

**COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH RESEARCH AND CARE
WEST MIDLANDS
(CLAHRC WM)**

**Supporting the emotional and psychological needs of end-
stage renal disease patients**

Study Report
Appendix 6: Literature Review

Authors:

Francesca Taylor

Dr Gill Combes

August 2014

Lead author and contact for correspondence: Francesca Taylor, School of Health and Population Sciences, University of Birmingham, Edgbaston B15 2TT
f.taylor@bham.ac.uk

This report presents independent research funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care West Midlands. The views expressed are those of the author(s) and not necessarily those of the CLAHRC-WM collaborative organisations, the NIHR or the Department of Health.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Acknowledgements:

This work was funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Research and Care West Midlands (CLAHRC WM).

The authors wish to thank:

The renal consultant clinical leads for their involvement in planning the research.

The medical secretaries who assisted with patient identification and recruitment in the Hospital Trusts.

Dr Jennifer Hare, Health Psychologist

Floating Harbour Films for filming and production of the intervention concept videos

All members of the CLAHRC WM team who contributed.

Most of all, we are very grateful to all the patients and clinicians who made such a valuable contribution to this study.

The research team were as follows:

Professor Richard Lilford, Principal Investigator, CLAHRC WM Director, School of Health and Population Sciences

Dr Gill Combes, Chief Investigator, CLAHRC WM Deputy Theme Lead, chronic diseases, School of Health and Population Sciences

Francesca Taylor, Research Fellow, CLAHRC WM, School of Health and Population Sciences

Pamela Nayyar, Project Officer, CLAHRC WM, School of Health and Population Sciences

Clayton Research Services, who transcribed the digital interview records

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Contents

| | Page |
|--|-------------|
| 1. Introduction and context | 5 |
| 2. Content of the review | 7 |
| 3. Prevalence, range and complexity of emotional and psychological problems | 8 |
| 3.1 Continuum of need | 8 |
| 3.2 Tools for screening depression | 10 |
| 3.3 Incidence of depression | 11 |
| 3.4 Incidence of anxiety | 16 |
| 3.5 Emotional and psychodynamic difficulties | 17 |
| 3.6 Influence of co-morbidities | 19 |
| 4. Impact of emotional and psychological problems on clinical outcomes | 19 |
| 4.1 Impact of depression on rates of hospitalisation and death | 20 |
| 4.2 Impact on compliance and adherence | 23 |
| 4.3 Withdrawal from dialysis | 23 |
| 4.4 Suicide | 24 |
| 4.5 Timely listing for transplantation | 24 |
| 4.6 Impact of emotional distress on diagnosis acceptance, information comprehension, and treatment decision-making | 25 |
| 5. Clinician identification of patient emotional and psychological support needs | 27 |
| 6. Provision of emotional and psychological support | 28 |

Contents (cont'd)

| | Page |
|---|-------------|
| 7. Emotional and psychological support needs from the patient perspective | 30 |
| 8. Effectiveness of interventions to address emotional and psychological needs | 31 |
| 8.1 Influence of dialysis modality on depression and anxiety | 32 |
| 8.2 Physical exercise | 33 |
| 8.3 Cognitive behaviour therapy (CBT) | 36 |
| 8.4 Computerised CBT | 37 |
| 8.5 Peer support | 39 |
| 8.6 Lay-led education and expert patient programmes | 41 |
| 8.7 Coping and empowerment | 41 |
| 8.8 Mindfulness-based therapy | 42 |
| 9. Changing clinician-patient communication through recognition and response to emotional issues | 45 |
| 10. References | 49 |

1. Introduction and context

A key finding to emerge from the WMC-HIEC research study 'Evaluation of case study sites for home therapies for people with chronic kidney disease' (Combes, Allen and Sein, 2013) was that people with chronic kidney disease and end-stage renal disease experience considerable emotional and psychological difficulties, often unrecognised and therefore not responded to by their clinicians.

The importance of responding appropriately and effectively to the emotional and psychological difficulties faced by renal patients is highlighted in a range of national guidelines and policy directives relating to chronic kidney disease and end-stage renal disease populations. Support for patients' emotional and psychological needs is also an integral part of the NHS's approach to the management of all long-term conditions and chronic diseases.

The National Service Framework for Renal Disease (Department of Health 2004, 2005) that sets out the national standards for treatment of renal disease recognises the significant psychological impact of kidney failure and the need for emotional and psychological services to support disease management. For example, Standard One of the Framework states 'all children, young people and adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life'; and Standard 2 states 'all children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.' A key marker of good practice for this standard is there should be 'referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation.'

The Royal College of Physicians (2008) guideline 74 for CKD is that, 'healthcare professionals working with people with CKD should take account of the psychological aspects of coping with the condition and offer access to appropriate support (for example, support groups, counselling or a specialist nurse).'

One of the key recommendations for effective support of home haemodialysis (HD) patients made by the Renal Association Home HD Working Party (Mactier et al, 2010) was that a psychologist should be included in a dedicated multidisciplinary team of community staff, 'trained in self care dialysis who should undertake holistic patient review and assessment regularly.'

The Kidney Health Advisory Group (2013) recommends that all people with advanced kidney disease should have access to timely psychological support centred on the patient. They also highlight that patients with a diagnosis of chronic kidney disease may experience psychological difficulties, and that dialysis patients have particular psychological needs.

Current NHS England draft service specifications for adult renal dialysis (2013) recommend that HD patients are offered access to psychology services as required, and that clinical psychology and/or counselling services are made available on a case by case basis for PD patients through referral from the multidisciplinary team or on request.

The National Institute for Health and Clinical Excellence (NICE) Chronic kidney disease quality standard (QS5) (2011) includes quality statement 10 stating, 'people with established renal failure have access to psychosocial support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances.'

Additionally, the NICE Clinical Guideline 91: Depression with a chronic physical health problem (G91) (2009) addresses the management of depression in adults with any chronic physical health problems. CG91 describes a 'stepped-care model', a four-step model starting with the least intrusive and most effective treatments, moving step-wise upwards on the basis of whether or not interventions are effective, or if the patient declines an intervention. The guideline also proposes a simple set of screening questions for healthcare professionals to ask patients who might be depressed: 'During the last month, have you often been bothered by,

- Feeling down, depressed or hopeless?
- Having little interest or pleasure in doing things?'

If the patient answers 'yes' to either question, and the practitioner is not competent in

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

mental health assessment, the patient should be referred to the appropriate professional. If the practitioner is competent, they should ask three further questions to improve the accuracy of the assessment: 'During the last month, have you often been bothered by,

- Feelings of worthlessness?
- Poor concentration?
- Thoughts of death?

The government's mental health strategy 'Closing the Gap: Priorities for essential change in mental health' (Department of Health, 2014) building on the earlier strategy 'No health without mental health' (HM Government, 2011) emphasises that mental health should have equal parity with physical health and the importance of promoting mental wellbeing. Integrating mental health care and physical health care is set out as a key priority, including the commitment to explore how psychological therapies can be integrated into care for people who have depression or anxiety that is related to a long-term condition. Current Department of Health (2012a) guidance on support for patients with any physical long term condition is that they should be 'assessed for the presence of depression and anxiety as part of their personalised care planning process'. Furthermore, since April 2014 anyone with complex health needs and eligible for NHS Continuing Healthcare funding has had the right to ask for a personal health budget with the opportunity to use their budget, if they wish to do so, on emotional and psychological support services. Clinical commissioning groups will also be able to offer personal health budgets to others they feel may benefit from additional flexibility and control (Department of Health 2012b; NHS Confederation and the Association of Directors of Social Services, 2012).

2. Content of the review

This summary literature review uses social science based literature published in the UK and internationally on the emotional and psychological needs and support for end-stage renal disease patients. The majority of studies identified for inclusion were undertaken in the USA with significantly fewer conducted in the UK. The aim of the literature review was to address the following research questions:

- What are the prevalence, range and complexity of emotional and psychological problems experienced by end-stage renal disease patients?

- Which measurement tools are used for the screening of emotional and psychological problems in end-stage renal disease patients?
- What is the impact of emotional and psychological problems on clinical outcomes for end-stage renal disease patients?
- What are the emotional and psychological needs of end-stage renal disease patients from the patient perspective?
- Are there specific approaches used by clinicians in consultations with patients that provide good emotional and psychological support?
- Are there non-pharmacological interventions that effectively address the emotional and psychological needs of end-stage renal disease patients?

3. Prevalence, range and complexity of emotional and psychological problems

- The notion of a continuum is helpful in considering the emotional and psychological problems experienced by ESRD patients and appropriate interventions to address these difficulties
- The 'Pyramid of Psychological Problem' is a useful conceptual model that describes 5 levels of emotional and psychological need
- Whilst there is a substantial body of evidence covering prevalence of psychological problems at levels 3-5 of the 'Pyramid', there is less evidence relating to lower levels
- Several self-report depression screening measures have been validated in CKD and ESRD patients, the Beck Depression Inventory being the most widely researched
- Reported prevalence levels of depression among ESRD patients very widely – generally between 15 and 40 per cent – but are significantly higher overall than those reported for the general population
- Evidence suggests a significant proportion of ESRD patients experience anxiety
- The multiple stressors associated with ESRD may have profound emotional and psychodynamic impacts
- Prevalence of mental health disorders seems to increase in relation to the number of physical morbidities experienced; multimorbidity being the norm for people with chronic disease including ESRD

3.1 Continuum of need

The emotional and psychological wellbeing of a person with end-stage renal disease
 CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

can be affected by several factors. These include the nature of response, acceptance and adjustment to diagnosis, progression of the disease, treatment or non-treatment choices, and co-morbidities. Patients will be challenged by many stressors with the potential to cause or exacerbate emotional and psychological difficulties including loss of biochemical and physiologic kidney functions, development of digestive and neurologic disorders, bone disease and anaemia, decreased mobility, loss of sexual function, needle phobia, altered body image, decreased physical and cognitive competence, and inability to maintain employment and lifestyle. Additionally drugs employed in the treatment of patients may intensify depressive effect (Kimmel, 2001 and 2002; Kimmel and Peterson, 2005).

The notion of a continuum is helpful in considering the emotional and psychological problems experienced by patients and appropriate interventions to address these difficulties. The National Renal Workforce Planning Group recommendations (British Renal Society, 2002) propose a tiered framework of three levels of psychological support and services to cover increasing severity of psychological difficulties: **'support'**, **'counselling'**, and **'psychological and psychotherapeutic services'**. **'Support'** refers to all activities within the renal care environment that help meet the psychological and social needs of renal patients and their carers, for example, information, advice, empathy; to be offered by all staff. **'Counselling'** encompasses information giving about the kidney condition, counselling to address the implications of the information, and supportive counselling about the emotional consequences of the information; to be offered by health professionals responsible for medical and nursing care plus input from other members of the multi-professional team as appropriate. **'Psychological and psychotherapeutic services'** involves psychological assessments and interventions in relation to the impact of kidney disease on the psychological health of the patient and their family, including adjustment, adaptation, coping strategies and problem solving skills; to be offered by clinical, health and counselling psychologists, counsellors and psychotherapists.

The tiered framework of psychological care recommended by the National Renal Workforce Planning Group is consistent with the 'Pyramid of Psychological Problem' model. This pyramid model describes five levels of psychological needs of people with diabetes, but could be used to conceptualise the range of psychological needs present in any population or, over time, in any individual (Trigwell, 2008). The different levels of the pyramid represent increasing complexity and severity of emotional and

psychological difficulties, although people may simultaneously have needs represented at several levels, and any individual may move up or down these levels at different point during their life and disease trajectory. It is estimated that prevalence is around 60 per cent at **level 1**, 40 per cent at **level 2**, 20 to 30 per cent at **level 3**, and 10 to 15 per cent at both **levels 4 and 5** (Polonsky, 1995; Anderson et al, 2001; Kenardy et al, 2001; Grigsby et al, 2002; Pibernik-Okanovic et al, 2008; Smith et al, 2008).

In summary, **level 1** is associated with general difficulties in coping with diagnosis and perceived consequences of living with diabetes and impact on lifestyle. Compared to the general population, people with difficulties at this level have higher rates of stress, poorer emotional adjustment and worse quality of life. At **level 2** the presenting issues include greater difficulty with coping, and significant anxiety or lower mood, with impaired ability to self-care. People may struggle emotionally with these issues without meeting the criteria for a diagnosable clinical condition. Emotional and psychological needs at **level 3** are defined by psychological conditions that are diagnosable and can generally be treated through psychological intervention alone. These psychological problems include mild depression and anxiety. More severe diagnosable psychological problems including major depression and severe anxiety disorder are present at **level 4**. There is a requirement for specialist psychological interventions, biological treatments and/or medication. At **level 5** severe and complex mental illness is experienced including severe depression and severe mental illness such as schizophrenia. These problems require specialist psychiatric intervention.

3.2 Tools for screening of depression

Several self-report depression screening measures have been validated in chronic kidney disease and end-stage renal disease patients against well-established psychiatric methods. These screening tools include the Beck Depression Inventory (BDI), the most widely researched of the measures (Craven et al, 1988; Finkelstein and Finkelstein, 2000; Watnick et al, 2005; Hedayati et al, 2006 and 2009); the Center for Epidemiologic Studies Depression Scale (CESD) (Hedayati et al, 2006); the 16-item Quick Inventory of Depressive Symptomatology Self-Report (QIDS-SR) (Hedayati et al, 2009); and the Patient Health Questionnaire (PHQ) (Watnick et al, 2005).

Reviewing these studies, Hedayati et al (2012) found that whilst cut-off scores with the best diagnostic accuracy for depressive disorder in patients with pre-dialysis chronic

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

kidney disease were similar to cut-offs used in the general population, the cut-offs for those with end-stage renal disease were generally higher. For example, the cut-off score for the BDI scale is more than 10 in the general population, more than 11 in chronic kidney disease patients and more than 14-16 in end-stage renal disease patients. The authors propose this might be a consequence of more frequent presence of somatic symptoms in end-stage renal disease, not manifest in earlier chronic kidney disease stages. These somatic symptoms - including fatigue, loss of energy, decreased appetite, and sleep disturbance - suggestive of depressive affect, may therefore be more commonly reported by end-stage renal disease patients. In this respect, the American Psychiatric Association (1994) argues that for a definitive diagnosis of depressive disorder either feelings of sadness (depressed mood) or loss of interest (anhedonia) must accompany the somatic symptom/s. If sadness or anhedonia is absent, Hedayati et al (2012) suggest consideration be given to other causes such as dialysis inadequacy, poor nutritional status, and/or cognitive dysfunction. To identify and distinguish these symptoms and confirm a depressive disorder, they recommend a structured interview be conducted in the clinic or dialysis centre, or referral to mental health professionals, before treatment is considered.

Most of these depression screening tool questionnaires can be completed in a few minutes making them relatively easy to integrate into routine patient care. It is recommended by Hedayati et al (2012) that screening take place on initial presentation of CKD patients for evaluation to clinic, at dialysis initiation for end-stage renal disease patients, and possibly 6 months after initiation and yearly thereafter. However Chilcot et al (2008) argue that whilst using an existing or modified depression screening measure such as the BDI for the end-stage renal disease population is viable, ideally a specific depression assessment tool should be developed for this patient group since the type of screening measure used may contribute to the varied level of reported prevalence.

3.3 Incidence of depression

There is a substantial body of evidence covering prevalence of psychological problems at **levels 3-5** of the 'Pyramid Psychological Problem' model among end-stage renal disease patients, but rather less evidence available relating to the lower levels. However, there is no generally accepted figure for incidence of depression in the end-stage renal disease population; the exact prevalence remains contentious. Variation appears dependent on the type of assessment undertaken and which depression

definition is used (see section 3.3.2.). In general, depression screening tools suggest a higher prevalence compared with diagnostic interviews (Chilcot et al, 2008). A particular difficulty for researchers investigating prevalence is that many of the symptoms of depression overlap with the physical symptoms of illness. O'Donnell and Chung (1997) found that where an exclusive approach is taken (criteria based on physical symptoms being excluded from the diagnostic criteria) depression is likely to be under-diagnosed, whereas an inclusive approach (criteria based on physical symptoms being included) or a substantive approach (alternative criteria substituted) there is more consistency in reported prevalence. Differences in prevalence levels also appear linked to length of the assessment period, and type of therapy treatment of the population assessed. A further difficulty is that many published papers do not discriminate in presenting their findings between the incidence of mild, major or severe depression.

Nonetheless whilst reported prevalence levels of depression among end-stage renal disease patients generally vary between 15 and 40 per cent, overall these levels are significantly higher than the 2 to 10 per cent depression prevalence in the general population (Hedayati et al, 2012). They are also generally higher than those reported for some other chronic diseases such as diabetes mellitus and congestive heart failure (Anderson et al, 2001; Jiang et al, 2001).

A systematic review undertaken by Murtagh et al (2007), that investigated the whole range of symptoms experienced in end-stage renal disease, recorded a particularly wide prevalence range of between 5 and 58 per cent for depression, with a weighted mean prevalence of 27 per cent. The inclusion criteria for this review was very broad though and covered: study populations of adult patients with a principal diagnosis of end-stage renal disease; studies collecting data on symptom incidence or prevalence; studies of any design provided the study population was to some extent representative of the population at risk; and any setting. Eighteen studies were identified describing prevalence of depression or prevalence as part of a survey of multiple symptoms. Eight of these studies used the BDI screening tool to screen for depression, although not all used even the standard general population cut-off of greater than 10.

A study conducted in the UK by Martin and Thompson (2000) used a single group, cross-sectional design study that demonstrated clinically relevant levels of depression among 23 per cent of end-stage renal disease patients. 72 people (46 males and 26 females) participated in the study all of whom were on continuous ambulatory

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

peritoneal dialysis (CAPD) and had been treated for a minimum of 2 months. The screening tools used were the Locus of Control of Behaviour Scale, the Hospital Anxiety and Depression Scale (HADS) and the short-form Kidney Disease Quality of Life (KDQOL) instrument.

Wuerth et al (2005) screened 380 peritoneal dialysis (PD) patients for depression using the BDI and identified 49 per cent as having at least a moderate level of depression and the need for further investigation. The patients were all from one free-standing PD unit the USA. The cut-off level for a measure of depression was a recorded score on the BDI of 11 or greater. There were no significant differences among those identified as being depressed in terms of their age, sex, race, or whether or not they had diabetes. Of the 25 patients amongst those identified as depressed who agreed to then be interviewed by a trained psychiatric interviewer, 22 (85 per cent) were felt to have clinical depression.

A large-scale study by Lopes et al (2002) using data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) adopted a novel methodology for assessing depression prevalence based on a combination of physician-diagnosed depression and patient self-reported responses to two simple questions. The DOPPS study was undertaken amongst randomly selected end-stage renal disease patients treated by HD in the USA (2,855 patients) and five European countries (2,401 patients). Each patient's medical record was assessed for diagnosis of depression within the past 12 months and in addition patients completed the short-form KDQOL which queried about the presence and frequency of depressive symptoms during the previous 4 weeks. In particular, patients were asked to respond to two questions – whether they had felt 'so down in the dumps that nothing could cheer you up' and 'downhearted and blue'. A response of 'a good bit', 'most' or 'all' of the time was classified as depressed. Physician-diagnosed depression was reported in the medical records of 18 per cent of patients; 16 per cent of patients from Europe and 19 per cent of patients from the USA. Depression as measured by the 'so down in the dumps' question was observed in 19 per cent of patients overall (23 per cent of European and 17 per cent of USA patients). For the 'downhearted and blue' question, a total of 21 per cent of patients were classified as depressed (25 per cent of European and 19 per cent of USA patients). However the study authors identified several methodological limitations, notably that depression was only assessed at the start of the follow-up. Since depressive symptoms vary over time there is therefore uncertainty as to whether the measures of depressive

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

symptoms reflect an average level of depression for patients during the follow-up period.

An early study by Kutner et al (1985) using self-rating scales, identified over half of the dialysis patients assessed as having symptoms of depression, with 27 per cent recording scores in the depressed range. A total of 128 dialysis patients participated in the study (82 males and 46 females), recruited from 9 chronic dialysis facilities in one metropolitan area of the USA. 18 home dialysis patients also participated. All participants were aged over 18 years and had been dialysing for at least 3 months, mostly three times a week for 4 hours at a time. 19 per cent of the sample had been dialysing less than a year, 43 per cent for 1 to 3 years, 32 per cent for 4 to 6 years, and 6 per cent for 7 years or more. Several different screening tools were used for the study: the Zung Self-Rating Depression Scale and Self-Rating Anxiety Scale, the Different Emotion Scale, the Test of Emotional Styles and the Social Dysfunction Scale. Interestingly the longer patients had been on dialysis the lower their levels of both depression and anxiety. The researchers suggested it might be possible that as patients obtain relief from, or are better able to tolerate the physical disturbances associated with renal failure and/or dialysis therapy, depression and anxiety are lessened. This hypothesis was supported by their finding that the longer patients had been on dialysis, the more likely they were to feel physically fit and the less likely they were to worry about their health.

More recently a study by Anand et al (2012), using data from the Comprehensive Dialysis Study undertaken in the USA, reported 28 per cent of dialysis patients experiencing depression. Data was collected from 1,678 patients on either PD (169 patients) or HD (1,509) using the two-item PHQ.

A recent systematic review and meta-analysis of observational studies by Palmer et al (2013) confirmed that prevalence estimates of depression in chronic kidney disease vary widely, dependent on the methods used to identify depression. The review included a total of 55,982 participants. When assessed by clinical interview, 23 per cent of adults with chronic kidney disease stage 5 (treated with dialysis) were recorded as depressed, with equivalent scores of 21 per cent for patients at chronic kidney disease stages 1-5, and 26 per cent for kidney transplant recipients. Whereas when questionnaire-based tools were used to identify depressive symptoms, estimated prevalence was significantly higher for people on dialysis with 39 per cent recorded as experiencing

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

depressive symptoms. Among both patients with chronic kidney disease stages 1-5, and kidney transplant recipients, assessed by questionnaire, 27 per cent were found to have depressive symptoms.

Several studies have assessed psychosocial factors in a longitudinal manner, either in relation to disease stage or lifecycle of an end-stage renal disease patient. A longitudinal study carried out by Husebye et al (1987) showed that 42 per cent of HD and PD patients over the age of 70 years had an unchanged level of depression when assessed over three years. On re-evaluation more than 25 per cent of patients were less depressed, but 33 per cent exhibited a higher level of depressive symptoms. The cross-sectional studies conducted by Kimmel (1995 and 1998) found no relationship between the amount of time a patient had been treated for end-stage renal disease and the level of depressive effect. However, the longitudinal studies revealed a tendency for levels of depression to decrease over time. Whilst this tendency is likely to reflect successful patient adjustment to the stresses of end-stage renal disease it may also be a consequence of survivor bias; although mean levels of depression tended to remain stable over time, there was variation in individuals (Kimmel, 2001).

Employing a one-year prospective longitudinal methodology that followed patients new to HD therapy through the first year of dialysis Walters et al (2002) identified 45 per cent of patients as experiencing depression. 422 new patients with end-stage renal disease were recruited to the study from 151 randomly selected dialysis units in the USA. Baseline questionnaires incorporating the short-form KDQOL and a three-item depression screening measure derived from the Diagnostic Interview Schedule were administered to patients in dialysis units, within 60 days of starting HD therapy.

Relying on a physician diagnosis of depression, a retrospective cohort study by Hedayati et al (2005) identified 15 per cent of male patients with end-stage renal disease as having depression. International Classification of Disease Codes from the Department of Veterans Affairs databases in the USA were used to identify physician diagnosed depression in 1,588 male patients with end-stage renal disease, receiving long-term outpatient HD. Patients with a physician depression diagnosis were more likely to be white and have more medical co-morbidities such as hypertension, ischemic heart disease, peripheral vascular disease, and/or liver disease than those without a depression diagnosis.

Nonetheless a survey by Weisbord et al (2007a) among African American and White HD patients in the USA found no racial differences in the prevalence of depression. 82 White patients and 78 African American patients were assessed for depression using the BDI and CDI. Symptoms were evaluated using the Dialysis Symptom Index. 27 per cent of White patients as well as 27 per cent of African American patients were recorded as having depression. Symptom burden was substantial in both racial groups with no differences in the overall burden or severity of symptoms.

3.4 Incidence of anxiety

There is less evidence on the incidence of anxiety among end-stage renal disease populations, but nonetheless the available evidence indicates anxiety being experienced by a significant proportion of patients. Many of the methodological issues described in relation to assessing prevalence of depression (see section 3.3.2.) are also applicable in relation to measuring anxiety levels.

The systematic review of symptom prevalence in end-stage renal disease undertaken by Murtagh et al (2007) identified only six studies that explored anxiety prevalence. The range of prevalence was 12 per cent to 52 per cent with a weighted mean prevalence of 38 per cent.

The level of self-reported anxiety amongst dialysis patients in the study undertaken by Kutner et al (1985) was 45 per cent, primarily in the symptomatic range. A cross-sectional study conducted by Curtin et al (2002), also using self-reports of HD patients to catalogue symptoms, reported 52 per cent of patients 'feeling anxious or worried'. Data was collected from 307 randomly selected HD patients from 14 dialysis units in the USA. To assess symptom experiences patients were presented with a list of 47 common symptoms identified from a review of the literature. Patients were asked to think of the past 4 weeks and report how often they experienced the listed symptoms. They completed the survey whilst on dialysis. Mean experience scores were calculated from the responses.

In a single group, cross-sectional study conducted in the UK by Martin and Thompson (2000), 39 per cent of the 72 end-stage renal disease patients treated with CAPD demonstrated clinically relevant levels of anxiety.

A more recent study by (Cukor, 2008a) that used the HADS and Diagnostic and Statistical Manual of Mental Disorders (DSM-1V) Axis 1 diagnosis, found 46 per cent of end-stage renal disease patients had an anxiety disorder and 40 per cent met the criteria for a mood disorder. The study was undertaken amongst 70 end-stage renal disease patients on HD from a single dialysis unit in the USA. Concordance between the two screening scales used was not significant. Interestingly the researchers undertook a follow-up study 16 months later (Cukor et al, 2008b) that showed 33 per cent of patients with an anxiety diagnosis at baseline, still had an anxiety disorder, although the sample base was small since follow-up study data was only available for 21 patients.

3.5 Emotional and psychodynamic difficulties

The multiple stressors associated with end-stage renal disease may have profound emotional and psychodynamic impacts. There is also some evidence that emotional and psychological factors can play a mediating role in relation to depression and anxiety in end-stage renal disease patients.

A qualitative study in Australia to investigate the biopsychosocial impact of end-stage renal disease on dialysis patients and their partners, conducted by White and Grenyer (1999), identified a complex interaction between emotional states and therapy, illness perceptions, relationship factors and social role disruptions. Prominent themes identified from the interviews included patient anxiety about the uncertainty of their health and future; and negative emotional responses to their disease and dialysis including anger, denial and depression.

The concept of loss in kidney disease emerges from several qualitative research studies. It appears that end-stage renal disease patients can experience a range of losses both tangible and symbolic: loss of freedom, control, physical strength, lifestyle, employment; and this may result in grief. For example, a qualitative study in the UK by Wright and Kirby (1999), exploring adjustment to end-stage renal disease among 10 CAPD patients and 5 partners/relatives, identified experiences of loss as a significant theme. Whilst patients might talk about how they had adjusted to their illness and treatment, they also appeared to be processing experiences of loss. This was manifest in various ways such as focusing on the personal meaning of what had happened, and recalling past roles and routines that had gone, maybe forever. Accompanying this

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

were feelings of sadness and sorrow.

A quantitative study undertaken by Chan et al (2009) used a specifically designed measure of kidney-disease-related loss, the Kidney Disease Loss Scale (KDLS) to test the validity of loss in relation to depression and quality of life for end-stage renal disease patients. The sample was composed of 151 end-stage renal disease patients aged over 18 years who had been on dialysis for approximately 2 years or more, recruited from two university teaching hospitals in Australia. 45 per cent (68 patients) were on home-based dialysis, either home haemodialysis (HHD) or PD, and the others were on hospital-based dialysis including satellite and in-centre HD. Study findings revealed kidney-disease-related loss to be a strong contributor to depression, particularly among home-based patients, although the findings do not appear to support depression being an extension of kidney-disease-related loss. Travel, leisure activities and physical functions were the most frequently mentioned types of loss. The researchers suggested that helping patients regain losses through support to travel or perform activities more, or to process their related cognitive 'ruminations', might improve patients' depression and quality of life.

An interesting cross-sectional design study undertaken by Billington et al (2008) found that hope is an important predictor of positive adjustment to end-stage renal disease and consequent dialysis. The study involved a sample of 103 end-stage renal disease patients (64 males and 39 females) aged over 18 years and currently dialysing who were from five renal units in North-West England. The patients completed a survey questionnaire that included the 12-item hope scale, a self-report measure of dispositional hope, and several other measurement scales: the Significant Others Scale measuring perceived emotional and physical support and satisfaction with support given, the Multidimensional Health Locus of Control Scale, the HADS, and the KDQOL measure. Results from the survey indicated that hope was a significant independent predictor of variance in anxiety, depression, effects and burden of kidney disease, but not of variance with regard to symptoms or physical quality of life.

Other researchers have found that mechanisms of control are associated with depression among renal patients. A study of health locus of control and depression in patients with chronic kidney disease progressing to end-stage renal disease carried out by Cvengros et al (2005), revealed that as the disease progressed to requiring dialysis, changes in internal control predicted depression. A more recent study undertaken in

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

France by Birmele et al (2012) showed that internal locus of control and external locus of control (the influence of 'powerful others') were positively correlated with mental quality of life measures. A key finding from the study was that patients who viewed themselves or someone other than themselves as having control over their situation had better self-perceived mental health.

Illness perceptions have also been shown to be closely associated with depression symptoms in ESRD patients. Griva et al (2009) reported that greater perceived illness consequences perceptions, lower perceptions of control and stronger levels of treatment disruptiveness among ESRD patients were associated with higher depressive symptoms as measured by the BDI. Chilcot et al (2011) found that lower perceptions of personal control and illness understanding and greater perceived consequences predicted significant depression symptoms among established HD patients, as measured by the BDI. Other studies have reported an association between illness perceptions and health-related quality of life among dialysis patients (Covic et al, 2004 and 2006; Timmes et al, 2008).

Additionally, a paper by Feroze et al (2012) on early findings from a cross-sectional study of anxiety and depression in HD patients, described how patients well established on dialysis can experience anxiety during individual dialysis sessions. The study sample was composed of 155 patients that had been undergoing maintenance dialysis for at least 6 months, the average time they had been dialysing being 55 months. The patients completed the BDI and Beck Anxiety Inventory as well as questionnaires that examined their feelings and anxiety related to individual HD sessions. The study findings showed that anxiety could be caused by particular events on the dialysis unit, such as an unknown person connecting the patient to the dialysis machine, when a patient hears the alarm sound on the dialysis machine, or paramedics are seen in the dialysis unit.

3.6 Influence of co-morbidities

The prevalence of mental health disorders seems to increase in relation to the number of physical morbidities a person has; multimorbidity being the norm for people with chronic disease including end-stage renal disease. A recent large-scale cross-sectional study undertaken by Barnett et al (2012) examined data on 40 morbidities among 1.75 million people registered with over 300 medical practices in Scotland, and reported that 42 per cent of all patients had one or more morbidities and 23 per cent were

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

multimorbid, having two or more chronic morbidities. The presence of a mental health disorder increased as the number of physical morbidities increased: by a ratio of 6.74 for five or more disorders, as compared with 1.95 for one disorder.

These findings support results from the study by Lopes et al (2002) that showed end-stage renal disease patients with depression identified by physicians were more likely to have co-morbid conditions. In particular, prevalence of depression was higher where there was presence of coronary artery disease, congestive heart failure, hypertension, cerebrovascular disease and/or diabetes mellitus.

4. Impact of emotional and psychological problems on clinical outcomes

- There is evidence of an association between depression and increased hospitalisation rates in ESRD patients
- Evidence is contradictory as to whether depression in ESRD patients is a predictor of mortality; key influencing factors appear to be differences in how depression is defined and the screening tools used
- Depression appears to have some influence on ESRD patients choosing to withdraw from dialysis
- Evidence suggests there may be a relationship between behavioural compliance and medication adherence, and level of depressive affect or a diagnosis of depression
- Low level emotional and psychological distress can impact on acceptance and understanding of a diagnosis of ESRD and the treatment information provided by clinicians; in turn this can influence treatment decision-making

4.1 Impact of depression on rates of hospitalisation and death

Several significant studies have demonstrated an association between depression and increased hospitalisation rates in end-stage renal disease patients. However, there is contradictory evidence as to whether depression in end-stage renal disease patients is a predictor of mortality. Key influencing factors appear to be differences in how depression is defined and the screening tools used. Variations in study design, sample populations studied, and statistical methods used, are also likely to have had a determining influence. Hedayati et al (2008) argued that differences in the proximity of depression measurement to the time of outcome assessment, as well as the

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

persistence of depressive symptoms over time, may also be factors.

A large-scale study undertaken by Lopes et al (2002) using DOPPS data, identified a diagnosis of depression as being associated with increased mortality and morbidity, whether depression was physician diagnosed or simply on the basis of self-reported responses to two basic questions. Among the sample base of HD patients living in the USA (2,855 patients) or Europe (2,401 patients), depression was shown to be independently correlated with higher risks of both mortality and hospitalisation. The association between depression and these outcomes remaining statistically significant even after adjustment for demographic factors, years on dialysis, co-morbidities and country of residence. Since the two simple questions used as indicators of depression were found to have predictive validity, the researchers proposed these be used in clinical practice to identify HD patients with depressive symptoms, so they can receive more detailed evaluation and attention to reduce risks of hospitalisation and death.

In another study, Kimmel et al (2000) administered the BDI and Cognitive Depression Index (CDI) to HD patients at 6-month intervals, and using time-varying covariate analysis found that both screening tools predicted mortality, with relative risks of 1.24 and 1.18 respectively. The prospective cohort study with longitudinal follow-up involved 295 end-stage renal disease patients on HD recruited from three outpatient dialysis units in the USA. Patients were assessed every 6 months for up to 2 years. The researchers argued that time-varying analyses in longitudinal studies may add greater power and sensitivity to establishing the association of psychosocial factors and survival in end-stage renal disease patients.

Similarly an investigation of the relationship between depressive symptoms, cardiovascular events and mortality using time-varying models by Boulware (2006), demonstrated that the symptoms of depression were associated with increased all-cause mortality, cardiovascular events and mortality. The study involved analysis of observational data from the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) survey. Whereas baseline high level of depressive affect was found not to be associated with increased overall 2-year mortality, persistently higher levels of depressive affect over time were associated with increased risk of death and cardiovascular events. The strength of this relationship was attenuated when a 6-month time lag was incorporated into analyses, leading the authors to argue that the association of depression with outcomes is due to worsening co-morbid illness resulting

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

in depression, rather than depression causing poor outcomes. This suggests a role for co-morbidity in the genesis of depression rather than depression leading to increased morbidity (Chilcot, 2008), an issue discussed in section 3.6.

An inception cohort study among patients starting dialysis, conducted in Spain by Lopez (2004), found patient-perceived mental health to be an independent predictor of all-cause mortality and morbidity. The study involved a total of 351 patients from 34 Spanish hospitals, the majority (66 per cent) of whom were diabetics. During the first month of the study all patients were instructed to complete a health-related quality of life questionnaire that used a validated Spanish version of the Short Form 36 (SF-36) Health Survey and Karnofsky Scale. The primary outcome variable measured by the study was time until death and the secondary outcome variable was hospitalisation days. Every 3 months over a follow-up period of between 1 and 3 years, researchers reported whether each patient was alive or dead and the number of hospitalisations experienced during the previous 3 months. Results from the study, after adjustment for socio-demographic and clinical variables, showed that the SF-36 mental component score predicted all-cause mortality, although in non-diabetics the effect on mortality was not statistically significant. A lower SF-36 mental component score was found to be the only variable associated with more hospitalisation days, both among diabetics and non-diabetics.

A retrospective cohort study by Hedayati et al (2005), used regression models over a 2-year observation period to determine whether there was an association among end-stage renal disease patients, between depression diagnosis and number of hospitalisations and cumulative hospital days. Patients with physician diagnosed depression were found to experience a 30 per cent greater rate of cumulative hospital days compared with those without depression, a level that remained significant after adjusting for patient demographics and co-morbidities. Although a depression diagnosis was shown not to be associated significantly with death.

A smaller-scale, observational study conducted by Hedayati et al (2008), found depressed end-stage renal disease patients on chronic HD to be almost twice as likely to die or require hospitalisation within a year, as compared with those without depression. A total of 98 patients were involved in the study and followed prospectively for up to one year after enrolment. They were assessed using the structured Clinical Interview for DSM, a DSM-validated psychiatric interview. Results from the study

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

revealed that 21 of 26 depressed patients (81 per cent), and 31 of 72 non-depressed patients (43 per cent), died or were hospitalised by the end of the study period. After adjustment for age, gender, race, time of dialysis and co-morbidities, there was shown to be a significant increased risk of hospitalisation and death for depressed patients.

Similarly, a more recent prospective observational cohort study undertaken among pre-dialysis chronic kidney disease patients by Hedayati et al (2010), demonstrated that a diagnosis of current major depressive episode was associated with an increased risk of hospitalisation, or progression to dialysis, independent of co-morbidities and kidney disease severity. Although no association with increased mortality was found. The study involved 267 consecutively recruited pre-dialysis outpatients with chronic kidney disease (stages 2-5), at a Veterans Association medical centre in USA. They were recruited over a six-month period and then followed up for one year. All patients underwent a structured interview at enrolment to determine the presence of a current major depressive episode (MDE) using the Mini International Neuropsychiatric Interview. Findings from the study revealed that more chronic kidney disease patients with a MDE were hospitalised than those without a MDE (55 per cent versus 40 per cent), and more patients with a MDE started maintenance dialysis compared to those without a MDE (27 per cent versus 11 per cent).

4.2 Impact on compliance and adherence

There is some evidence suggesting a relationship between behavioural compliance and medication adherence, and level of depressive affect or a diagnosis of depression. Cukor et al (2009) demonstrated that depressive affect is an important contributor to low medication adherence in patients with end-stage renal disease, whether on HD or kidney transplant recipients. The study compared psychological measures based on the BDI, and self-reported medication adherence using the Medication Therapy Adherence Scale and Mental Health Locus of Control Scales, between 65 HD patients and 94 kidney transplant recipients at one medical centre in the USA. In contrast with the kidney transplant group, the HD cohort was found to be significantly more depressed as well as having significantly lower adherence to medication. Hierarchical multiple regression analysis showed that variance in depression was the only statistically significant predictor of medication adherence, beyond gender and mode of treatment, accounting for 12 per cent of variance.

Similarly a recent survey among CKD patients in Greece by Theofilu (2012) found medication adherence was negatively related to depression. A sample of 168 patients undergoing in-centre HD were recruited from 6 general hospitals in Athens and measured using the Medication Adherence Rating Scale, the CESD and the Multidimensional Health Locus of Control Scale. The research participants were all aged over 18 years and had been on dialysis for at least a year. 58 per cent had been dialysing for less than 4 years and 42 per cent for 4 years or more. An analysis of differences between HD patients with a normal pattern of medication adherence, and those with an abnormal pattern, revealed that patients more adherent to medication had less symptoms of depression. More adherent patients also presented higher scores on both internal and doctors' health locus of control. Additionally patients assessed as having severe depression, were less adherent to medication than those presenting mild depression.

4.3 Withdrawal from dialysis

Depression appears to have some influence on end-stage renal disease patients choosing to withdraw from dialysis. Cohen et al (2002) attempted to identify and evaluate patients for depression after they had already withdrawn from dialysis, but this proved problematic since the psychological condition of the patient can deteriorate leading to non-consent or participation; only 29 per cent of patients referred for study participation could be meaningfully evaluated. Furthermore the researchers felt that once the decision to terminate life-sustaining treatment had been made, patients may be reluctant to disclose depressive symptomology.

Adopting a different methodological approach by following patients after depressive symptom assessment, McDade-Montez et al (2006) found that level of depressive symptoms was a unique and significant predictive factor for the subsequent decision to withdraw from dialysis. Patient data was drawn from several earlier studies conducted over a 9-year period in the USA by the same research team. The sample studied consisted of 240 end-stage renal disease patients (133 male, 107 female) aged 18 years and over, who were followed for an average of 4 years after depression symptom assessments. All the research participants were on HD at the time of assessment, depression symptomatology being measured through the BDI. At follow-up, 18 per cent of patients had died as a result of withdrawing from dialysis. Using multivariate survival analysis and after controlling for the effects of age and clinical variables, the

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

researchers concluded that patient depression significantly predicted the subsequent decision to terminate life-sustaining dialysis. Patients with relatively high scores on the BDI had a 36 per cent increased risk of withdrawing from dialysis over the average 48-month follow-up period.

4.4 Suicide

There is limited evidence to suggest that suicide contributes to the mortality rate associated with depression among end-stage renal disease patients. Whereas suicide accounts for around 0.2 deaths per 1,000 patient years, a study of suicide among end-stage renal disease patients in the USA found the incidence rate of suicide to be 1.84. This equates to an 84 per cent higher suicide risk compared with the general population (Kurella, 2005; Kimmel, 2005).

4.5 Timely listing for transplantation

Some evidence of an association between depression and a lower rate of timely listing and transplantation is recorded in an interesting recent study by Szeifert et al (2012). The cross-sectional study among HD patients was based on data from the DOPPS study and found that more severe depressive symptoms was one of the variables associated with lower likelihood of being on the transplant waiting list. The study involved 2,033 HD patients in the USA and 4,350 HD patients across seven European countries. Self-reported depressive symptoms were measured using the CESD. Findings from the study showed that fewer depressive symptoms are associated with being on the transplant waiting list, but among wait-listed patients there was no association between depression and lower transplantation rates. The researchers concluded that regular assessment of subjective wellbeing may help identify patients with reduced access to wait-listing and kidney transplantation.

4.6 Impact of emotional distress on diagnosis acceptance, information comprehension, and treatment decision-making

Low level, mild to moderate emotional and psychological distress can impact on acceptance and understanding of a diagnosis of end-stage kidney disease, and the treatment information provided by clinicians. In turn this can influence treatment decision-making.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

A qualitative study undertaken in Australia by Tong et al (2009) found that emotional distress experienced by chronic kidney disease patients at the time of diagnosis influenced their understanding and acceptance. The study involved nine focus groups among patients aged 18 to 80 years, at different stages of chronic kidney disease (pre-dialysis, dialysis, transplantation) and from four kidney units. Findings revealed that most patients initially experienced despair and disbelief after receiving their diagnosis. This resulted in them feeling vulnerable, helpless and confused whilst trying to grasp the new clinical language and environment. Many also expressed feeling shock and described the experience as traumatic and overwhelming. Participants said they were made more fearful and anxious because of the apparent uncertainty about their treatment and prognosis.

Similarly in a systematic review of qualitative studies on decision making and choice for dialysis, transplantation or palliative care, Morton et al (2010) described renal patients feeling 'startled' by their diagnosis and the conscious realisation they could die from their disease. The researchers recommended patients be given more time than currently to absorb information and adjust to their diagnosis before making treatment decisions.

Providing a descriptive overview of the psychological problems experienced by renal patients, Major and Glass (2010) highlighted particular points in the patient pathway when patients can struggle to adjust or cope: after initial diagnosis, and at the start of new treatment options. They proposed using a conceptual framework based on the stages of grief developed by Kubler Ross (1969) to describe and explain the stages of adjustment that patients may experience and their various emotional reactions, covering shock and disbelief, anger, depression, bargaining and acceptance. Gregory et al (1998) found that HD patients who experienced more critical events – frequent illness episodes and periodic access site or machine functioning problems – have greater emotional and psychological difficulties than those who rarely experience such events.

A recent small-scale qualitative study undertaken in the USA by Schell et al (2012), revealed that older chronic kidney disease patients, over 65 years, experience strong emotions throughout their disease course, beginning at the time of diagnosis. These strong emotions can act as a barrier to patients understanding their disease and

preparing for the future. The researchers described how emotionally unprepared the study patients were for their diagnosis, the trajectory of their disease and HD treatment, having had no preparation from their clinician and because there were no obvious symptoms of illness. After a diagnosis, patients described living in fear of when dialysis would be necessary, with lack of information leading to a sense of powerlessness. Whilst patients on HD explained how unprepared they had been for the emotional experience of day-to-day life on dialysis therapy and the adjustments they would have to make; the mental adjustment was considered just as intense as the physical one.

These findings are supported by evidence from the wider literature on long term chronic diseases. For example, evidence from the literature on care and treatment of certain cancers associates emotion with psychological distress, which in turn can affect patient understanding (Anderson et al, 2008; Ryan et al, 2005). The review of the literature on doctor-patient communication undertaken by Ong et al (1995) found that when information is particularly upsetting like learning the diagnosis of cancer, most patients are too stunned to register any further information given to them. This can lead them to feel they lack information which in turn can result in feelings of anxiety, uncertainty and depression. Furthermore difficulty in accepting diagnosis can limit people's ability to be actively involved in decision-making (Beaver et al, 2007).

A systematic review across all health conditions of interventions that may affect informed decision making, by Bekker et al (1999), incorporating 336 RCTs, identified degree of anxiety or depression experienced by patients as one of the personal health states affecting the extent to which informed decisions are made. Interestingly it was noted that whilst reduced anxiety may be desirable it is not necessarily associated with more informed decision making. It is the extent to which a person is experiencing anxiety that appears to be the important determinant. For example, moderately raised anxiety is associated with a more systematic evaluation of the information, but great anxiety is more linked to quick, emotive decision making without any rational consideration.

5. Clinician identification of patient emotional and psychological support needs

- Although the burden of psychological and emotional difficulties in ESRD patients is often substantial, renal clinicians appear to give insufficient recognition to these

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

symptoms

- Clinicians often experience difficulties in identifying patient need for low level emotional and psychological support

A small-scale qualitative study undertaken in the USA by Bass et al (1999) revealed that whilst renal health professionals understood patients' views about the effects of end-stage renal disease and dialysis on their lives, they did not appreciate some of the emotional and psychological aspects. The researchers conducted separate focus group discussions with 13 adult HD patients, and 17 nephrologists and other health professionals involved in dialysis care (nurses, dieticians, social workers and technicians). During the focus groups, patients made comments about ten different quality of life domains affected by end-stage renal disease and dialysis treatment: freedom/control, social relationships, anxiety, role functioning, mental attitude, cognitive function, sexual relations, body image, sleep and energy. By contrast the healthcare providers commented on only five quality of life domains: freedom/control, social relationships, role functioning, and sexual relations. They made no comment about the effects of end-stage renal disease and dialysis on mental attitude, and the effects of symptoms on anxiety, body image, sleep and cognitive function.

An assessment of renal providers' recognition of symptoms in patients on maintenance HD by Weisbord et al (2007b), showed that clinicians were largely unaware of the presence of emotional symptoms in their patients. Participants in the study were 75 long-term HD patients and 18 renal clinicians from three dialysis units in the USA. The Dialysis Symptom Index, a 30-item measure of symptoms and their severity was administered to patients during a routine HD session, and immediately after surveying the patients the renal clinician who evaluated the patient completed the same Index to report the symptoms they believed present in the patient. The study findings revealed the clinicians were largely unaware of many emotional, as well as physical symptoms. Even when providers did correctly identify symptoms, the severity of the symptoms was commonly underestimated. Symptoms recording particularly significant differences in reported prevalence between patient and provider were 'feeling sad' (24 per cent versus 12 per cent respectively), 'difficulty becoming sexually aroused' (28 per cent versus 7 per cent), and 'feeling anxious' (23 per cent versus 12 per cent).

Schell et al (2012) found that whilst nephrologists often recognised patients were uninformed about their disease, they tended to respond by tailoring the information given, rather than responding to patient emotion. The researchers argued that

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

responding to emotion was often made more challenging because many patients expressed emotion nonverbally. This is not an issue unique to nephrologists. Physicians specialising in other long term chronic illnesses have also been found to have difficulty recognising and responding to patient emotion (Detmar et al, 2001; Ford, Fallowfield and Lewis 1994). Discussing the literature on communication in cancer care, Schofield and Butow (2004) argue that since psychological conditions are subjective in nature, their identification is mostly dependent on verbal and non-verbal cues the patient provides to the clinician about their feelings. The difficulty is that many patients do not spontaneously disclose emotional difficulties during consultations (Fallowfield et al, 2001) and may even block such discussions (Byrne et al, 2002).

6. Provision of emotional and psychological support

- Only a minority of patients appear to receive adequate support and treatment for their psychological and emotional needs
- Determining factors for the low levels of support and treatment are likely to include lack of clarity over which clinicians should be responsible for handling these issues, and insufficient counselling and psychology resources

Despite the apparently high prevalence of psychological and emotional symptoms including depressive disorder among end-stage renal disease patients, and association with poor clinical outcomes, the indications are that only a minority of patients appear to receive adequate support and treatment. The prospective observational cohort study conducted by Hedayati et al (2008) revealed that only 23 per cent of 98 HD patients with a current diagnosis of depressive disorder had received an intervention. An intervention being defined as referral to a mental health clinic, initiation of an antidepressant medication, or increasing the dose of previously prescribed antidepressant. Similarly Watnick et al (2003) found that only 16 per cent of end-stage renal disease patients starting HD and recording BDI scores of over 15 (above the threshold for validated depression), were on antidepressants.

In the UK a non-peer reviewed study by Molyneux, Jones and Brooks (2010), revealed that only 6 per cent of the end-stage renal disease patient population in the North Yorkshire and York PCT area had been referred over a one-year period to a clinical psychologist. This was well below the level of recorded psychological distress – using a Distress Thermometer questionnaire modified for a renal population, 21 per cent of

patients reported moderate levels of stress and 19 per cent severe levels of distress.

A determining factor for the low levels of support and treatment may be lack of counselling and psychology resources. There are no current figures available on numbers of renal counsellors and renal psychologists employed in the UK. The most recent data taken from the National Renal Workforce Planning Group study (British Renal Society, 2002), showed very limited availability of clinical psychological support and counselling, as well as marked variations across renal units. There were found to be only 7 clinical psychology posts (2.5 whole time equivalent (wte)) and 16 identified counselling positions with dedicated renal time. Based on evidence available at the time, it was recommended that clinical psychology needs should be met by a minimum of one wte clinical psychologist per 1000 renal replacement therapy patients, in units with adequate social work and renal counselling workforce. In the absence of such support, the recommended requirement was a minimum of one wte clinical psychologist per 500 renal replacement therapy patients. This study is currently being updated by the British Renal Society.

Another influencing factor is likely to be the issue of who should assume responsibility for treatment of psychological and emotional problems. There is some recent, low-quality evidence suggesting renal providers believe non-renal clinicians are primarily responsible for treating depression. Green et al (2012) surveyed a small sample of 35 renal providers whose patients were participating in a clinical trial of symptom management at nine HD units in one USA state. Whilst the majority of renal providers believed symptom management of depression, pain and sexual dysfunction to be 'very' important and reported spending either a 'moderate' or 'a lot' of time managing the symptoms, most providers believed it was non-renal providers' responsibility to treat the symptoms and as a consequence described not treating the symptoms themselves.

It is also important to consider that not all patients identified as having emotional and/or psychological difficulties will want to receive support. Interestingly 55 per cent of the PD patients identified in the study by Wuerth et al (2005) as having depression refused further assessment and treatment, despite discussions with the medical team and social worker about the potential benefits. Two of the renal unit social workers systematically reviewed the records of those patients refusing further assessment for depression. The main reasons included denying being depressed and unwillingness to consider taking further medications. In addition, some patients felt they would be

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

stigmatised if they were to acknowledge symptoms of depression.

7. Emotional and psychological support needs from the patient perspective

- There is limited evidence relating to what ESRD patients want and need in terms of emotional and psychological support
- However it is clear from descriptive studies that patients want improved support, particularly in the areas of adjustment, coping, and maintaining control.
- Patients also want more support to assist their close family in coping

Qualitative research undertaken in Australia by Tong et al (2008) to determine chronic kidney disease patients' priorities for health research, identified psychosocial aspects of living with chronic kidney disease and improvements in caregiver support as two of eight key research priority areas. The need for more research on psychological and social support was frequently discussed across the nine focus groups. It was felt that health professionals often overlooked the range of mental health and social problems patients experienced.

Similar qualitative research undertaken in The Netherlands by Schipper and Abma (2011) to elicit priorities for social science research from the perspective of chronic kidney disease patients, identified as top priorities research on coping, family life, and maintaining control in the face of demanding treatment. Individual interviews were conducted with 20 patients and seven focus groups with a total of 54 patients. All the patients were on dialysis treatment or had a kidney transplant and were aged over 18 years. 17 research themes were prioritised with research to consider dealing with and acceptance of the illness given top priority. Patients described initially experiencing the disease as an 'enemy' with future perspectives and ambitions having to be adjusted. There was a need to adapt themselves to permanent changes and deal with different stressors. Their families also needed to deal with changes which could result in tensions. To prevent overburdening, patients therefore asked for research on how they and their families could be better supported in adapting to the illness. Research linked to maintaining control over their lives and treatment was prioritised third. In this context, the study elicited interesting views from patients about their relationships with professionals. Patients clearly preferred an approach in which the focus is not exclusively on their kidney and the replacement of its function, but on themselves as

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

persons. Yet in their contact with clinicians they could experience a significant dilemma - whilst they did not want to accept all they were told unthinkingly, for some patients being assertive could evoke emotions of fear as a consequence of feeling dependent and vulnerable. They were therefore keen for research on how patients and professionals could develop a good relationship balance between independence and dependence.

Additionally a non-peer reviewed quantitative and qualitative study conducted in the UK by Ormandy et al (2007) identified information about how to cope and adjust to the disease, and who could provide support when needed, as one of nine core information needs among chronic kidney disease patients.

8. Effectiveness of interventions to address lower level emotional and psychological needs

- There is a lack of evidence on interventions to address lower level emotional and psychological needs of ESRD patients
- However there is some evidence on positive outcomes delivered by exercise, CBT, types of dialysis modality, and interventions designed to build coping and empowerment skills among ESRD patients
- There is more robust evidence for people with chronic diseases in general
- Clinical guidance from NICE suggests that for adults with mild to moderate depression and a chronic physical health problem, consideration be given to offering one or more of the following interventions: a structured group physical activity programme; group based peer support programme; individual guided self-help based on the principles of cognitive behavioural therapy (CBT); computerised CBT
- Studies on the effectiveness of mindfulness-based therapies have generally reported positive effects in terms of reductions in levels of anxiety, stress and depression

There is a lack of good evidence on interventions to address the lower level emotional and psychological needs of end-stage renal disease patients other than for pharmacological interventions, which are beyond the remit of this review. Rabindranath

et al (2009) failed to identify a single RCT in a Cochrane review assessing psychosocial interventions in depressed dialysis patients. Although they found certain therapy interventions to show some positive impacts for renal patients including exercise and CBT, types of dialysis modality, and some interventions focused on addressing coping and adjustment difficulties.

However, there is more robust evidence on interventions to address mild to moderate depression in people with chronic diseases in general. Additionally, clinical guidance from the NICE (2009) on the treatment and management of adults with mild to moderate depression and a chronic physical health problem, suggests consideration should be given to offering one or more of the following interventions, guided by patient choice:

- a structured group physical activity programme
- group based peer support programme
- individual guided self-help based on the principles of cognitive behavioural therapy (CBT)
- computerised CBT

8.1 Influence of dialysis modality on depression and anxiety

More effective dialysis may have a role in reducing anxiety and depression in end-stage renal disease patients. Some studies show daily HD to have a positive impact on emotional wellbeing although the sample sizes involved in these studies are generally small and they are mostly uncontrolled. For example, the broadening options for long term dialysis in the elderly (BOLDE) study undertaken by Brown et al (2010) identified that patients on PD and aged over 65 years, experience less anxiety and depression as well as lower illness intrusion than their matched counterparts on HD. The multicentre, cross-sectional study involved 140 patients, 70 patients on PD and 70 patients on HD recruited from three hospitals in SE England. All patients involved in the study were aged 65 years and over, had been on dialysis for a minimum of 90 days, and had not been hospitalised for 30 days. Quality of life measures used in the study included HADS, the SF-12 Mental Component Score (MCS), and the Illness Intrusion Ratings Scale. The study findings showed no significant differences in the unadjusted values for the HADS, SF-12 MCS and Illness Intrusion Ratings Scale among the 14 PD and 14 HD patients who had been dialysing for less than a year. Whereas among those dialysing for longer than 12 months (56 HD patients and 56 PD patients), HD patients

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

recorded significantly more illness intrusion, higher depression scores and worse SF-12 MCS scores than their PD equivalents.

An interim report from the Following Rehabilitation, Economics and Everyday-Dialysis Outcome Measurements (FREEDOM) study by Bertrand et al (2011), reported that short daily HHD is associated with improvement in the prevalence and severity of restless leg syndrome and sleep disturbances, proximal effects that can negatively impact on emotional wellbeing. The FREEDOM study is an ongoing prospective cohort study being undertaken in the USA.

8.2 Physical exercise

The National Collaborating Centre for Mental Health's (2010a) review of evidence for the NICE (2009) guideline, on treatment and management of depression in adults with a chronic physical health problem, concluded that physical activity is moderately more effective than standard care. There was also found to be a moderate effect on quality of life although the outcomes were of marginal statistical significance. The review included only 4 RCTs of physical activity programmes. All the programmes had a recommended frequency, intensity and duration, were used as a treatment for depression in people with a chronic physical health problem, and were undertaken individually or in a group. Three of the interventions involved were aimed at reducing depression and one focused on reducing psychosocial stresses and improving quality of life. The interventions were all based on supervised activity: two involved both aerobic physical activity and resistance training, and one involved aerobic physical activity alone.

Looking more specifically at the literature on kidney disease and exercise, a Cochrane review of RCTs among chronic kidney disease patients and kidney transplant recipients undergoing physical exercise interventions, by Haiwe and Jacobsen (2011), was unable to draw any conclusions about an association between exercise and depression levels given significant heterogeneity. Therefore we have separately looked at the findings from each of the included studies (Carmack et al, 1995; van Vilsteren et al, 2005; and Ouzoni et al, 2009).

Van Vilsteren et al (2005) found three months of supervised low intensity mixed cardiovascular and resistance training linked with exercise counselling decreased levels of depression. 96 HD patients in the Netherlands were randomised into an exercise

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

group (53 patients) and a control group (46 patients). The exercise programme consisted of cycling during dialysis together with a pre-dialysis strength training programme. Motivational interviewing techniques were used for exercise counselling. Before and after the intervention both groups were tested on health related quality of life measures including depression, the 20-item Self-Rating Depression Scale being used to assess depression.

Similarly a study in Greece by Ouzouni et al (2009) demonstrated that ten months of supervised, high intensity, mixed cardiovascular and resistance training decreased levels of depression among end-stage renal disease patients. 35 patients on HD (27 males and 8 females) were randomised to either a rehabilitation or control group. All patients at the start and end of the study were assessed using measurements that included the BDI, health-related quality of life questions and personality parameters. The intervention group underwent a 10-month supervised exercise-training programme during their HD sessions. Baseline values were similar between the two groups, but after training the intervention group showed a decrease in self-reported depression of 39 per cent.

Conversely Carmack et al (1995) recorded no change in depression after a short exercise programme. 70 end-stage renal disease patients were recruited from a small number of outpatient dialysis clinics in the USA and divided between an intervention group that participated in a 10-week exercise treatment programme and a control group. At one-month follow-up there were no recorded differences between the two groups on depression or anxiety measures.

Haiwe and Jacobsen (2011) also examined the effect of exercise on health related quality of life. They identified 18 RCTs that reported on this association, although the studies used different instruments to measure effect, most of the instruments being generic and not disease-specific. Findings from 14 of the RCTs showed improved total scores and/or sub-scores in health related quality of life following regular exercise training. The other 4 RCTs showed no effect. The authors concluded that regular exercise for more than 30 minutes/session and 3 times a week would increase health related quality of life among chronic kidney disease patients and kidney transplant recipients.

Although not a RCT, a recent study in the UK reported on by Greenwood et al (2012),

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

found that physical activity can substantially improve mental wellbeing for CKD patients. The study involved 131 chronic kidney disease patients who over a 4-year period started a 12-week renal rehabilitation programme delivered by the NHS. Research participants were assessed at baseline and at 12 weeks. Anxiety and depression were measured using the HADS and self-reported level of fitness by the Duke's activity status index. Exercise capacity was also measured. Results revealed significant improvements of 15 per cent in anxiety and 29 per cent in depression among the 77 patients who completed the programme. It is important to note though that 41 per cent of those patients who started the programme, failed to complete 12 or more of the 24 scheduled sessions. Rabinadranah et al (2009) also drew attention to the issue of compliance in relation to exercise interventions. Referencing studies showing referral levels of only 20 to 50 per cent for 'exercise on prescription' schemes, the researchers claimed it is very likely compliance rates with an exercise regime in the depressed dialysis population will be similar or even worse.

Analysing self-reported exercise frequency data from 20,920 HD patients participating in the Dialysis Outcomes and Practice Patterns Study (DOPPS), Tentori et al (2010) found regular exercise was correlated with fewer depressive symptoms and higher quality of life. Whilst 47.4% of patients were classified as regular exercisers on the basis of reporting they exercised at least once a week, exercise levels varied markedly across the 12 DOPPS countries and across HD facilities within these countries. Interestingly regular exercise levels were significantly higher for patients from dialysis facilities that offered exercise programmes, suggesting that dialysis unit practices may be able to influence exercise habits among their patients.

Anand et al (2012) reporting on findings from the Comprehensive Dialysis Study (CDS) in the USA identified an association between physical activity and depression. The CDS was a large-scale survey that collected data from 1,678 patients new to dialysis who were either on HD (1,509 patients) or PD (169 patients). The Human Activity Profile was used to measure self-reported physical activity and depression was assessed using the two-item Patient Health Questionnaire. Results showed that patients who reported lower levels of physical activity were noticeably more likely to report symptoms of depression.

Apart from the study by Van Vilsteren et al (2005), to date there is limited evidence as to the effectiveness of cycling whilst on dialysis in reducing anxiety and depression.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Nonetheless there is some qualitative data indicating intra-dialytic cycling is a positive experience for patients with beneficial effects on both physical and psychological well-being. Heine and Tollin (2012) qualitatively interviewed a purposive sample of 10 adults, men and women aged 54-81 years, who participated at least once in a 30-minute intra-dialytic cycling session at an in-centre HD unit in Sweden. Respondents' reactions to implementation of the cycling intervention were mainly positive, in particular because it was perceived as possible to save valuable non-dialysis time while using HD time to do something of benefit to their health. Cycling also proved a positive distraction during HD. It was associated with positive wellbeing, the feeling of being an active participant in the treatment process, a sense of control and increased self-esteem, as well as the feeling of greater self-efficacy following successful cycling attempts. All the patient cycling participants wanted to continue with the cycling as part of their routine HD care. However many respondents also reported that prior to participation they felt fear, worry and doubt that they would not have the physical capacity to cycle for 30 minutes and would have to interrupt the session.

8.3 Cognitive behaviour therapy (CBT)

While one RCT by Duarte et al (2009) found group CBT to be an effective intervention for depression in HD patients, there is limited evidence regarding the effectiveness of this type of intervention for depression in end-stage renal disease patients. The RCT was undertaken in Brazil among HD patients from two dialysis units. 41 patients received the intervention of 12 weekly sessions of CBT led by a trained psychologist, over 3 months. A control group of 44 patients continued their usual treatment. Both groups were assessed using the BDI at baseline, after 3 months of intervention or usual treatment, and after 9 months of follow-up. Significant improvements were recorded in the average scores of the BDI for the intervention group, with the BDI improving by 42 per cent at the end of the 3 months. This positive effect was maintained 6 months after the main intervention period. Even though a decrease in the BDI was also observed in the control group, it was substantially lower. The researchers suggested this was probably the result of patients in the intervention group being encouraged to talk about their thoughts, instructed to identify and reorganise the thoughts that might be interfering with their mood, and taught how to create coping strategies to deal with their kidney disease, dialysis and depression.

A small-scale, non-RCT study by Cukor (2007) indicated that CBT can result in a
CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

significant and sustained reduction in depressive effect among end-stage renal disease patients. 16 patients with major depression were treated individually with a 15-week CBT intervention that focused on the techniques of challenging distorted thoughts and encouraging behavioural activation. All patients showed a significant decrease in their BDI-11 score at the conclusion of treatment. The average BDI-11 score fell from 29 to 18 per cent at the end of treatment, and to 19 per cent at the three-month follow-up.

Looking at the wider literature on chronic conditions, there is some good evidence of CBT having a small-scale effect as an intervention for addressing depression. The National Collaborating Centre for Mental Health (2010a) concluded that among people with a chronic disease, guided self-help based on CBT principles had a moderate and marginally statistically non-significant effect on depression at the end of treatment as compared with standard treatment. Individual-based cognitive and behavioural interventions were found to have a moderate and statistically significant effect on depression at the end of treatment in contrast with standard care. Also in comparison with standard care, group-based cognitive and behavioural interventions were shown at the end of treatment to exert a moderate and statistically significant effect on mild to moderate depression.

8.4 Computerised CBT

Computerised CBT programmes involve patients participating in a structured online programme with content that is similar to and based on the principles of standard therapist-led CBT programmes. Most computerised CBT programmes have been developed to treat a range of depressive and anxiety disorders. The National Collaborating Centre for Mental Health (2010a) in reviewing evidence for NICE found no specific studies of computerised CBT focused on treating depression in people with a chronic physical health problem. Although an evidence update by NICE (2012) that reported on a RCT conducted among 2055 patients with diabetes and depressive symptoms by van Bastelaar et al (2011), found depressive symptoms were significantly reduced by web-based CBT.

The National Collaborating Centre for Mental Health (2010b) also examined evidence from 7 RCTs for the effectiveness of computerised CBT in the treatment of people with depression. The 1,676 patients involved in the RCTs were mainly from groups in the mild to moderate range of depressive symptoms (BDI scores 18-25). Just under half

(47 per cent) had no formal diagnosis. Overall the results for depressive scores suggested a significant small to medium positive effect for computerised CBT in patients with a range of severity of depressive symptoms, although there was more limited evidence of effectiveness at follow-up. Also when compared with active controls (psychoeducation and group CBT) no clinically important differences were identified.

A meta-review by Foroushani et al (2011) similarly concluded that computerised CBT is effective in treating depression. The study involved 12 systematic reviews from 10 studies of computerised CBT for depression in adults, with or without anxiety. For both depression and anxiety disorder, computerised CBT was found to be more effective than treatment as usual and no less effective than therapist-led CBT but with the advantage of reduced therapist-time. There was also good evidence that the computer programmes improved symptoms, although the effect size was greater for anxiety than depression.

At present 'Beating the Blues' is the only computerised CBT programme recommended by NICE (2009) for treating depression. It is a CBT-based package for people with anxiety and/or depression and consists of a 15-minute introductory video and eight one-hour interactive computer sessions. Homework projects are completed between sessions. Whilst a number of computerised CBT packages have been developed, 'Beating the Blues' is the only programme with an established evidence based. Three RCTs and 8 treatment outcome studies have provided evidence supporting use of 'Beating the Blues' for treating depression (Mc Murchie, 2013). The largest-scale RCT was undertaken by Proudfoot et al (2004), designed to assess the effectiveness of the programme in treating depression and anxiety. The trial involved a total of 274 GP patients in London and the South-East, aged 18-75 years, suffering from depression, mixed anxiety and depression, or anxiety disorder, and not currently receiving any psychological treatment or counselling. Patients were randomised to using 'Beating the Blues' online computer therapy, or usual treatment – receiving whatever therapy the GP prescribed. The primary outcome measure was the BDI. Findings from the study showed that treatment of patients with 'Beating the Blues' led to significant improvements on all variables measured – depression and anxiety decreased, work and social adjustment improved, negative attributions decreased, positive attributions increased and satisfaction with treatment was enhanced. As measured by BDI, the average starting levels of depression and anxiety in the patient sample were moderate to severe whereas the finishing levels were close to normal range.

Kaltenthaker et al (2008) systematically reviewed the evidence for effectiveness of computerised CBT for treatment of mild to moderate depression and identified 'Beating the Blues' as the one programme more effective than treatment as usual for depression. However the authors noted that all the programmes reviewed were associated with considerable drop-out rates and that there was little evidence of participants' preferences and the acceptability of the therapy. The later study by Foroushani et al (2011) suggested that several computer packages – 'Mood Gym', 'Beating the Blues' and 'Colour Your Life' – could have a positive effect on symptoms of depression. Yet the authors concluded there was insufficient evidence to prefer one package for depression over another.

8.5 Peer support

Peer support interventions within the context of care for long term conditions generally have the objective of providing support based on sharing of experience and information, and mutual exchange, among peers with the same chronic condition. To date there is inconclusive evidence to demonstrate its benefits in terms of improved health outcomes. There is also a paucity of research that addresses peer support for end-stage renal disease patients. Diverse outcomes are reported from studies of peer support programmes for long-term conditions in general; many do not include emotional or psychological measures. There is also an interesting divergence between descriptive studies that tend to report positive comments from patients about their experiences of peer support, and studies that quantitatively measure emotional and psychological outcomes for many of the same participants showing only small, non-existent or negative results.

Most of the RCTs reporting on the emotional and psychological outcomes of peer support interventions are from studies among people with cancer. Zabalegui et al (2005) conducted a meta-analysis of 20 RCTs relating to group support in cancer patients that found low-level positive results for impact on depression, anxiety, quality of life, and adaptation. However the three RCTs reviewed Campbell et al (2004) in an evaluation of peer support programmes provided by peers rather than professionals, for people with cancer, evidenced no improvement in quality of life. Furthermore all three studies found varying degrees of adverse outcomes in terms of anxiety and depression. The National Collaborating Centre for Mental Health (2010a) reviewed 3 RCTs focused on peer support interventions - two conducted among cancer patients and one among

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

patients with HIV - and concluded that peer support had a large positive effect on depression among people with a chronic physical health problem. Compared with group based CBT, peer support was also shown to have a small but non-statistically significant effect on depression. Participants in two of the studies were encouraged to share their feelings associated with having a chronic physical health problem within a peer support group, and the other study emphasised assigning programme members to one peer.

A systematic review by Hoey et al (2008) of 44 papers on peer support for people with cancer found results from the RCTs were very mixed and in general far less positive than those from qualitative studies. Similarly a review of empirical studies of peer support groups for people with cancer by Gottlieb and Wachala (2007) reported high levels of participant satisfaction but inconclusive measured outcomes.

Yet qualitative studies highlight how emotional support is a core mechanism underlying how peer support operates. Dennis (2003) identified and described emotional support as involving expressions of empathy, caring, encouragement, reflection, attentive listening and reassurance between patients with a general lack of criticism. As a consequence there is generally enhanced self-confidence and self-esteem. A qualitative study by Taylor and Gutteridge (2013) similarly found that for chronic kidney disease patients and carers, peer support was perceived to offer specific emotional support benefits, in particular feeling accepted and understood and therefore less isolated.

Peer support also appears to be popular among renal patients who are users. A qualitative study conducted by Hughes et al (2009) showed that the majority of renal patients were positive about their experience of peer support. The research involved semi-structured telephone interviews with 20 people from two Renal Units in London who had received peer support in a previous 9-month period. Peer support was praised for providing: an opportunity to talk to someone '*who's gone through what you're going through*', who could sympathetically listen and empathise; reassurance and encouragement, leading to greater sense of control; access to practical information based on the lived experience of treatment for kidney disease, information not available from clinicians; help in adjusting to chronic illness and coming to terms with starting treatment; and help making or confirming treatment decisions. It is interesting to note that for the majority of patients involved in the study, these benefits were experienced

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

after just one short meeting with a peer supporter. Respondents' accounts of the process indicated they were adept at directing this encounter so the peer supporter addressed their specific needs for information and emotional support.

8.6 Lay-led education and expert patient programmes

Whilst there is no evidence relating specifically to lay-led education and expert patient programmes (EPP) among end-stage renal disease patients, there is good evidence covering chronic conditions in general that these interventions have only minimal positive effect on emotional and psychological wellbeing. A Cochrane review by Foster et al (2009) of RCTs on lay-led self-management education programmes, including the EPP, found only non-significant improvements in psychological wellbeing. 17 RCTs were reviewed in total, the interventions being defined for the purposes of the review as structured programmes for people with chronic conditions that were primarily educational, primarily addressing self-management of disease and where the majority of the course was delivered by lay people. Data was available on changes in depression in 6 of these studies and anxiety level in 3 studies. From a synthesis of these studies it does not appear that lay-led self-management interventions have any clinically important effect on self-reported depression or anxiety at six-month follow-up. However, the two-arm pragmatic RCT by Kennedy et al (2007) used to evaluate the EPP in community settings in England, reported marginally significant better psychological wellbeing scores than the control group.

8.7 Coping and empowerment

There is some evidence, although insubstantial, on positive outcomes delivered by interventions designed to build coping and empowerment skills among end-stage renal disease patients. An experimental study undertaken by Leake et al (1999) indicated that an intervention to improve patients' coping skills can assist adjustment to dialysis. 42 dialysis patients who had been dialysing for at least 5 months and matched for diabetes, gender and length of time of dialysis, were randomly assigned to one of three experimental conditions: strategic presentation, problem disclosure, or a control condition. In a videotaped structured interview, participants in the strategic presentation group were individually asked questions concerning their positive coping strategies. Patients in the problem disclosure group were asked to discuss their problems in a similarly structured interview. The control group watched a video containing helpful

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

information about end-stage renal disease and were asked to evaluate how well it would serve as a training tool for new patients. Patients in all three groups completed a questionnaire assessing adjustment at baseline, 2 days post-intervention and one month post-intervention. Depression was used as the measure of adjustment, assessed using the shortened version of the CESD. Analysis of the results showed that depression scores decreased significantly for the strategic presentation group from baseline to 2 days post-intervention and remained significantly lower at the second follow-up assessment one month later. In contrast, no significant differences in depression were found over time for either the problem disclosure or the control conditions group.

Results from a small-scale RCT carried out in Taiwan by Tsay et al (2004) suggested that an empowerment intervention can improve HD patients' levels of depression. HD patients from two dialysis centres were randomly assigned to either an intervention group (25 patients) or a control group (25 patients). Those patients in the intervention group participated in an empowerment programme that included identification of problem areas for self-management, exploration of emotions associated with these problems, development of a set of goals and strategies to overcome these problems to achieve the goals, creation and implementation of behavioural change plans, and stress management. The control group continued to receive normal care and support from the dialysis units. The study findings indicated significantly greater improvement on scores for depression, empowerment and self-care efficacy among the intervention group as compared with the control group.

8.8 Mindfulness-based therapy

Based on ancient Buddhist and Yoga practices, mindfulness-based therapy (MBT) includes mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT) (Hofmann et al, 2010). MBSR is a structured group programme that uses mindfulness meditation to alleviate suffering associated with physical, psychosomatic and psychiatric disorders. Participants are invited to focus with an interested, accepting and non-judgemental attitude on their difficult sensations, emotions, pain, cognitions and behaviour. MBCT is an adaptation of MBSR and incorporates elements of cognitive therapy facilitating a detached or decentred view of one's thoughts and is designed to prevent depressive relapse (Fjorback et al, 2011). NICE clinical guidance (2009) on the treatment and management of depression in

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

adults recommends MBCT as a psychological intervention for relapse prevention, for people who are currently well but have experienced three or more previous episodes of depression.

Although there is no evidence specifically relating to patients with kidney disease, several recent meta-analyses and systematic reviews have investigated the effectiveness of mindfulness-based therapy on patients with a range of chronic diseases, mental and physical. These have generally reported positive effects in terms of reductions in levels of anxiety, stress and depression although findings have been inconsistent about the extent of the benefits.

An early review of the empirical literature on mindfulness-based interventions by Baer (2003) concluded that MBSR is effective in alleviating distress in the treatment of several chronic diseases, notably chronic pain, anxiety disorders and fibromyalgia. The studies reviewed also suggested that many patients who enrol in mindfulness-based programmes will complete them despite the necessity for homework practice, and that a substantial subset will continue to practice mindfulness skills beyond the timeframe of the treatment programme.

A meta-analysis by Hofmann et al (2010) concluded that MBT is moderately effective for improving anxiety and mood symptoms in clinical populations. A total of 39 studies were included in the review, 16 comparative studies and 24 uncontrolled studies, selected on the basis they included a mindfulness-based intervention, an adult clinical sample (diagnosable psychological or physical/medical disorder), and a measure of anxiety and/or mood symptoms at both pre and post intervention. The review findings showed that MBT produced a significant reduction in anxiety for patients with cancer, anxiety disorders and pain disorders, but not in patients with depression. MBT was also shown to produce significant reductions in depression regardless of clinical disease type.

Bohlmeijer et al (2010) undertook a meta-analysis to examine the effects of MBT specifically on the mental health of adults with a chronic disease. They found MBT to have a small positive impact on depression, anxiety and psychological distress. Only a small number of studies were included in the review, with some methodological flaws: 8 RCTs conducted among adult patients with a chronic disease, all comparing MBT with a control. Most study participants were women with a mean age of 45 to 55 years who

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

had a variety of chronic conditions including cancer, chronic pain, fibromyalgia, chronic fatigue and rheumatoid arthritis.

The systematic review conducted by Fjorback et al (2011) assessed 17 RCTs of MBSR and 4 RCTs of MBCT and concluded that MBSR improves mental health in non-clinical and clinical populations. It was not clear though whether MBSR can also improve physical health. The authors argued that in clinical populations with physical illness, MBSR complements medical disease management by relieving psychological distress and strengthening wellbeing. Also that in clinical populations with psychiatric disorders, MBSR has some benefits as it reduces symptoms of distress anxiety and depression or teaches patients coping skills to handle these symptoms. Additionally it was suggested that MBCT is an effective and efficient way to prevent relapses in recovered depressed patients, with 3 or more episodes.

A meta-analysis undertaken by Khoury et al (2013) similarly concluded that MBT was more effective in treating psychological disorder than physical or medical conditions. The large-scale review involved 209 studies with a combined total of 12,145 participants. Studies were eligible for inclusion if they evaluated before-and-after or controlled effects of MBT for physical or medical conditions, psychological disorders or a non-clinical population. 109 studies were RCTs, 26 were non-RCTs, and 72 were uncontrolled before-and-after studies. The studies used a variety of mindfulness therapies. In relation to treating anxiety and depression, the review findings showed MBT to have large and clinically significant positive effects. Whilst not found to be more effective than traditional CBT, the average rate of attrition among participants was notably lower. However these findings should be treated with caution, given the variable quality and wide variation in results found in the included studies

Reviewing evidence specifically on the effectiveness of MBCT group treatment in relapse prevention, the National Collaborating Centre for Mental Health (2010b) found a significantly lower risk of relapse amongst users of MBCT. In relation to reduction in relapse rates, when compared with antidepressants, group MBCT showed a small to medium effect of lowering depression scores at one month and fifteen months follow-up.

9. Changing clinician-patient communication through recognition and response to emotional issues

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

- Patients who are able to disclose their emotional issues and feel empathised with and supported, have lower levels of distress and anxiety
- Yet patients often do not express their emotional concerns in consultations with clinicians
- When clinicians acknowledge patients' emotions and encourage discussion, they create the opportunity for expression of emotional feelings and concerns
- However clinicians frequently fail to recognise their patients' emotional needs and concerns, therefore it can often be difficult for them to respond empathetically
- Interventions that prompt question-asking by patients during consultations have been found to help generate discussion of emotional issues

A systematic review by Griffin et al (2004) of RCTs across all health conditions of interventions to alter the interaction between patients and practitioners found the large majority of interventions that gave explicit attention to emotional issues were associated with significantly positive health outcomes. A total of 35 RCTs were included in the review and 14 of these studies involved interventions with attention to emotion. Most of the interventions involved were not complex. Two out of four studies where practitioners solely altered their consultation style (Thomas, 1987; Olsson, 1989) resulted in significant positive health-related outcomes. Interventions that involved patients simply providing clinicians with written information about their needs and emotional concerns, in advance of consultation, were also found to be effective in improving patients' health related quality of life (Greenfield et al, 1985 and 1988).

Interventions that prompt patients to ask questions during consultations have been found to encourage discussion of emotional issues. Butow et al (1994) reported that provision of a question prompt sheet given to cancer patients before their initial consultation with an oncologist had a significant impact on the number of questions about prognosis, although there was no increase in the total number of questions asked. Similarly a RCT by Brown et al (2001) found that cancer patients given a question prompt sheet before an initial consultation with an oncologist, and whose oncologist specifically endorsed and addressed the prompt sheet, asked significantly

more questions about their prognosis and were less anxious.

Nonetheless, as highlighted by Roter (1977), patients tend to ask very few questions during consultations. Roter argued that patients' question-asking behaviour could be influenced by addressing three contributing elements: enabling, predisposing and reinforcing factors. On the basis of this model, Roter evaluated a short coaching session by a psychologist which encouraged patients attending a community health centre in the USA to ask questions of their physician. The results showed that although question asking was increased, there were also increased levels of anxiety, anger and dissatisfaction recorded among patients receiving the intervention. Roter suggested this may be because the expected patient behaviour during consultations was patient passivity, and increased patient participation was a new situation for the patient (as well as the provider).

Kidd et al (2004), building on the work of Roter, suggested that disabling barriers can be divided into two categories - cognitive and affective. Cognitive disabling factors include; the patient's perceived lack of ability to ask questions, their perception of time barriers within the consultation, perceiving that it is unacceptable to ask questions and forgetting the questions they wanted to ask. Affective barriers relate to patients being too embarrassed to ask questions or feeling that they will be humiliated if they do so. On the basis of this evidence the researchers designed three different interventions to increase the ability of patients to ask questions in consultations. They undertook an experimental study to evaluate the effectiveness of the interventions among 202 patients attending diabetic outpatient appointments in UK. However, the study found that those patients in the intervention groups did not ask any more questions than those in the control groups.

Kaplan, Greenfield and Ware (1989) identified that expression of emotion whether positive or negative, by patients and physicians, was related to reporting of better functional status and subjective evaluations of health by patients. Data was analysed from three separately conducted RCTs in the USA among patients with ulcer disease, hypertension, and diabetes as well as a fourth non-equivalent controlled trial among patients with breast cancer. A total of 252 patients across the four trials participated in the research study. The intervention evaluated was designed to improve physician-patient communication by providing patients with individualised information about their medical care in the form of their medical record, combined with an algorithm describing

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

disease management with which to interpret this information, and coaching in behavioural strategies designed to increase their participation during the consultation. These behavioural strategies included techniques for improving question asking and negotiating skills, as well as decreasing barriers such as embarrassment, anxiety and intimidation likely to reduce patients' effectiveness during the visit. The goal of the experimental programme was to change the behaviour of patients as well as physicians by training patients to take a more active role in their care.

An interesting but non-RCT study by White, White and Russell (2007) found that multiple sclerosis patients who wanted to talk with healthcare professionals at the time of their diagnosis and while they were living with the illness, about their fears, sadness and anger, and were able to do so, experienced positive outcomes in relation to both total mental health and depression. Under half (44 per cent) of the 145 patients who participated in the research, claimed that a healthcare provider had discussed their emotional wellbeing at the time of diagnosis, and 56 per cent claimed their healthcare professional had talked to them about emotions related to living with their illness. Mental health and depression were measured using the 18-item Mental Health Inventory that involves four sub-scales assessed in relation to the last 4 weeks: 'Have you been a very nervous person?'; 'Have you felt downhearted and blue?'; 'Have you been in firm control of your behaviour, thoughts, emotions, feelings?'; and 'Have you felt cheerful and lighthearted?'

Recognition and response to emotion can also facilitate patients' ability to receive and understand information. It has also been shown to reduce emotional distress (Roter et al, 1995), increase the trust of cancer patients and reduce anxiety (Suchman et al, 1997; Pollack et al 2007).

However patients often fail to express their emotional concerns in consultations with clinicians. Anderson et al (2008) audio-recorded 415 outpatient visits between 59 oncologists and 281 patients with advanced cancer and found that patients verbally expressed an emotion in only 17 per cent of the visits, despite high rates of reported distress in cancer patients. A study by Butow et al (2002) among 298 cancer patients seeing one of five medical and four radiation oncologists for the first time, reported that patients gave emotional cues (32 per cent of total cues) less than half as often as they gave informational cues (68 per cent of total cues).

Patients may not discuss emotional concerns because they feel it is not the role of their clinician to address such issues (Ryan et al, 2005). They could also be discouraged from mentioning emotional and psychological needs when clinicians concentrate on the physical aspects of the disease, or because they do not want to burden their doctors (Maguire, 1985). Although a significant influence on patient's disclosure of emotional issues appears to be the way clinicians communicate. Patients whose clinicians are empathetic and invite discussion seem to disclose more concerns. Maguire et al (1996) revealed that cancer patient disclosure of significant emotional information was promoted by use of open directive questions, focusing on and clarifying psychological aspects, empathetic statements, summarising and making educated guesses. Conversely patients can feel inhibited to disclose their emotional concerns if clinicians use leading questions, focus on and clarify physical aspects, and move into advice and reassurance mode. These findings were based on asking 206 cancer health professionals attending workshops on communication and counselling skills to interview a simulated patient before and after the workshop to establish the patient's current problems.

Furthermore when patients do express emotional issues or feelings, it seems clinicians frequently fail to respond empathetically thereby constraining further disclosure. Combes, Allen and Sein (2013) reported that even skilled, compassionate and highly experienced renal clinicians did not appear to engage fully with patients about feelings and emotions, even when patients expressed distress quite openly, with an observed tendency to tackle emotional issues in a practical manner through problem-solving. Butow et al (2002) found that doctors responded with appropriate empathy to only 28 per cent of emotional cues given by cancer patients. Similarly Pollack et al (2007) revealed that oncologists responded empathetically to advanced cancer patients' expressions of emotion less than one third of the time. Anderson et al (2008) argued that since the majority of cancer patients in their study knew their clinician, the low levels of emotional expression could be because patients had 'learned' not to express emotion, underlining the importance of clinicians recognising and responding empathetically to patient expressions of emotion.

10. References

Alam R, Sturt J, Lall R, Winkley K. An updated meta-analysis to assess the effectiveness of psychological interventions delivered by psychological specialists and generalist clinicians on glycaemic control and on psychological status. *Patient Educ Couns* 2009; **75**(1):25-36.

American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders 4th edn*. American Psychiatric Association, Washington DC, 1994

Anand S, Johansen KL, Grimes B *et al*. Physical activity and self-reported symptoms of insomnia, restless legs syndrome, and depression: The comprehensive dialysis study. *Hemodial Int* July 20 2012: 1542-4758

Anderson RJ *et al*. (2001) The prevalence of comorbid depression in adults with diabetes: a meta-analysis. *Diabetes Care* 2001; **24**:1069-78

Anderson WG, Alexander SC, Rodriguez KL *et al*. "What concerns me is . . ." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer* 2008; **16**(7):803-811.

Baer RA Mindfulness Training as a Clinical Intervention: A Conceptual and Empirical Review *Clinical Psychology: Science and Practice* 2003; **10**(2):125-143

Barnett K, Mercer SW, Norbury M *et al*. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross sectional study. *The Lancet* 2012; **380**:37-43

Bass EB, Jenckes MW, Fink NE *et al*. Use of Focus Groups to Identify Concerns about Dialysis. *Med Decis Making* 1999; **19**:287-295

Beaver K, Craven O, Witham G *et al*. Patient participation in decision-making: views of health professionals caring for people with colorectal cancer. *Journal of Clinical Nursing*, 2007;**16**: 725-733.

Bekker H, Thornton JG, Aierey CM *et al*. Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment* 1999; **3**(1)
CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Bertrand LJ, Schiller B, Burkart JM *et al.* Impact of Short Daily Hemodialysis on Restless Legs Symptoms and Sleep Disturbances. *Clin J Am Soc Nephrol* 2011; **6**(5):1049-1056

Billington E, Simpson J, Unwin J *et al.* Does hope predict adjustment to end-stage renal failure and consequent dialysis? *British Journal of Health Psychology* 2008; **13**:683-699

Birmele B, Le Gall A, Sautenet B *et al.* Clinical, Sociodemographic, and Psychological Correlates of Health-Related Quality of Life in Chronic Hemodialysis Patients. *Psychosomatics* 2012; **53**(1):30-37

Bohlmeijer E, Prenger R, Taal E, Cuijpers P. The effects of mindfulness-based stress reduction therapy on mental health of adults with a chronic medical disease: A meta-analysis. *Journal of Psychomatic Research*, 2010;**68**: 539-544

Boulware LE, Liu Y, Fink NE *et al.* Temporal relation among depression symptoms, cardiovascular disease events, and mortality in end-stage renal disease: contribution of reverse causality. *Clin J Am Soc Nephrol* 2006; **1**: 496–504.

British Renal Society *The Renal Team. A multi-professional renal workforce plan for adults and children with renal disease. Recommendations of the National Renal Workforce Planning Group 2002.* http://www.britishrenal.org/getattachment/Workforce-Planning/WFP_Renal_Book1.pdf.aspx (last accessed 14/04/14)

Brown EA, Johansson L, Farrington K *et al.* Broadening Options for Long-Term Dialysis in the Elderly (BOLDE): differences in quality of life on peritoneal dialysis compared to haemodialysis for older patients. *Nephrol Dial Transplant* 2010; **25**:3755-3763

Brown RF, Butow PN, Boyer MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *British Journal of Cancer* 1999;**80**: 242–8

Brown RF, Butow PN, Dunn SM and Tattersall MHN. Promoting patient participation and shortening cancer consultations: a randomised trial. *British Journal of Cancer* 2001;**85**: 1273-1279

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Burnard P. *Counselling Skills for Health Professionals 3rd edn.* Stanley Thomas, 1999

Butow PN, Dunn SM, Tattersall MHN and Jones QL. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Annals of Oncology* 1994; **5**:199-204

Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*, 2002;**11**:47–58.

Byrne A, Ellershaw J, Holcombe C, Salmon P. Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Education and Counseling*, 2002;**48**(1): 15–21

Campbell H S, Phaneuf M R, Deane K. Cancer peer support programs: do they work? *Patient Education and Counseling* 2004; **55**(1): 3-15

Carmack CL, Amarel-Melendez M, Boudreaux E *et al.* Exercise as a component of the physical and psychological rehabilitation of hemodialysis patients. *International Journal of Rehabilitation and Health* 1995; **1**(1):13-23

Chan R, Brooks R, Erlich J *et al.* The Effects of Kidney-Disease-Related Loss on Long-Term Dialysis Patients' Depression and Quality of Life. *Clin J Am Soc Nephrol* 2009; **4**(1): 160-167

Chilcot J, Wellsted D, Da Silva-Gane M, Farrington K. Depression on Dialysis. *Nephron Clin Pract* 2008; **108**:c256-264

Chilcot J, Wellsted D, Davenport A, Farrington K. Illness representations and concurrent depression symptoms in haemodialysis patients. *J Health Psychol* 2011; **16**(7):1127-137

Cohen LM, Dobscha SK, Hails KC *et al.* Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. *Psychosomatic Medicine* 2002; **64**:889–896.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Cooney GB, Dwan K, Greig CA *et al.* Exercise for depression. *The Cochrane Library*, Issue 9, 2013

Combes G, Allen K, Sein K. *Evaluation of case study sites for home therapies for people with chronic kidney disease*, West Midlands Central Health Innovation and Education Cluster, Birmingham, University of Birmingham, 2013 <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC>(last accessed 14/04/14)

Covic A, Seica A, Gusbeth-Tatomir P *et al.* Illness representations and quality of life scores in haemodialysis patients. *Nephrol Dial Transplant* 2004; **19**(8):2078–2083

Covic A, Seica A, Mardare N, Gusbeth-Tatomir P. A longitudinal study on changes in quality of life and illness representations in long-term hemodialysis patients with low comorbidity. *Maedica* 2006; **4**:12–19

Craven JL, Rodin GM, Littlefield C. The BDI as a screening device for major depression in renal dialysis patients. *Int J Psychiatry Med* 1988; **18**:365–374

Cukor D. Use of CBT to Treat Depression Among Patients on Hemodialysis. *Psychiatric Services* May 2007; **58**(5):711-712

Cukor D, Coplan J, Brown C *et al.* Anxiety Disorder in Adults Treated by Hemodialysis: A Single-Center Study. *American Journal of Kidney Disease* 2008a; **52**(1):128-136

Cukor D, Coplan J, Brown C *et al.* Course of Depression and Anxiety Diagnosis in Patients with Hemodialysis: A 16-month Follow-up. *Clin J Am Soc Nephrol* 2008b; **3**:1752-1758

Cukor D, Rosenthal DS, Jindal RM *et al.* Depression is an important contributor to low medication adherence in hemodialysed patients and transplant recipients *Kidney International* 2009; **751**:1223-1229

Curtin RB, Bultman DC, Thomas-Hawkins C *et al.* Hemodialysis Patients' Symptom Experience: Effects on Physical and Mental Functioning. *Nephrology Nursing Journal* 2002; **29**(6):562-574

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Cvengros JA, Christensen AJ, Lawton WJ. Health locus of control and depression in chronic kidney disease: A dynamic perspective. *J Health Psychol* 2005; **10**:677-86.

Dennis CL. Peer support within a health care context: a concept analysis *Int J Nurs Stud* 2003; **40**(3):321-332

Department of Health. *The National Service Framework for Renal Services Part 1: Dialysis and transplantation*. Department of Health, London, 2004 Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199001/National_Service_Framework_for_Renal_Services_Part_One_-_Dialysis_and_Transplantation.pdf (last accessed 14/04/14)

Department of Health. *The National Service Framework for Renal Services Part 2: Chronic kidney disease, acute renal failure and end of life care*. Department of Health, London, 2005 Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199002/National_Service_Framework_for_Renal_Services_Part_Two_-_Chronic_Kidney_Disease__Acute_Renal_Failure_and_End_of_Life_Care.pdf (last accessed 14/04/14)

Department of Health *Long Term Conditions Compendium of Information Third Edition* London, Department of Health, 2012a Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf (last accessed 14/04/14)

Department of Health. *Understanding personal health budgets* Department of Health, London, 2012b Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216813/Understanding-personal-health-budgets-2012.pdf (last accessed 14/04/14)

Department of Health *Closing the gap: priorities for essential change in mental health* London, Department of Health, 2014 Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/281250/Closing_the_gap_V2_-_17_Feb_2014.pdf (last accessed at 14/04/14)

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient- physician relationship. Patient-physician communication during outpatient palliative treatment visits: an observational study. *JAMA* 2001; **285**(10):1351-1357.

Drayer RA, Piraino B, Reynolds III CF *et al.* Characteristics of depression in hemodialysis patients: symptoms, quality of life, and mortality risk. *Gen Hosp Psychiatry* 2006; **28**: 306–312.

Duarte PS, Miyazaki MC, Blay SL and Sesso R *et al.* Cognitive-behavioural group therapy is an effective treatment for major depression in hemodialysis patients. *Kidney International* 2009; **76**:414-421

Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer* 2001;**84**(8):1011–5

Feroze U, Martin D, Kalantar-Zadeh K. Anxiety and Depression in Maintenance Dialysis Patients: Preliminary Data of a Cross-Sectional Study and Brief Literature Review. *Journal of Renal Nutrition* 2012; **22**(1) 207-210

Finkelstein FO, Finkelstein SH. Depression in chronic dialysis patients: assessment and treatment. *Nephrol Dial Transplant* 2000; **15**:1911-1913

Fjorback CO, Arendt M, Ornbol E *et al.* Mindfulness-Based Stress Reduction and Mindfulness-Based Cognitive Therapy – a systematic review of randomized controlled trials *Acta Psychiatr Scand*, 2011;**124**: 102-119

Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer* 1994; **70**(4):767-770.

Foroushani PS, Schnieder J and Assareh N Meta-review of the effectiveness of computerised CBT in treating depression *BMC Psychiatry* 2011; **11**:131-136

Foster G, Taylor SJC, Eldridge S *et al.* Self-management education programmes by lay leaders for people with chronic conditions. *The Cochrane Library* Issue 1, 2009

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Gottlieb B, Wachala E. Cancer support groups: a critical review of empirical studies. *Psycho-Oncology* 2007; **16**:379-400

Green JA, Mor MK, Shields AM *et al*. Renal provider perceptions and practice patterns regarding the management of pain, sexual dysfunction, and depression in hemodialysis patients. *J Palliat Med* Feb 2012;**15**(2):163-7

Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med* 1985; **102**:520-528.

Greenfield S, Kaplan SH, Ware JE Jr *et al*. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med*. 1988; **3**:448-457.

Greenwood SA, Lindup H, Taylor K *et al*. Evaluation of a pragmatic exercise rehabilitation programme in chronic kidney disease. *Nephrol Dial Transplant* 2012; **26** (Suppl 3):26-34

Gregory DM, Way CY, Hutchinson TA *et al* Patients' Perceptions of their Experiences with ESRD and Hemodialysis Treatment *Qual Health Res* 1998;**8**:764-783

Griffin SJ, Kinmouth AL, Veltman MWM *et al*. Effect on Health-Related Outcomes of Interactions to Alter the Interaction Between Patients and Practitioners: A Systematic Review of Trials *Annals of Family Medicine* 2004; **2**(6):595-608

Grigsby AB, Anderson RJ, Freedland KE *et al*. Prevalence of anxiety in adults with diabetes: a systematic review. *J. Psychosom Res* 2002; **53**:1053-1060.

Griva K, Jayasena D, Davenport A *et al*. Illness and treatment cognitions and health related quality of life in end stage renal disease. *BrJHealthPsychol* 2009; **14**(1):17-34

HM Government No health without mental health. *A cross-government mental health outcomes strategy for people of all ages* COI, London, 2011 Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf (last accessed 14/04/14)

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Haiwe S, Jacobsen H. Exercise training for adults with chronic kidney disease (Review). *The Cochrane Library* Issue 10, 2011

Hedayati SS, Grambow SC, Szczech LA *et al.* Physician-diagnosed depression as a correlate of hospitalizations in patients receiving long-term hemodialysis. *Am J Kidney Dis* 2005; 46: 642–649

Hedayati SS, Bosworth HB, Kuchibhatla M *et al.* The predictive value of self-report scales compared with physician diagnosis of depression in hemodialysis patients. *Kidney International* 2006; **69**:1662-1668

Hedayati SS, Bosworth HB, Briley LP. Death or hospitalization of patients on chronic hemodialysis is associated with a physician-based diagnosis of depression. *Kidney International* 2008; **74**:930-936

Hedayati S, Minhajuddin AT, Toto RD *et al.* Validation of Depression Screening Scales in Patients with CKD. *Am J Kidney Dis* 2009; **54**(3):433-439

Hedayati SS, Minhajuddin AT, Afshar M *et al.* Association Between Major Depressive Episodes in Patients With Chronic Kidney Disease and Initiation of Dialysis, Hospitalization, or Death. *JAMA* 2010; **303**(19):1946-1953

Hedayati SS, Yalamanchili V and Finkelstein FO. A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. *Kidney international* 2012; **81**:247-255

Heine S and Tollin H. Patients' perceptions on the implementation of intra-dialytic cycling – a phenomenographic study. *Implementation Science*, 2012;**7**: 68-76

Hoey L, Leropoli S, White V, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling* 2008; **70**: 315-337

Hofmann SG, Sawyer AT, Witt AA, Oh D. The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *J Consult Clin Psychol* 2010; **78**(2):169-183

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Hughes J, Wood E, Smith G. Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations* 2009; **12**:396-406

Husebye DG, Westliel L, Styrvoky TJ *et al.* Psychological, social and somatic prognostic indicators in old patients undergoing long-term dialysis. *Arch Intern Med* 1987; **177**:1921-1924

Ismail K, Maissi E, Thomas S *et al.* A randomised controlled trial of cognitive behaviour therapy and motivational interviewing for people with Type 1 diabetes mellitus with persistent sub-optimal glycaemic control: a Diabetes and Psychological Therapies (ADaPT) study. *Health Technology Assessment* May 2010; **14** (22):1-101, iii-iv.

Jiang W, Alexander J, Christopher E *et al.* Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Arch Intern Med* 2001; **161**:1849-1856

Kaltenthaker E, Parry G and Beverley C Computerised cognitive-behavioural therapy for depression: systematic review *The British Journal of Psychiatry* 2008; **193**:818-184

Kaplan SH, Greenfield MD and Ware JE. Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease *Medical Care* 1989; **27**(3): Spl.

Kenardy J, Mensch M, Bowen K *et al.* Disordered eating behaviours in women with Type 2 diabetes mellitus. *Eating Behaviour* 2001; **2**(2):183-92.

Kennedy A, Reeves D, Bower P *et al.* The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health* 2007; **61**:254-261

Khoury B, Lecompte T, Fortin G *et al.* Mindfulness-based therapy: A comprehensive meta-analysis *Clinical Psychology Review*, 2013;**33**: 763-771

Kidd J, Marteau TM, Robinson S *et al.* Promoting patient participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. *Patient Education & Counseling* 2004; **52**:107-112

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Kimmel PL, Weis K and Peterson RA. Survival in Hemodialysis Patients: The Role of Depression. *Journal of the American Society of Nephrology* 1993; **3**:12-27

Kimmel PL, Peterson RA, Weihs KL. Behavioural Compliance With Dialysis Prescription in Hemodialysis Patients. *Journal of the American Society of Nephrology* 1995; **5**:1826-1834

Kimmel PL, Boyle DH, Umana WO. Psychologic Functioning, Quality of Life, and Behavioural Compliance in Patients Beginning Hemodialysis. *Journal of the American Society of Nephrology* 1996; **7**(10):2152-2159

Kimmel PL, Peterson RA, Weihs KL. Psychosocial factors, behavioural compliance and survival in urban hemodialysis patients. *Kidney International* 1998; **54**:245-254

Kimmel PL, Peterson RA, Weihs KL. Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis outpatients *Kidney International* 2000; **57**:2093-2098

Kimmel PL. Psychosocial factors in dialysis patients. *Kidney International* 2001; **59**:1599-1613

Kimmel PL. Depression in patients with chronic renal disease. What we know and what we need to know. *Journal of Psychosomatic Research* 2002; **53**:951-956

Kimmel PL and Peterson RA. Depression in End-Stage Renal Disease Patients Treated with Hemodialysis: Tools, Correlates, Outcomes and Needs. *Seminars in Dialysis* 2005; **18**(2):91-97

Kübler-Ross E. *On Death and Dying*. Toronto, Macmillan, 1969

Kurella M, Kimmel PL, Young BS, Chertow GM. Suicide in the US End-Stage Renal Disease Program. *J Am Soc Nephrol* 2005; **16**:774-781

Kutner NG, Fair PL and Kutner MH. Assessing Depression and Anxiety in Chronic Dialysis Patients. *Journal of Psychosomatic Research* 1985; **29**(1):23-31

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Leake R, Friend R and Wadhwa N. Improving Adjustment to Chronic Illness Through Strategic Self-Presentation: An Experimental Study on a Renal Dialysis Unit. *Health Psychology* 1999; **18**(1):54-62

Lopes AA, Bragg J, Young E *et al*. Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International* 2002; **62**:199-207

Lopes AA, Albert JM, Young EW *et al*. Screening for depression in hemodialysis patients: associations with diagnosis, treatment, and outcomes in the DOPPS. *Kidney International* 2004; **66**:2047–2053.

Lopez KR, Lopez FJG, de Alvaro FM and Alonso J. Perceived mental health at the start of dialysis as a predictor of morbidity and mortality in patients with end-stage renal disorder (CALVIDIA Study). *Nephrol Dial Transplant* 2004; **19**:2347-2353

Mactier R, Mitra S, Boakes S *et al* *Renal Association Home Haemodialysis Working Party Report*, The Renal Association, 2010 http://www.renal.org/docs/default-source/what-we-do/RA_Home_HD_Working_Party_Report_January_2010.pdf?sfvrsn=0
(last accessed 14/04/14)

Maguire P. Improving the detection of psychiatric problems in cancer patients. *Soc Sci Med*, 1985; **20**: 819–823.

Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *Eur J Cancer*, 1996;**32**: 78–81.

Major B and Glass D. Common psychological problems experienced by renal patients. *Journal of Renal Nursing* July 2010; **2**(4):172-177

Martin CR and Thompson DR. Prediction of quality of life in patients with end-stage renal disease. *British Journal of Health Psychology* 2000; **5**:41-55

McDade-Montez EA, Christensen AJ, Cvengros JA and Lawton WJ. The Role of Depression Symptoms in Dialysis Withdrawal *Health Psychology* 2006; **25**(2):198-204
CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

McMurchie W, Macleod F, Power K et al Computerised cognitive behavioural therapy for depression and anxiety with older people: A pilot study to examine patient acceptability and treatment outcome *International Journal of Geriatric Psychiatry* 2013; **28**(11):1147-1156

Molyneux PJ, Jones C and Brooks A. *Local service evaluation of psychological distress in a renal population*. Renal Association Abstract, 2010

Morton RL, Tong A, Howard K et al. The views of patients and carers in treatment decision making for chronic kidney disease; systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; **340**:c112

Murtagh FEM, Addington-Hall J and Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Diseases* 2007; **14**(1):82-99

National Institute for Health and Clinical Excellence. *The treatment and management of depression in adults with chronic physical health problems: CG91 Depression with a chronic physical health problem*, 2009 <http://guidance.nice.org.uk/CG91> (last accessed 14/04/14)

National Collaborating Centre for Mental Health. *Depression in adults with a chronic physical health problem. The NICE guidance on the treatment and management*. Leicester and London: The British Psychological Society and The Royal College of Psychiatrists, 2010a

National Collaborating Centre for Mental Health. *Depression. The treatment and management of depression in adults. Updated edition*. Leicester and London: The British Psychological Society and The Royal College of Psychiatrists, 2010b

National Institute for Health and Clinical Excellence. *GS5 Chronic kidney disease quality standard*, 2011 <http://www.nice.org.uk/GS5> (last accessed 14/04/14)

NHS Confederation and the Association of Directors of Social Services *Joint personal budgets: A new solution to the problem of integrated care* NHS Confederation, 2012

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

<http://www.nhsconfed.org> (last accessed 14/04/14)

NHS England 2013/14 *NHS Standard Contract for Renal Dialysis: Hospital and Satellite (Adult)*, NHS England, 2013 <http://www.england.nhs.uk/wp-content/uploads/2013/06/a06-renal-dia-hosp-sat-ad.pdf> (last accessed 14/04/14)

NHS England 2013/14 *NHS Standard Contract for Renal Dialysis: Peritoneal (Adult)*, NHS England, 2013 <http://www.england.nhs.uk/wp-content/uploads/2013/06/a06-renal-dial-peri-ad.pdf> (last accessed 14/04/14)

NHS Evidence *Depression in adults with a chronic physical health problem: Evidence Update March 2012* Manchester: National Institute for Health and Clinical Excellence, 2012 Available at: <https://www.evidence.nhs.uk/evidence-update-12> (last accessed 14/04/14)

O'Donnell K and Chung JY. The diagnosis of major depression in end-stage renal disease. *Psychotherapy and Psychosomatics* 1997; **66**(1):38-43

Olsson B, Olsson B, Tibblin G. Effect of patients' expectations on recovery from acute tonsillitis. *Fam Pract* 1989; **6**:188-192.

Ong LM, De Haes JCJM, Hoos AM and Lammes FB Doctor-patient communication: A review of the literature *Soc Sci Med*, 1995;**40**(7): 903-918

Ormandy P, Hulme C, Caress AL *et al*. *Identifying chronic kidney disease patients' preferences for information topics*. University of Salford, 2007

Ouzouni S, Kouidi E, Sioulis A *et al* Effects of intradialytic exercise training on health-related quality of life indices in haemodialysis patients. *Clin Rehabil* 2009; **23**:53

Palmer S, Vecchio M, Criag JC *et al* Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies *Kidney International*, 2013;**84**: 179-191

Pibernik-Okanovic M, Grgurevic M, Begic D *et al*. Interaction of depressive symptoms and diabetes-related distress with glycaemic control in Type 2 diabetic patients. *Diabetic Medicine* 2008; **25**(10):1252-1254.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Polonsky WH *et al.* Assessment of diabetes related distress. *Diabetes Care* 1995; **18**: 754-760

Pollack KI, Arnold RM, Jeffreys AS *et al.* Oncologist Communication About Emotion During Visits With Patients With Advanced Cancer. *Journal of Clinical Oncology* 2007; **25**(26):5748-5752

Proudfoot J, Ryden C, Everitt B *et al* Clinical efficacy of computerised cognitive-behavioural therapy for anxiety and depression in primary care: randomised controlled trial *British Journal of Psychiatry* 2004; **185**:46-54

Rabindranath KS, Daly C, Butler J *et al.* *Psychosocial interventions for depression in dialysis patients (Review)*. The Cochrane Library, 2009

Roter DL Patient Participation in the Patient-Provider Interaction: The Effects of Patient Question Asking on the Quality of Interaction, Satisfaction and Compliance. *Health Education and Behaviour*. 1977; **5**:281-315

Roter DL, Hall JA, Kern DE *et al.* Improving Physicians' Interviewing Skills and Reducing Patients' Emotional Distress. A Randomized Clinical Trial. *Archives of Internal Medicine*. 1995; **155**(17):1877-1884

Ryan H, Schofield P, Cockburn J *et al.* How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care (Engl)*. 2005; **14**(1):7-15.

Schell JO, Patel UD, Steinhauser PD. Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study. *Am J Kidney Dis* 2012; **59**(4):495-503

Schipper K and Abma TA. Coping, family and mastery: top priorities for social science research by patients with chronic kidney disease. *Nephrol Dial Transplant* 2011; **26**:3189-3195

Schofield PE and Butow PN. Towards better communication in cancer care: a framework for developing evidence-based interventions *Patient Education and*
CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Counseling 2004;**55**: 32-39

Smith M, Hopkins D, Peveler RC *et al.* First- v. second-generation antipsychotics and risk for diabetes in schizophrenia: systematic review and meta-analysis. *The British Journal of Psychiatry* 2008; **192**:406-11.

Srippoli, G *et al.* The Number, Quality and Coverage of Randomized Controlled Trials in Nephrology. *Journal of the American Society of Nephrology* 2004; **15**:411-419

Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathetic communication in medical interview *JAMA* 1997; 277(8):678-682

Szeifert L, Bragg-Gresham JL, Thumma J *et al.* Psychosocial variables are associated with being wait-listed, but not with receiving a kidney transplant in the dialysis outcomes and practice patterns study (DOPPS). *Nephrol Dial Transplant* 2012; **27**(5):2107-2113

Taskapan H, Ales F, Kaya B *et al.* Psychiatric disorders and large interdialytic weight gain in patients on chronic hemodialysis *Nephrology* 2005; **10**:15-20

Taylor F, Gutteridge R. *Overcoming barriers and facilitating access to peer support for CKD patients and carers*, West Midlands Central Health Innovation and Education Cluster, Birmingham, University of Birmingham, 2013 <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC>(last accessed 14/04/14)

Tentori F, Elder SJ, Thumma J *et al.* Physical exercise among participants in the Daily Dialysis Outcomes and Practice Patterns Study (DOPPS): correlates and associated outcomes *Nephrol Dial Transplant* 2010; **25**:3050-3062

The Kidney Health Advisory Group *Kidney Health: Delivering Excellence. A Kidney Health Report*, The Kidney Health Advisory Group, 2013 Available at: <http://www.britishrenal.org/getattachment/NewsLinks/Kidney-Health-Delivering-Excellence/Kidney-Health-Delivering-Excellence.pdf.aspx> (last accessed 14/04/14)

The Royal College of Physicians. *Chronic kidney disease. National clinical guideline for early identification and management in adults in primary and secondary care*. Royal

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

College of Physicians, London, 2008

Theofilou P. Medication Adherence in Greek Hemodialysis Patients: The Contribution of Depression and Health Cognitions. *Int J Behav Med* March 2012; DOI 10.1007/s12529-012-9231-8

Thomas KB. General practice consultations: is there any point in being positive? *BMJ*. 1987; **294**:1200-1202.

Timmers L, Thong M, Dekker FW *et al*. Illness perceptions in dialysis patients and their association with quality of life. *PsycholHealth* 2008; **23**(6):679–6908

Tong A, Sainsbury P, Carter SM *et al*. Patients' priorities for health research: focus group study of patients with chronic kidney disease. *Nephrol Dial Transplant* 2008; **23**:3206-3214

Tong A, Sainsbury P, Chadblan S *et al*. Patients' Experiences and Perspectives of Living with CKD. *Am J Kidney Disease* 2009; **53**:689-700

Trigwell P *et al*. *Minding the Gap. The provision of psychological support and care for people with diabetes in the UK*. Diabetes UK, 2008 Available at: http://www.diabetes.org.uk/Documents/Reports/Minding_the_Gap_psychological_report.pdf (last accessed 14/04/14)

Tsay S-L, Hung L-O. Empowerment of patients with end-stage renal disease – a randomized controlled trial International. *Journal of Nursing Studies* 2004; **41**:59-65

Van Bastelaar KMP, Pouwer F, Cuijpers P *et al* Web-based depression treatment for type 1 and type 2 diabetic patients: a randomized controlled trial *Diabetes Care* 2011; **34**:320-325

van Vilsteren MCBA, de Greef MHG, Huisman RM. The effects of a low-to-moderate intensity pre-conditioning exercise programme linked with exercise counselling for sedentary hemodialysis patients in The Netherlands: results of a randomized clinical trial. *Nephrol Dial Transplant* 2005; **20**:141-146.

van Bastelaar KMP, Pouwer F, Cuijpers P *et al*. Web-based depression treatment for CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

- type 1 and type 2 diabetic patients: a randomized controlled trial. *Diabetes Care*, 2011; **34**: 320–5
- Walters BAJ, Hays RD, Spritzer KL *et al.* Health-Related Quality of Life, Depressive Symptoms, Anemia, and Malnutrition at Hemodialysis Initiation. *Am J Kid Dis* 2002; **40**(6):1185-1194
- Watnick S, Kirwin P, Mahnensmith R, Concato J. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003; **41**(1):105-10
- Watnick S, Wang PL, Demadura T and Ganzini L. Validation of 2 depression screening tools in dialysis patients. *Am J Kidney Dis* 2005; **46**:919–24
- Weisbord SD, Fried LF, Unruh ML *et al.* Associations of race with depression and symptoms in patients for maintenance haemodialysis. *Nephrol Dial Transplant* 2007a; **22**:203-208
- Weisbord SD, Fried LF, Mor MK *et al.* Renal Provider Recognition of Symptoms in Patients on Maintenance Hemodialysis. *Clin J Am Soc Nephrol* 2007b; **2**:960-967
- White Y and Grenyer BFS. The biopsychosocial impact of end-stage renal disease: the experiences of dialysis patients and their partners. *Journal of Advanced Nursing* 1999; **30**(6):1312-1320
- White M, White PW, Russell CS. Multiple Sclerosis Patients Talking with Healthcare Providers About Emotions. *Journal of Neuroscience Nursing* 2007; **39**(2):89-101
- Wright SJ and Kirby A. Deconstructing Conceptualizations of 'Adjustment' To Chronic Illness. A proposed framework. *Journal of Health Psychology* 1999; **4**:259
- Wuerth, Finkelstein SH and Finkelstein FO. The Identification and Treatment of Depression in Patients Maintained on Dialysis. *Seminars in Dialysis* 2005; **18**(2):142-146
- Zabalegui A, Sanchez S, Sancez P, Juando C. Nursing and Cancer Support Groups. *Journal of Advanced Nursing* 2005; **51**(4):36
- CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.