/management as appropriate, and consistent with the limitations.

Where appropriate, consider whether one or more nursing conceptual or theoretical frameworks could guide future research about the topic of the review.

# Links to useful resources

- Moher D, Cook DJ, Eastwood S, Olkin I, Rennie D, Stroup DF, for the QUOROM Group. • Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. Lancet 1999; 354:1896-1900. www.thelancet.com
- Popay J, Roen, K, Sowden A, Rodgers M, Roberts H, Arai L, Pettigrew M. Baldwin S. (2006) • Developing Methods for the Narrative Synthesis of Quantitative and Qualitative Data in Systematic Reviews of Effectiveness. ESRC Research Methods Programme. http://www.ccsr.ac.uk/methods/projects/posters/popay.shtml

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- Centre for Reviews and Dissemination http://www.york.ac.uk/inst/crd/
- Cochrane Collaboration http://www.cochrane.org/
- EPPI Centre http://eppl.ioe.ac.uk/cms/
- Joanna Briggs Institute www.joannabriggs.edu.au •
- National Institute for health and Clinical Excellence www.nice.org.uk/ ۲
- Social Care Institute for Excellence www.scie.org.uk •

Appendix B. Descriptions of medical technology included in the review.

## Artificial pacemakers

An artificial pacemaker uses electrical impulses to regulate heartbeat in a person whose natural pacemaker in the heart is not working. Electrodes providing the electrical impulses are placed within a chamber, or chambers, of the heart whilst the pacemaker generator (comprising a battery, sensors to monitor the heart's rhythm and computer controller) is implanted below the subcutaneous fat of the chest wall, above the muscles and bones of the chest.

## Implantable cardioverter-defibrillator

An implantable cardioverter-defibrillator (ICD) is a small battery-powered electrical impulse generator is implanted in participants who have experienced or are at risk of sudden cardiac death due to heart rhythm defects. The device is programmed to detect cardiac arrhythmia and correct it by delivering a jolt of electricity. Similar to pacemakers, these devices typically include electrode wire/s which passes through a vein to the right chambers of the heart.

## <u>Dialysis</u>

Dialysis removes body wastes and water from the blood via diffusion, usually undertaken via healthy kidneys, comprises two types of Dialysis: haemodialysis (HD) and peritoneal dialysis (PD). In the latter, fluid from a bag is drained into the peritoneal cavity in the abdomen via a catheter (which remains in situ permanently) where the abdominal lining acts as a membrane for dialysis. The fluid is left in situ until dialysis is complete and then drained out. This is usually carried out by the patient themselves about three times a day. In HD, a machine removes blood from the body, pumps it through a dialysis machine where the blood is cleaned and pumped back into the body. This is usually done three times a week and sessions last 3-5 hours. Access to the blood stream is by a dialysis catheter inserted into a large vein or by a fistula (made by joining a vein to an artery).

## Insulin pumps

An insulin pump administers insulin to treat diabetes mellitus as an alternative to multiple daily injections of insulin by insulin syringe or an insulin pen. The pump (including controls, processing module, batteries and insulin reservoir) is kept on the skin surface whilst the cannula delivering the insulin is implanted subcutaneously.

## Mechanical ventilation

Mechanical ventilation is a method to mechanically assist or replace spontaneous breathing when participants cannot do so on their own. The main form of mechanical ventilation currently is positive pressure ventilation, which works by increasing the pressure in the patient's airway forcing additional air into the lungs. Appendix C. Timeframes of databases searched.
- MEDLINE 1950 to 2008
- EMBASE 1980 to 2008
- PsycINFO 1984 to 2008
- ISI Web of Science 1970 to 2008
- AMED 1985 to 2008
- World Cat Dissertations 1978 to 2008
- National Library for Health
- Kings Fund 1979 to 2008
- CINAHL(R) 1982 to 2008
- The Cochrane Library
- Healthcare Commission

### Appendix D. Guidelines for authors: Kidney International



# Table of Contents

About the Journal Preparation of Manuscripts Content Types Format of Manuscripts Figures and Tables Supplementary Information Submission and Publication Appendix

<u>p1</u>  New Membership Category Introduced for Members in Training

Trainees in nephrology up to the age of 37 years are now encouraged to apply to become ISN Members in Training at a greatly reduced annual membership rate of US\$ 50 (all benefits included). Eligible individuals must submit a copy of a valid form of identification stating their date of birth as well as a proof of their current training status to the ISN Global Headquarters together with their completed application.

# About the Journal

PUBLICATION CHARGES (Do not apply to invited authors)

### Page charges

Manuscripts accepted for publication in Kidney International will incur page charges to cover, in part, the cost of publication. A charge of \$70 will be issued for each journal page.

## Color charges

 All figures that are submitted as color artwork must be published in color. The authors will be expected to contribute towards the cost of color art . The cost for reproducing color artwork in print is \$500 per page. Color figures will be set close to the citation and in the best possible position. Figure re-ordering cannot be undertaken at proof stage to reduce the number of pages featuring color artwork.

Upon acceptance authors must fill in the artwork form available at http://mc.manuscriptcentral.com/societyimages/ki/KI%20Artwork% 20Form.pdf

context. These will form a research tool for clinical and basic investigators.

- Editorials that highlight important issues in international nephrology
- Nephrology sans Frontieres occasional short articles that • discuss matters of local interest to nephrologists around the world, but which we feel need to be known by nephrologists world-wide
- Short reviews on hot topics and in depth reviews about ma-• jor issues in renal research.
- Controversial discussions on renal therapeutics or diagnosis written by two opposing authorities
- State of the Art teaching materials including Renal Consults ٠ and clinico-pathological conferences where eminent clinicians discuss difficult or interesting cases illustrated by multiple pathology, imaging studies and charts
- Images in Nephrology which are presentations of interesting images in renal pathology, radiology chosen for their illustrative nature or simply for their esthetic qualities.
- Issues of importance to the international renal community

## Offprints

Offprints may be ordered using the order form available for download with the proofs.

## **IMPACT FACTOR**

2006 impact factor 4.773 3/55 Urology and Nephrology

## ISSN ISSN: 0085-2538 EISSN: 1523-1755

## FREQUENCY

Printed twice a month. Advance online Publication once a week

## SCOPE

Kidney International aims to inform the renal researcher and the practicing nephrologist on all aspects of renal research, including:

The latest clinical studies on emerging developments in re-•

including the politics of funding; of organ transplantation, of adequacy of dialysis, of world-wide affordability of end stage renal care and many other topical issues.

- Journal Club are synopses that bring you the latest research highlights from across a wide spectrum of journals in fields relevant to renal research
- **Book Reviews** •

## **ABSTRACTED/ INDEXED IN**

- Index Medicus/Medline
- Science Citation Index
- **Current Contents/Life Sciences**
- **Current Contents/Clinical Medicine**
- SciSearch
- BIOSIS
- Chemical Abstracts
- EMBASE/Excerpta Medica
- Reference Update
- CABS
- **Biological Abstracts**
- Global Health
- MDX Health Digest
- EBSCO

nal medicine.

- The highest level of original research studies in clinical and • basic renal research.
- In each issue, some articles will be highlighted by commen-۲ taries that aim to put these studies in the appropriate

Adonis PASCAL

# Preparation of manuscripts

Manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review.

# **Content Types**

The types of manuscripts accepted by KI are: (1) Review, (2) Minireview, (3) Original Article, (4) Rapid Communication, (5) Commentaries, (6) Technical Notes, (7) Letters to the Editors (8), Editorial (9), Renal Consult, (10) Nephrology Images, (11) Make Your Diagnosis, (12) Book Reviews, (13) ISN Forefronts in Nephrology, ISN Nexus, Meeting Report, (14) Cover Image. Abstract: 75 words maximum References: up to 10 including the article discussed Figures/tables: 1 figure (will be redrawn) Disclosure statement required (see page 3 for details) Commentaries discuss a paper published in a specific issue and should set the problems addressed by the paper in the wider context of the field.

(6) Technical Notes

Word limit: 1500 words including abstract but excluding references, tables and figures.

Abstract: 1500 characters maximum

References: up to 20

Disclosure statement required (see page 3 for details)

Examples of appropriate subject matter include descriptions of new laboratory or clinical methods, new apparatus, or critical modifications of established techniques. Organization of Technical Notes should be the same as for regular manuscripts except that section headings should be omitted.

## (1) Review

Word limit: 5,000 words including abstract but excluding references, tables and figures.

Abstract: 1500 characters maximum

References: no maximum

Figures/tables: at least 1 image or figure

Disclosure statement required (see page 3 for details)

Reviews are comprehensive analyses of specific topics in nephrology that are usually solicited by the Editors. Proposals for reviews may be submitted; however, in this case authors should only send an outline of the proposed paper for initial consideration. Both solicited and unsolicited review articles will undergo peer review prior to acceptance. *Kidney International* will cover charges for color images invited by the Editors, and for images in which color was added by the journal.

## (2) Minireview

Word limit: 3000 words including abstract but excluding references, tables and figures.

Abstract: 1500 characters maximum

References: up to 20

Figures/tables: at least 1 image or figure

Disclosure statement required (see page 3 for details)

Minireviews of topical and highly focused subjects are usually solicited by the Editors. Proposals for minireviews may be submitted; however, in this case authors should only send an outline of the proposed paper for initial consideration. Both solicited and unsolicited review articles will undergo peer review prior to acceptance. *Kidney International* will cover charges for color images invited by the Editors, and for images in which color was added by the journal.

### (7) Letters to the Editor

Word limit: 250 words

Abstract: no abstract required for this manuscript type

References: Up to 4

Figures/ tables: Up to 1

Letters to the Editor will be considered for publication, subject to editing. Letters must contain information critical to a certain area or must be confirmatory of data recently published in *Kidney International*. A Letter must reference the original source, and a Response to a Letter must reference the Letter in the first few paragraphs. Letters can use an arbitrary title, but a Response must cite the title of the Letter: e.g. Response to [title of Letter].

(8) Editorial [only by invitation of Editors]

Word Limit: 1600 words

Abstract: no abstract required for this manuscript type

References: up to 5

Proposals for Editorials may be submitted; however, in this case authors should only send an outline of the proposed paper for initial consideration.

## (9) The Renal Consult

Word Limit: 2000 words including abstract but excluding refer-, ences, tables and figures.

Abstract: no abstract required for this manuscript type Figure/ Table: up to 5

## (3) Original Article

Word limit: 4000 words including abstract but excluding references, tables and figures.

Abstract: 1500 characters maximum

References: no limit

Disclosure statement required (see page 3 for details)

Full-length reports of current research in either basic or clinical science.

(4) Rapid Communication

Word limit: 1500 words including abstract but excluding references, tables and figures.

Abstract: 1500 characters maximum

References: up to 35

Figures/ tables: up to 4 in total

Disclosure statement required (see page 3 for details)

Methods or findings that will substantially and immediately affect research or clinical practice will be considered for publication as a Rapid Communication. The words "Rapid Communication" and the category chosen must appear at the top left corner of the title page. Organization of Rapid Communications should be the same as for regular manuscripts.

### References: up to 20

This is designed to enhance the value of the journal for the practicing nephrologist and nephropathologist. In this series, focused problems in the diagnosis and treatment of renal disease will be published. A short case vignette will be followed by a discussion and relevant references. The use of clinical illustrative materials, such as x-ray films and biopsies is encouraged as are flow diagrams and tables.

### (10) Nephrology Images

Word limit: Title: 70 characters; text: 300 words (1700 characters) Figures: up to 2 single panel figures. No multi-part figures allowed. References: none

Abstract: no abstract required for this manuscript type

Illustrative images that are unique or highly illustrative of specific occurrences in Nephrology. They might include renal pathology, radiology, specific skin lesions, etc. They will be reviewed by the Editorial Board prior to acceptance. They should be accompanied by a brief one-paragraph description of relevant clinical information. Article must fit onto one page. You will be asked to cut text or part of your figure in the proof if article is longer than one page.

### (11) Make Your Diagnosis

Word limit: Title: 70 characters; The Case (page 1): 245 words

(5) Commentaries [only by invitation of Editors] Word limit: 1500 words including abstract but excluding references Title: up to 115 characters including spaces (1400 characters); The Diagnosis (page 2): 405 words (2300 characters). Word limit excludes references, tables and figures. Abstract: no abstract required for this manuscript type References: up to 5 Figures/tables: up to 2 per page

This column provides readers with an opportunity to make clinical diagnoses based on an image accompanied by the history and physical exam, all of which will be on the first page. The second

2



page will include the answers, a brief discussion and any other relevant follow up images and laboratory data.

### (12) Book Reviews

Word limit: 500-1000 words excluding references Abstract: no abstract required for this manuscript type References: up to 3

Book Reviews are intended to alert readers to work that is potentially important to the field of nephrology and to put a certain work in context with the rest of the nephrology literature. Book Reviews will follow this outline: (a) exact title of book, full name(s) of author(s) as listed on the cover, publisher's name, publication date, number of pages and price, (b) summary of the content (general discussion of what the book covers and its major topics; NOT a chapter by chapter summary), (c) discussion of author(s) (for example, background, experience, why they are qualified to write the book and whether they present a certain view), (d) strong points of the book, (e) weak points of the book, (f) identification of the audience of this book and the background needed for the reader to understand its contents, (g) discussion of why one should or should not buy the book, and if yes, for what purpose (as a text, a reference, etc.), (h) comparison to other books in the field, and (i) if possible, a "quotable quote" or annotation regarding the book.

- Discussion
- Methods
- Disclosure
- References
- Acknowledgements

### **Abbreviations**

Abbreviations should be defined at the first mention in the text and in each table and figure. For a list of standard abbreviations, please consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

### Disclosure

For original articles and reviews only, the submitting author must include a disclosure statement in the body of the manuscript. The statement will describe all of the authors' relationships with companies that may have a financial interest in the information contained in the manuscript. This information should be provided under the heading titled 'Disclosure,' which should appear after the 'Methods' section and before the 'References' section. The absence of any interest to disclose must also be stated. In addition, any financial interests must be detailed in the Financial Disclosure form, which will be provided to the corresponding author upon acceptance for distribution to each author.

(13) ISN Forefronts in Nephrology, ISN Nexus, Meeting Report [only by invitation of Editors]

Word limit: To be determined in consultation with Editors

Abstract: 1500 characters maximum

References: no maximum

Figures/tables: at least 1 image or figure

Disclosure statement required (see page 3 for details)

These are authoritative proceedings of specific topics in nephrology that are usually solicited by the Editors. Proposals for these articles may be submitted; however, in this case authors should only send an outline of the proposed paper for initial consideration. Both solicited and unsolicited articles will undergo peer review prior to acceptance. Kidney International will cover charges for color images in articles invited by the Editors.

(14) Cover Image Size: approximately 8.5"x5.5" (216x140mm) Resolution: 300 dpi File type: TIFF or JPEG Color images: CMYK (no RGB) Caption: 50 words maximum

### References

References should be listed in order of appearance (Vancouver style). In the text, number references in order of appearance using Arabic numerals (e.g. 1, 2, 3) in parentheses for citations. The reference list (starting on a separate page) should contain the references in the order in which they are cited in the text. Only published works (as well as manuscripts already accepted for publication) which are referred to in the text should be listed in the reference list. The reference list must not contain any unpublished observations, personal communications, etc. Kindly cite such sources solely within the text (in parentheses), not in the reference list. Do not list more than three authors per reference. Should there be four or more, please include only the first three followed by "et al."

The following examples demonstrate correct reference style:

# Format of Manuscripts

## **GENERAL FORMAT**

Manuscripts must be typed in English and double-spaced. All text including legends, footnotes, tables and references are to be on one side of the page only. All manuscript pages must be numbered.

### Title page

This should include (a) the complete manuscript title; (b) all authors' full names (listed as first name, middle initial, last name), highest academic degrees, and affiliations; (c) the name and address for correspondence, fax number, telephone number, and email address; and (d) the sources of support that require acknowledgment. A running headline of no more than 50 characters (not counting space) should be supplied.

### Abstract and Keywords

The abstract should be no longer than 1500 characters, stating the main problem, methods, results, and conclusions. There should be no subheadings in the abstract. It must be factual and comprehensive. The use of abbreviations and acronyms should be limited and general statements (e.g. "the significance of the results is discussed") should be avoided.

Journal articles:

Fan SL-S, Almond MK, Ball E, et al. Pamidronate therapy as prevention of bone loss following renal transplantation. Kidney Int 2000; 57: 684-690.

### Supplement articles:

Fogo AB. Glomerular hypertension abnormal glomerular growth, and progression of renal diseases. Kidney Int 2000; 57 (Suppl 75): S15-S21.

### Books:

Lameire N, Mehta RL (eds.). Complications of Dialysis. Marcel Dekker, Inc.: New York, 2000.

### Articles in books:

Weidner N, Buckalew VM Jr. Sickle cell anemia, sickle cell trait, and polycythemic states, in Renal Pathology (vol 2), eds. Tisher CC, Brenner BM. JB Lippincott Company: Philadelphia, 1989, pp 1417-1436.

### ORIGINALITY

A submitted manuscript must be an original contribution not previously published (except as an abstract or preliminary report), must not be under consideration for publication elsewhere, and, if accepted, must not be published elsewhere in a similar form, in any language, without the consent of the ISN. Each person listed as an author is expected to have participated in the study to a significant extent and agrees with submission of the paper for publication. Although the editors and referees make every effort to ensure the validity of published manuscripts, the final responsibility rests with the authors, not with Kidney International, its editors, the International Society of Nephrology or Nature Publishing Group.

## Text

The manuscript should be organized under the following seven headings:

- Introduction
- Results



## **INFORMED CONSENT AND ETHICS**

When reporting experiments on human subjects, indicate whether the procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Helsinki Declaration of 1975 (and as revised in 1983). Include any Institutional Review Board or Animal Care and Use Committee protocol numbers as warranted by experimental design.

## **CLINICAL TRIALS REGISTRY**

We require, as a condition of consideration for publication, registration in a public trials registry. Trials must register at or before the onset of patient enrollment. This policy applies to any clinical trial starting enrollment after January 1, 2006. For trials that began enrollment before this date, we require registration by April 1, 2006, before considering the trial for publication. We define a clinical trial as any research project that prospectively assigns human subjects to intervention or comparison groups to study the causeand-effect relationship between a medical intervention and a health outcome. Studies designed for other purposes, such as to study pharmacokinetics or major toxicity (e.g., phase 1 trials) are exempt. 3. Use a coarse hatching pattern rather than shading for tints in graphs

4. Color should be distinct when used as an identifying tool

5. Use SI units throughout

6. Spaces, not commas, should be used to separate thousands

7. Abbreviations should be preceded by the words for which they stand in the first instance of use in the text

8. No abbreviations should be used in the title or the abstract

9. The abstract should be written as a single paragraph; do not include headings

10. Text should be double spaced with a wide margin

11. At the first mention of a manufacturer, the town (state if USA) and country should be provided

## **FILE FORMATS**

### Manuscripts

Use a common word-processing package (such as Microsoft Word) for the text of your article Files in MS Office 2007 format cannot be accepted for publication. For instructions on how to save MS Office 2007 files in a format acceptable for publication, please see the Appendix.

We do not advocate one particular registry, but registration must be with a registry that meets the following minimum criteria: (1) accessible to the public at no charge; (2) searchable by standard, electronic (Internet-based) methods; (3) open to all prospective registrants free of charge or at minimal cost; (4) validates registered information; (5) identifies trials with a unique number; and (6) includes information on the investigator(s), research question or hypothesis, methodology, intervention and comparisons, eligibility criteria, primary and secondary outcomes measured, date of registration, anticipated or actual start date, anticipated or actual date of last follow-up, target number of subjects, status (anticipated, ongoing or closed) and funding source(s). You will be asked to provide the name of your trial's registry upon submission.

Registries that currently meet these criteria include: (1) the registry sponsored by the United States National Library of Medicine (www.clinicaltrials.gov); (2) the International Standard Randomized Controlled Trial Number Registry (<u>http://www.controlled-triais.com</u>); (3) the Australian Clinical Trials Registry (<u>http://www.actr.org.au</u>); (4) the Chinese Clinical Trials Register (<u>http://www.chictr.org</u>); and (5) the Clinical Trials Registry - India (<u>http://www.ctri.in</u>).

### Figures, Images and Tables

Figures and images should be labeled sequentially, numbered and cited in the text. Figures should be referred to specifically in the text of the paper but should not be embedded within the text. Each table should be double-spaced on a separate sheet and numbered consecutively in the order of first citation in the text. Make sure that each table is cited in the text. Do not use internal horizontal and vertical lines. The use of three-dimensional histograms is strongly discouraged when the addition of the third dimension gives no extra information. If a table or figure has been published before, the authors must obtain written permission to reproduce the material in both print and electronic formats from the copyright owner and submit the permission with the manuscript. This rule applies for quotes, illustrations and other materials taken from previously published works not in the public domain. The original source should be cited in the figure caption or table footnote.

### Legends and Titles

Legends must be submitted for all figures and images, and titles for all tables. They should be brief and specific, double spaced, and placed on a separate sheet titled 'Titles and legends' after the Reference section. Use scale markers in the image for electron micrographs and indicate the type of stain used. Place explanatory matter of tables in the footnotes rather than in the titles.

## **REPORTING RANDOMIZED CONTROLLED TRIALS**

Reporting of randomized controlled trials should follow the guidelines of The CONSORT Statement (<u>http://www.consort-</u> <u>statement.org</u>).

## STYLE

The American Medical Association Manual of Style (9th edition), Stedman's Medical Dictionary (27th edition) and Merriam Webster's Collegiate Dictionary (10th edition) should be used as standard references. Refer to drugs and therapeutic agents by their accepted generic or chemical name, and do not abbreviate them (a proprietary name may be given only with the first use of the generic name). Code numbers should be used only when a generic name is not yet available (the chemical name and a figure giving the chemical structure of the drug are required). Copyright or trade names of drugs should be capitalized and placed in parentheses after the name of the drug. Names and locations (city and state in USA; city and country outside USA) of manufacturers of drugs, supplies, or equipment cited in a manuscript are required to comply with trademark law and should be provided in parentheses. Quantitative data may be reported in the units used in the original measurement, but SI units are preferred, including those applicable to body weight, mass (weight) and temperature.

## **ARTWORK GUIDELINES**

Detailed guidelines for submitting artwork can be found by downloading the guidelines PDF:

http://www.nature.com/aj/artworkguidelines.pdf. Using the guidelines, please submit production quality artwork with your submission. At submission, all figures must be high enough quality (no less than 300 dpi) to be assessed in the peer review process. We prefer artwork to be submitted as either .tif or .jpg files. Do not submit in .pdf format. If you have not followed the artwork guidelines, we will require artwork to be resubmitted if your paper is accepted for publication.

Minimum Resolutions:

Halftone images 300 dpi (dots per inch) Color images 300 dpi saved as CMYK Images containing text 400 dpi Line art 1000 dpi

## Sizes:

Figure Width - single image

86mm (Should be able to fit into a single column of the printed journal)

### Journal style

As the electronic submission will provide the basic material for typesetting, it is important that papers are prepared in the general editorial style of the journal.

 For information on labeling of figures, see the artwork guidelines: <u>http://www.nature.com/aj/artworkguidelines.pdf</u>
Do not make rules thinner than 1 pt (0.36mm) Figure Width – multi-part image 178mm (Should be able to fit into a double column of the printed journal)

## Text Size

8 point (Should be readable after reduction - avoid large type or thick lines) Line Width Between 0.5 and 1 point



**Color Artwork Charges** 

Artwork provided in color upon submission must be printed in color, and the author must agree to pay for the cost of printing said artwork in color. The cost to produce color artwork is \$500 per page. Color figures will be set close to the citation and in the best possible position. Figure re-ordering cannot be undertaken at proof stage to reduce the number of pages featuring color artwork.

## Supplementary Information

Supplementary information is peer-reviewed material directly relevant to the conclusion of an article that cannot be included in the printed version owing to space or format constraints. It is posted on the journal's web site and linked to the article when the article is published and may consist of data files, graphics, movies or extensive tables. The printed article must be complete and selfexplanatory without the supplementary information. Supplementary information enhances a reader's understanding of the paper, but is not essential to that understanding. Supplementary information must be supplied to the editorial office in its final form for peer review. On acceptance, the final version of the peer-reviewed supplementary information should be submitted with the accepted paper. To ensure that the contents of the supplementary information files can be viewed by the editor(s), referees and readers, please also submit a 'read-me' file containing brief instructions on how to use the file.

Further questions about the submission or preparation of supplementary information should be directed to the editorial office.

# Submission and publication

## SUBMISSION OF PAPERS

If you are ready to submit an article please visit the Online Submission page: http://mc.manuscriptcentral.com/ki All text should be submitted in Microsoft Word (.doc) and figures as .tif or .jpg files

## LICENSE TO PUBLISH

The corresponding author must complete and sign the License to Publish form upon acceptance of the manuscript and return it to the editorial office. Failure to do so will result in delays to the publication of your paper. A copy of the License to Publish form can be found under "Instructions & Forms" on the online submission page: http://mc.manuscriptcentral.com/ki

If your manuscript or any significant part of it has been under consideration for publication elsewhere, or has appeared elsewhere in a manner that could be construed as a prior or duplication publication of the same, or very similar, work, the said material must be included and marked appropriately as a supplemental file.

### Supplying supplementary information files

Authors should ensure that supplementary information is supplied in its FINAL format as it is not copy edited and will appear online exactly as originally submitted. It cannot be altered, nor new supplementary information added, after the paper has been accepted for publication. Please supply the supplementary information via the electronic manuscript submission and tracking system, in an acceptable file format (see below). Authors should: include a text summary (no more than 50 words) to describe the contents of each file; identify the types of files (file formats) submitted and include the text 'Supplementary information is available at Kidney International's website' at the end of the article and before the references.

The International Society of Nephrology does not require authors of original research papers to assign copyright of their published contributions. Authors grant the International Society of Nephrology an exclusive license to publish, in return for which they can re-use their papers in their future printed work. Authors are encouraged to submit their version of the accepted, peerreviewed manuscript to their funding body's archive for public release six months after publication. In addition, authors are encouraged to archive their version of the manuscript in their Institution's repositories (as well as on their personal web sites), also six months after the original publication. Authors should cite the publication reference and doi number on any deposited version, and provide a link from it to the published article on the NPG website. This policy complements the policies of the US National Institutes of Health, the Wellcome Trust and other research funding bodies around the world. NPG recognizes the efforts of funding bodies to increase access to the research they fund, and strongly encourages authors to participate in such efforts.

## More information is available online at the following link: http://www.nature.com/authors/editorial\_policies/license.html

### Accepted file formats

Quick Time files (.mov), graphical image files (.gif), HTML files (.html), MPEG movie files (.mpg), JPEG image files (.jpg), sound files (.wav), plain ASCII text (.txt), MS Word documents (.doc), Postscript files (.ps), MS Excel spreadsheet documents (.xls) and PowerPoint files (.ppt). We cannot accept TeX and LaTeX.

File sizes must be as small as possible so that they can be downloaded quickly. Images should not exceed 640 x 480 pixels but we would recommend 480 x 360 pixels as the maximum frame size for movies. We would also recommend a frame rate of 15 frames per second. If applicable to the presentation of the supplementary information, use a 256-color palette. Please consider the use of lower specification for all of these points if the supplementary information can still be represented clearly. Our recommended maximum data rate is 150 KB/s.

The number of files should be limited to eight, and the total file size should not exceed 8 MB. Individual files should not exceed 1 MB. Please seek advice from the editorial office before sending files larger than our maximum size to avoid delays in publication.

## **ADVANCE ONLINE PUBLICATION**

All original articles and reviews are published ahead of print on Advance Online Publication. This will be the final version of the manuscript and will subsequently appear, unchanged, in print.

## PROOFS

An e-mail will be sent to the corresponding author with a URL link from where proofs can be collected. Proofs must be returned by fax within 48 hours of receipt. Failure to do so may result in a delay to publication. Extensive corrections cannot be made at this stage.

### **BUSINESS MATTERS**

For contact information regarding business correspondence and inquiries such as advertising, subscriptions, permissions, papers in production or publishing a supplement, please visit our publisher's contacts page at http://www.nature.com/ki/contact\_npg.html.

Alternatively, you can write to: Kidney International, Academic Journals Division, Nature Publishing Group, 75 Varick Street, 9th Floor, New York, NY 10013, USA.





### Appendix E. Ethics Approval – National Research Ethics Service



# National Research Ethics Service

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1 1 Standard Court

Park Row Nottingham NG1 6GN

Telephone: 0115 9123344 Facsimile: 0115 9123300

23 April 2007

Mrs Kate Partridge Trainee Clinical Psychologist Leicestershire Partnership Trust. 43 Saville Close Hinckley Leicestershire LE10 1SZ

Dear Mrs Partridge

Full title of study:An investigation into body image changes in adult end-<br/>stage renal failure patients undergoing dialysisREC reference number:07/Q2501/68

The Research Ethics Committee reviewed the above application at the meeting held on 13 April 2007.

**Ethical opinion** 

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

## Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

## **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

## 07/Q2501/68



## **Approved documents**

## The documents reviewed and approved at the meeting were:

Document	Version	Date
Application		12 March 2007
Investigator CV	1	02 February 2007
Protocol	2	23 February 2007
Summary/Synopsis	2 - Flowchart	23 February 2007
Peer Review		23 January 2007
Peer Review		05 February 2007
Questionnaire: Demographic Sheet	1	02 February 2007
Questionnaire: Scale of General Personality Style	1	02 February 2007
Questionnaire: Disagree or Agree	1	02 February 2007
Questionnaire: Concerns about Physical Appearance	1	02 February 2007
Questionnaire: Feelings in the Past Week	1	02 February 2007
Advertisement	1	02 February 2007
Letter of invitation to participant	1 - Haemodialys is Patients	23 February 2007
Letter of invitation to participant	1 - Peritoneal Dialysis Patients	23 February 2007
Participant Information Sheet: Peritoneal Dialysis Patients	2	23 February 2007
Participant Information Sheet: Haemodialysis Patients	2	16 February 2007
Prize Draw Information	1.1	02 February 2007
Letter from Funder		19 February 2006
Honorary Appointment		29 January 2007
CV - Dr Neolle Robertson	1	05 February 2007

## **R&D** approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

## **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

## **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating

# Procedures for Research Ethics Committees in the UK.



(delete Chief following subsequent notifications from site assessors. **REC** reference number: Approved This Mrs Kate organisation has been confirmed. opinion is Full title Principal Investigator study was given a favourable ethical opinion by Leicestershire, Investigator: as suspension : of study: he Partridge applicable) extended to each of the by the Chair on behalf of notes column may of termination of the Mrs 07/Q2501/68 Post Psychologist Trainee Clinical be Kate Partridge e used sites the



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## 07/Q2501/68

## Please quote this number on all correspondence

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

Yours sincerely

Dr Carl Edwards/Ms Linda Ellis Chair/Co-ordinator

Email: linda.ellis@nottinghamshirecounty-tpct.nhs.uk

- #

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments Standard approval conditions SL-AC2 for other studies Site approval form (SF1)

Copy to:

R&D office for NHS care organisation at lead site



## Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

## Attendance at Committee meeting on 13 April 2007

## **Committee Members:**

Name	Profession	Present?	Notes
Dr Carl Edwards	Director	Yes	
Dr Wilson Firth	<b>Consultant Psychiatrist</b>	Yes	
Mr John Baker	Lay Member	Yes	
Dr Jonathan Barratt	Senior Clinical Research Fellow	No	
Dr Susan Corr	Reader in Occupational Science (Occupational Therapist)	No	
Mr Martin Dennis	Consultant Vascular Surgeon	No	
Mrs Sandra Hall	Principal Lecturer in Clinical Pharmacy & Pharmacy Practice	Yes	
Mrs Jennifer Hutson	Retired Lecturer in Teacher Education	No	
Dr Syed Javed Iqbal	Consultant in Biomedical Medicine	No	
Ms Marion Lewin	Direct Services Manager	No	
Miss Athalie Melville	Lay Member	Yes	
Mr Amrat Mistry	Program Manager	No	
Dr Jane Sutton	Retired Public Health Specialist	Yes	
Dr Douglas Tincello	Senior Lecturer in Urogynaecology	No	
Dr Esther Waterhouse	Consultant in Palliative Medicine	Yes	
Mrs Valerie Webb	Nurse	No	
Ms Rose Webster	Senior Nurse for Education	Yes	

## Also in attendance:

1 1

Name Ms Linda Ellis Co-ordinator



### Appendix F. Ethics Approval – Research and Development Directorate for NHS Trust

## M:5 University Hospitals of **NHS Trust**

# DIRECTORATE OF RESEARCH AND DEVELOPMENT

Director:

**Assistant Director: Co-ordinator: Direct Dial:** Fax No: EMail:











01 May 2007

Mrs Kate Partridge Leicestershire Partnership Trust 43 Saville Close Hinckley Leicestershire **LE10 1SZ** 

Dear Mrs Partridge

An investigation into body image changes in adult end-stage renal 10301 ID: failure patients undergoing dialysis

LREC Ref: 07/Q2501/68 **MREC Ref:** 

Sponsor

Funder



## Please note that Trust Indemnity ceases on: 01/05/2008

As you are aware all research undertaken within the NHS requires both a favourable ethical opinion from an independent ethics committee, and R&D Approval from each NHS Trust it is taking place within. We have received confirmation that your study has gained a favourable opinion from the local Ethics Committee. All papers submitted have also been reviewed by University Hospitals of NHS Trust R&D Office and I am pleased to confirm NHS R&D Approval from the Trust, on the following conditions:

- All papers submitted to this office are followed to the letter; should any amendments or changes be required these must be submitted to this office.

- Only researchers detailed on the second page of this letter are to be involved in the study. If this changes, the changes must be submitted to this office as a non-substantial amendment.

- Your study is now covered by NHS Indemnity, as required, and excluding aspects covered by external indemnity, e.g. ABPI, University. This indemnity is in place to the above date - the end date you supplied. Should you wish your study to extend past this date you must notify the R&D Office, as not doing so would mean you are no longer covered to conduct your research. One method for this is through Annual Reports, see over page. - Ongoing Pharmacovigilance and safety reporting is essential in all research studies. Serious Adverse Events (SAE), Serious Adverse Reactions (SAR) and Suspected Unexpected Serious Adverse Events (SUSAR) must be reported appropriately and timely. Please ensure you are aware of our SOP on Safety Reporting which is available on the R&D web pages: http://www.mains.uk/ourservices/research-development - Your application detailed resources to be used in this study, you must ensure the budget detailed is followed as the Trust will not cover any additional costs associated to this research.

- If honorary research contracts have been issued it is your responsibility to ensure this/these are kept Trust Headquarters, the second s up to date.



**Reporting Requirements** Within University Hospitals of **contracts we are keen to encourage well structured, good quality** research; to ensure this high standard is achieved and maintained we are keen to make you aware of national and local reporting requirements:

- Annual & Final Reports on the progress are required each year, or final on completion. These reports are needed by both the R&D Office and local Ethics Committee. Templates for these reports are available on the R&D & NRES website, and we look forward to the receipt of these on the anniversary of your ethics approval, and on the completion of your study.

- Additionally Annual Safety Reports are required for CT-IMP (Clinical Trials of Investigational Medicinal Products) studies and should be submitted to the MHRA annually 60 days prior to the anniversary of MHRA Approval.

We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities and have attached to this letter, forming part of your R&D approval, an information sheet to ensure you are aware of these responsibilities.

The R&D Office is keen to support research, researchers and facilitate approval. If you have any questions regarding this or other research you wish to undertake in the Trust please feel welcome to contact this office again. The Trust wishes you success with your research.

Below is a list of the Researchers Approved to work on this Application within

Dr Jenny Hainsworth

Mrs Kate Partridge

**Dr N Robertson** 

Yours sincerely-DIRECTOR OF R&D

John Hampton

Assistant Director for Research and Development



Appendix G. Invitation letter for peritoneal dialysis patients.



**NHS Trust** 

Hospital <Address details>

Tel: Fax: Minicom:

Date:

Dear Sir/Madam,

Re: "An investigation into body image disturbances in adult end-stage renal failure patients undergoing dialysis"

You are invited to take part in a research study on body image and dialysis, which is being undertaken by a Trainee Clinical Psychologist from the University of Leicester.

If you are interested in taking part, please read the enclosed information sheet, which will tell you in more detail what the study is about and answers some of the questions you may have. Please take your time to decide whether you wish to take part and feel free to contact the researcher, Kate Partridge, using the contact details on the information sheet should you require any further information.

Also enclosed in this envelope is a questionnaire pack. If you decide that you would like to participate in the study, complete the questionnaires, ensuring that all questions are answered and return the pack in the pre-paid envelope provided. Please also complete and return the prize draw slip if you wish to be entered into the prize draw.

Thank you for your interest in this research.

Yours sincerely

Dr <NAME>

Renal and Urology Directorate

<TRUST HEADQUARTERS INFORMATION>

Appendix H. Information sheet for peritoneal dialysis patients.



NHS

Trust Hospital <Address details>

> Tel: Fax: Minicom:

Patient Information Sheet

### An investigation into body image disturbances in adult end-stage renal failure patients undergoing dialysis.

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve before you decide whether or not to take part. Please take time to read the following information carefully. Talk to others about the study if you wish.

### What is the purpose of the study?

This study is looking at the way people on dialysis think and feel about their body, and whether this is affected by having dialysis. At the moment there is little known about this subject. We hope that this research may help improve the treatment of people with renal failure in the future.

### Why have I been chosen?

Everyone over the age of 18 and has been using dialysis services at <NAME OF HOSPITAL> for longer than 6 months is being asked to take part.

### What will happen if I take part?

The research involves completing this pack of questionnaires. This should take about **10 to 15 minutes**. The questionnaires are anonymous – we do not need your name on them. The questionnaires look at:

- Your thoughts and feelings about your physical appearance
- Levels of everyday stress and anxiety
- Basic information about you (your age, gender, type of dialysis etc.)

If possible please try and complete all of the questions but if you feel uncomfortable about any of the questions you can leave them blank and go on to the next question.

### **Prize Draw**



Everybody who fills in the questionnaires will go into a prize draw to win: £50 of High Street Vouchers

#### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do not want to take part this will <u>not affect the treatment or care that you receive.</u>

#### What if there is a problem?

If filling in the questionnaires becomes distressing, you can be referred to Medical Psychology at <NAME OF HOSPITAL>. This can be done by asking the Renal staff, your GP or the researcher.

If you are unhappy and wish to complain formally, you can contact the Patient Advisory Liaison Service (PALS) by telephone on <NUMBER>, by email at <EMAIL ADDRESS> or by writing to: PALS Office, <HOSPITAL INFORMATION>.

#### Will my taking part in the study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential, the questionnaires will not ask for your name. The prize draw information will be kept separately from the questionnaires. Your GP will not be informed about your involvement. The questionnaires will be kept in a locked filing cabinet and destroyed after five years.

### **Contact Details**

If you want further information or have any concerns you can ask the Doctor you see in your appointment or the researcher Kate Partridge on 07832 136599. Please do <u>not</u> ask the administrator at reception questions.

#### Who is funding and organising the study?

This research is being carried out by the researcher as part of their Doctorate in Clinical Psychology at the University of Leicester. The Researcher is not being paid to carry out the research but their administration costs are funded by the University of Leicester.

#### What will happen to the results of the research study?

The results will be put together and reported as a whole. Comments made on the questionnaires may be used in the report but will be anonymised. This means that the results can not be identified as being from any individual.

I hope to publish the results in a scientific journal. I will be meeting with staff to let them know the results. There will be a printed leaflet for patients. These will be available at outpatients' appointments or on the haemodialysis ward for people to take if they want to.

#### Who has reviewed the study?

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision. Completing the questionnaires means that you have given informed consent to be included in the study.

#### Thank you for taking time to read this sheet.

Kate Partridge Trainee Clinical Psychologist

School of Psychology – Clinical Section 104 Regent Road Leicester LE1 7LT Tel: 07832 136599 Email: kap12@le.ac.uk Appendix I. Invitation letter for haemodialysis patients.



Hospital <Address details>

Tel: Fax: Minicom:

Date:

Dear Sir/Madam,

Re: "An investigation into body image disturbances in adult end-stage renal failure patients undergoing dialysis"

You are invited to take part in a research study on body image and dialysis, which is being undertaken by a Trainee Clinical Psychologist from the University of Leicester.

If you are interested in taking part, please read the enclosed information sheet, which will tell you in more detail what the study is about and answers some of the questions you may have. Please take your time to decide whether you wish to take part and feel free to contact the researcher, Kate Partridge, using the contact details on the information sheet should you require any further information.

Also enclosed in this envelope is a questionnaire pack. If you decide that you would like to participate in the study, complete the questionnaires, ensuring that all questions are answered and return the pack in the pre-paid envelope provided. Please also complete and return the prize draw slip if you wish to be entered into the prize draw.

Thank you for your interest in this research.

Yours sincerely

Dr <NAME>

Renal and Urology Directorate

Appendix J. Information sheet for haemodialysis patients.



Hospital <**Address details**>

> Tel: Fax: Minicom:

#### Patient Information Sheet

#### An investigation into body image disturbances in adult end-stage renal failure patients undergoing dialysis.

You are being invited to take part in a research study. It is important for you to understand why the research is being done and what it will involve before you decide whether or not to take part. Please take time to read the following information carefully. Talk to others about the study if you wish.

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

This study is looking at the way people on dialysis think and feel about their body, and whether this is affected by having dialysis. At the moment there is little known about this subject. We hope that this research may help improve the treatment of people with renal failure in the future.

#### Why have I been chosen?

Everyone over the age of 18 and has been using dialysis services at <NAME OF HOSPITAL> for longer than 6 months is being asked to take part.

#### What will happen if I take part?

The research involves completing this pack of questionnaires. This should take about **10 to 15 minutes**. The questionnaires are anonymous – we do not need your name on them. The questionnaires look at:

- Your thoughts and feelings about your physical appearance
- Levels of everyday stress and anxiety
- Basic information about you (your age, gender, type of dialysis etc.)

If possible please try and complete all of the questions but if you feel uncomfortable about any of the questions you can leave them blank and go on to the next question.

### **Prize Draw**

Everybody who fills in the questionnaires will go into a prize draw to win: **£50 of High Street Vouchers** 



### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do not want to take part this will <u>not affect the treatment or care that you receive.</u>

### What if there is a problem?

If filling in the questionnaires becomes distressing, you can be referred to Medical Psychology at <NAME OF HOSPITAL>. This can be done by asking the Renal staff, your GP or the researcher.

If you are unhappy and wish to complain formally, you can contact the Patient Advisory Liaison Service (PALS) by telephone on <NUMBER>, by email at <EMAIL ADDRESS> or by writing to: PALS Office, <HOSPITAL INFORMATION>.

### Will my taking part in the study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential, the questionnaires will not ask for your name. The prize draw information will be kept separately from the questionnaires. Your GP will not be informed about your involvement. The questionnaires will be kept in a locked filing cabinet and destroyed after five years.

### **Contact Details**

If you would like further information or have any questions or concerns you can ask the researcher Kate Partridge on 07832 136599.

### Who is funding and organising the study?

This research is being carried out by the researcher as part of their Doctorate in Clinical Psychology at the University of Leicester. The Researcher is not being paid to carry out the research but their administration costs are funded by the University of Leicester.

#### What will happen to the results of the research study?

The results will be put together and reported as a whole. Comments made on the questionnaires may be used in the report but will be anonymised. This means that the results can not be identified as being from any individual.

I hope to publish the results in a scientific journal. I will be meeting with staff to let them know the results. There will be a printed leaflet for patients. These will be available at outpatients' appointments or on the haemodialysis ward for people to take if they want to.

#### Who has reviewed the study?

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision. Completing the questionnaires means that you have given informed consent to be included in the study.

#### Thank you for taking time to read this information.

#### Kate Partridge Trainee Clinical Psychologist

School of Psychology – Clinical Section 104 Regent Road Leicester LE1 7LT Tel: 07832 136599 Email: kap12@le.ac.uk

<TRUST HEADQUARTERS INFORMATION>

### Appendix K. Demographic form

### Information about you:

Are you? MALE / FEMALE

How old are you? \_\_\_\_ years

### How would you describe your ethnic background?

White	Mixed	Asian or Asian	Black or Black
British	White and Black Caribbean		Caribbean
□ Irish	White and Black African	Pakistani	□ African
Traveller of Irish Heritage	White and Asian	Bangladeshi	Any other Black background
🗌 Gypsy/ Roma	Any other mixed background	Any other Asian background	
Any other White background			
☐ Chinese	Any other ethnic background	I do not wish an ethnic background category to be recorded	

What type of dialysis are you on?	Peritoneal Dialysis	
	Haemodialysis in hospital	
	Haemodialysis at home	

Approximately how long have you been on dialysis? \_\_\_\_ months \_\_\_years

## Thank you for completing these questionnaires.

Don't forget to fill in the prize draw sheet.

### Appendix L. Hospital Anxiety and Depression Scale

Read each item and place a **firm tick in the box** opposite the reply which comes closest to how you have been feeling in the **past week**. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up': Most of the time A lot of the time Time to time, occasionally Not at all		<b>A</b> 3 2 1 0	I feel as if I am slowed down: Nearly all of the time Very often Sometimes Not at all	D 3 2 1 0	
I still enjoy the things I used to enjoy:	D		I get a sort of frightened feeling like 'butterflies in the stomach':		Α
Definitely as much Not quite so much Only a little Not at all	0 1 2 3		Not at all Occasionally Quite often Very often		0 1 2 3
I get a sort of frightened feeling like something awful is about to happen:		Α	I have lost interest in my appearance:	D	
Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all		3 2 1 0	Definitely I don't take as much care as I should I may not take quite as much care I take just as much care as ever	3 2 1 0	
I can laugh and see the funny side of	D		I feel restless as if I have to be on the		Α
As much as I always could Not quite so much now Definitely not so much now Not at all	0 1 2 3		Very much indeed Quite a lot Not very much Not at all		3 2 1 0
Worrying thoughts go through my		Α	I look forward with enjoyment to things:	D	
A great deal of the time A lot of the time From time to time but not too often Only occasionally		3 2 1 0	A much as I ever did Rather less than I used to Definitely less than I used to Hardly at all	0 1 3 2	
I feel cheerful: Not at all Not often Sometimes Most of the time	D 3 2 1 0		I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all		A 3 2 1 0
I can sit at ease and feel relaxed:		Α	I can enjoy a good book or radio or TV programme:	D	
Definitely Usually Not often Not at all		0 1 2 3	Often Sometimes Not often Very seldom	0 1 2 3	

### Appendix M. Body Image Disturbance Questionnaire

This questionnaire assesses concerns about physical appearance. Please read each question carefully and <u>circle the answer</u> that best describes your experience. Also write in answers where indicated.

1. Are you concerned about the appearance of some part(s) of your body which you consider especially unattractive? (Circle the best answer)

1	2	3	4	5
Not at all	Somewhat	Moderately	Very	Extremely
concerned	concerned	concerned	concerned	concerned

What are these concerns? What specifically bothers you about the appearance of these body parts?

 If you are at least somewhat concerned, do these concerns preoccupy you? That is, you think about them a lot and they're hard to stop thinking about? (Circle the best answer)

1	2	3	4	5
Not at all	Somewhat	Moderately	Very	Extremely
preoccupied	preoccupied	preoccupied	preoccupied	preoccupied

What effect has your preoccupation with your appearance had on your life? (Please describe):

 Has your physical "defect" often caused you a lot of distress, torment, or pain? How much?
(Circle the best answer)

	51 aliswel)			
1	2	3	4	5
No distress	Mild, and not too disturbing	Moderate and disturbing but still manageable	Severe, and very disturbing	Extreme, and disabling

4. Has your physical "defect" caused you impairment in social, occupational or other important areas of functioning? How much?(Circle the best answer)

1 No imitation	2 Mild interference but overall performance not impaired	3 Moderate, definite interference but still manageable	4 Severe, causes substantial impairment	5 Extreme, incapacitatin g
5. Has yo much?	ur physical "defect" (Circle the best and	significantly interfe	ered with your s	ocial life? How
1 Never	ک Occasionally	3 Moderately Often	4 Often	5 Very Often
If so, how	?			
6. Has yo your jol best an 1 Never	ur physical "defect" b, or your ability to f nswer) 2 Occasionally	significantly interfe function in your role 3 Moderately Often	ered with your s e? How much? 4 Often	choolwork, (Circle the 5 Very Often
If so, how	?			
7. Do you (Circle	ever avoid things b the best answer) 2	because of your phy 3 Moderately	ysical "defect"? 4 Often	How often? 5
1 Never	Occasionally	0(1		very Oiten

### Appendix N. Appearance Schemas Inventory – Revised
The statements below are beliefs that people may or may not have about their physical appearance and its influence on life. Decide on the extent to which you personally **disagree or agree** with each statement and enter a number from 1 to 5 in the space on the left. There are no right or wrong answers. Just be truthful about your personal beliefs.

1	2	3	4	5
Strongly Disagree	Mostly Disagree	Neither Agree	Mostly Agree	Strongly Agree
2.009.00	c.g. cc	or Disagree		. g. c c

- \_\_\_\_ 1. I spend little time on my physical appearance.
- 2. When I see good-looking people, I wonder about how my own looks measure up.
- \_\_\_\_ 3. I try to be as physically attractive as I can be.
- \_\_\_\_\_ 4. I have never paid much attention to what I look like.
- 5. I seldom compare my appearance to that of other people I see.
- \_\_\_\_ 6. I often check my appearance in a mirror just to make sure I look okay.
- \_\_\_\_7. When something makes me feel good or bad about my looks, I tend to dwell on it.
- 8. If I like how I look on a given day, it's easy to feel happy about other things.
- 9. If somebody had a negative reaction to what I look like, it wouldn't bother me.
- \_\_\_\_\_10. When it comes to my physical appearance, I have high standards.
- \_\_\_\_\_ 11. My physical appearance has had little influence on my life.
- \_\_\_\_ 12. Dressing well is not a priority for me.

1	2	3	4	5
Strongly	Mostly	Neither	Mostly	Strongly
Disagree	Disagree	Agree	Agree	Agree
		or Disagree		

- 13. When I meet people for the first time, I wonder what they think about how I look.
- \_\_\_\_ 14. In my everyday life, lots of things happen that make me think about what I look like.
- \_\_\_\_ 15. If I dislike how I look on a given day, it's hard to feel happy about other things.
- \_\_\_\_\_16. I fantasize about what it would be like to be better looking than I am.
- \_\_\_\_\_17. Before going out, I make sure that I look as good as I possibly can.
- \_\_\_\_\_18. What I look like is an important part of who I am.
- \_\_\_\_ 19. By controlling my appearance, I can control many of the social and emotional events in my life.
- \_\_\_\_ 20. My appearance is responsible for much of what's happened to me in my life.

### Appendix O. Self-Consciousness Scale

# Using the scale below, please indicate how well or poorly each description corresponds to your general personality style.

1	2	3	4
Extremely	Slightly	Slightly	Extremely
Uncharacteristic	Uncharacteristic	Characteristic	Characteristic

Please place your response in the space provided to the left of each statement.

- \_\_\_\_ I'm always trying to figure myself out.
- \_\_\_\_\_ I'm concerned about my style of doing things.
- \_\_\_\_ Generally, I'm not very aware of myself.
- \_\_\_\_ It takes me time to overcome my shyness in new situations.
- \_\_\_\_ I reflect about myself a lot.
- \_\_\_\_ I'm concerned about the way I present myself.
- \_\_\_\_ I'm often the subject of my own fantasies.
- \_\_\_\_ I have trouble working when someone is watching me.
- \_\_\_\_ I never scrutinize myself.
- \_\_\_\_ I get embarrassed very easily.
- \_\_\_\_ I usually worry about making a good impression.
- \_\_\_\_ I don't find it hard to talk to strangers.
- \_\_\_\_\_ I'm generally attentive to my inner feelings.
- \_\_\_\_ I usually worry about making a good impression.
- \_\_\_\_ I'm constantly examining my own motives.
- \_\_\_\_ I feel anxious when I speak in front of a group.
- \_\_\_\_ One of the last things I do before I leave my house is look in the mirror.

# Using the scale below, please indicate how well or poorly each description corresponds to your general personality style.

1	2	3	4
Extremely	Slightly	Slightly	Extremely
Uncharacteristic	Uncharacteristic	Characteristic	Characteristic

# Please place your response in the space provided to the left of each statement.

\_\_\_\_ I sometimes have the feeling that I'm off somewhere watching myself.

- \_\_\_\_\_ I'm concerned about what other people think of me.
- \_\_\_\_ I'm alert to changes in my mood.
- \_\_\_\_\_ I'm usually aware of my appearance.
- \_\_\_\_\_ I'm aware of the way my mind works when I work through a problem.
- \_\_\_\_ Large groups make me nervous.

### Appendix P. Prize draw form

Prize draw information – Only used for sending out the vouchers if you win. Name: \_\_\_\_\_

Address:

Prize draw information – Only used for sending out the vouchers if you win. Name: \_\_\_\_\_ Address: \_\_\_\_\_

Prize draw information – Only used for sending out the vouchers if you win. Name: \_\_\_\_\_ Address: \_\_\_\_\_

Prize draw information - Only used for sending out the vouchers if you win. Name: \_\_\_\_\_ Address:\_\_\_\_\_