

This is the peer reviewed version of the following article: Taylor F., Hare J., Combes G.. (2016) Exploring patients' attitudes to different intervention approaches for supporting psychosocial needs. Journal of Renal Care, which has been published in final form at <http://dx.doi.org/10.1111/jorc.12182>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

Exploring patients' attitudes to different intervention approaches for supporting psychosocial needs

Francesca Taylor^a (f.taylor@bham.ac.uk)

Jennifer Hare^b (jennifer.hare@gstt.nhs.uk)

Gill Combes^a (g.combes@bham.ac.uk)

^a Institute of Applied Health Research, University of Birmingham, Birmingham UK

^b Royal Wolverhampton NHS Trust: Renal Psychology Service, New Cross Hospital, Wolverhampton, UK

Correspondence

Francesca Taylor

Institute of Applied Health Research

College of Medical and Dental Sciences

University of Birmingham

Birmingham B15 2TT, UK

Tel: +44 (0)12 1414 7661

Fax: +44 (0)12 1414 3971

Email: f.taylor@bham.ac.uk

Source of funding

This study was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care for Birmingham and the Black Country (CLAHRC BBC) and the NIHR Collaboration for Leadership in Applied Health Research and Care West Midlands (CLAHRC WM).

Conflicts of interest

No conflict of interest has been declared by the authors.

Keywords

End-stage kidney disease, coping, distress, psychosocial.

SUMMARY

Background: Many patients with end-stage kidney disease (ESKD) have significant psychosocial needs as a consequence of their illness and treatment. Unmet needs can impact negatively on their health and wellbeing. Patients want improved psychosocial support particularly in relation to coping and adjustment. Little is known about the relevance and applicability to patients of intervention approaches to support their psychosocial needs.

Objectives: To explore patients' attitudes to different intervention approaches that could be developed to help them cope with the psychosocial stressors of ESKD, and to assess the potential acceptability of these approaches.

Methods and materials: Qualitative interviews and mini-focus groups were undertaken with 15 patients who have ESKD. Different interventions approaches were shown to participants through use of audio-visual films. Constant comparative data analysis was employed to derive a framework of categories and themes, guided by stress and coping theory.

Results: Psychosocial support was viewed by patients as an essential constituent of quality care. While some intervention approaches were more or less popular than others, responses were overall variable and individualistic, seemingly influenced by participants' personal coping strategies. Any perceived connection with depression could make an intervention approach less attractive; physical exercise was particularly acceptable because there was no explicit association with someone not coping.

Conclusions: There is value in clinicians making available a choice of appropriately timed and tailored interventions to meet patients' different psychosocial support needs at key points of distress across the ESKD pathway. Congruence between intervention features and patient coping style could stimulate interest and take-up.

Exploring patients' attitudes to different intervention approaches for supporting psychosocial needs

INTRODUCTION

As a result of difficulties related to their illness, diagnosis and treatment, patients who have end-stage kidney disease (ESKD) can experience significant psychosocial problems. Many patients find the transition to dialysis frightening and traumatic. They can continue to experience periods of distress throughout their time on dialysis, due to the stress of treatment, loss of sexual function, altered body image, and decreased physical and cognitive functioning, as well as consequent effects for employment, relationships and lifestyle (Kimmel & Peterson 2005; White & McDonnell 2014). Patients who have received transplants experience many of the same stresses, along with fear of transplant failure and significant distress if a transplant does fail (Chilcot *et al.* 2014). This paper explores the attitudes of patients to different intervention approaches that could be developed to help them cope with the psychosocial stressors of ESKD.

A recent study reported that more than a third of people who are new to dialysis had experienced emotional and psychological difficulties, yet there was an absence of support for patients whose psychosocial problems fell below the threshold of clinical depression (Combes *et al.* 2015). Although patients who have ESKD want improved support, particularly in the areas of coping and adjustment, their needs tend to be ignored and frequently remain untreated (Schell *et al.* 2012; Gill & Lowes 2014). Furthermore, unmet psychosocial needs are associated with reduced ability to engage in treatment choice (Morton *et al.* 2010); poor medication and diet compliance (Khalil *et al.* 2011; Clark *et al.* 2014); and, withdrawal from dialysis treatment (McDade-Montez *et al.* 2006). Several local NHS Trusts were interested in implementing interventions to better support the psychosocial needs of their patients who have ESKD. Given the significant proportion of patients with ESKD who could potentially benefit from improved psychosocial support, the most feasible interventions were likely to be low-cost and easy to incorporate into clinical practice. There is limited robust evidence on interventions of this type used by patients who have ESKD, although positive health impacts have been recorded in response to physical exercise (Barcellos *et al.* 2015), and coping and empowerment skills (Tsay & Hung 2014). Two good studies evaluated the impact of peer support in patients with ESKD, one found the intervention was associated with improved well-being and reduced anxiety in African Americans but not White Americans (Perry *et al.* 2005), the other reported it helped normalise illness and demanding

treatment regimes, and increased patients' sense of empowerment (Hughes *et al.* 2009). A further study explored the attitudes towards peer support of patients with ESKD who were non-users of the intervention, and suggested several facilitation methods to address identified barriers to participation (Taylor *et al.* 2016). More substantive evidence within the context of long-term conditions in general, highlights the psychosocial benefits of mindfulness-based therapy (Gotink *et al.* 2015); and, computerised cognitive behaviour therapy (CBT) (Foroushani *et al.* 2011). Additionally, interventions that promote discussion of emotional issues during clinician consultations have been found to improve patients' wellbeing (Ryan *et al.* 2005).

However, little was known about the relevance and applicability to patients with ESKD of these intervention approaches. A preliminary assessment of the attitudes of patients with ESKD could help clinicians decide which interventions to develop, implement and then evaluate. Therefore, the aims of this study were to explore: patients' attitudes to different intervention approaches that could be developed to help them cope with the psychosocial stressors of ESKD, and the potential acceptability of these approaches. Stress and coping theory (Lazarus 1984) was used to help organise the data and explain the findings. This theory posits that adjustment in response to external stressors is influenced by a person's appraisals of stressors, their coping strategies for managing stressors, and evaluation of these strategies. Existing evidence suggested it could play an important role in understanding how interventions impact on the process of adjustment to distress by helping patients manage negative emotions (Moss-Morris 2013).

MATERIAL AND METHODS

A qualitative design was employed to understand patients' attitudes to and their perspectives of the different intervention approaches (Pope & Mays 2006). Guidance provided by Bristowe *et al.* (2015) for ensuring quality when undertaking qualitative research in renal medicine, was used to assess reliability and validity in methodological design, data analysis and interpretation.

Individual interviews and focus groups were selected as complementary methodologies. Mini-focus groups of 3-4 participants were chosen over standard-sized focus groups because patients have significant time constraints arising from their treatment, making recruitment difficult. Patients were interviewed individually in their home or Renal Unit, or participated in a mini-focus group in their Renal Unit. Individual interviews lasted 45-60 minutes, and

mini-focus groups 75-90 minutes. The interviews and groups were semi-structured (Table 1) to allow the key areas of research interest to be explored without being overly prescriptive in terms of content and direction (Holloway & Wheeler 2010). They were digitally recorded and professionally transcribed in full.

Five audio-visual films were shown to participants by a study researcher using a laptop computer. To avoid response-order bias, film sequences were rotated to a structured format between interviews and groups. Each film presented evidence-based information about a particular type of intervention approach: training in mindfulness; peer support; computerised CBT; physical activity programmes (cycling while on a dialysis machine, and walking); and, clinic time given to discussion of emotional needs - prompted by use of a Patient Issues Sheet, or consultants asking patients a question adapted from the Patient Health Questionnaire-9 (Spitzer *et al.* 1999) recommended by the National Institute for Health and Clinical Excellence (2009), about whether they had been feeling down or miserable in the last week.

Audio-visual films were chosen to present the different intervention approaches since participants were thought likely to have limited awareness of these approaches (Lawrence *et al.* 2013; Taylor *et al.* 2016), and verbal and/or written descriptions were therefore judged insufficient to allow patients to understand each approach. A methodology was developed in order to produce the films to a consistent format. Using existing theory on effective information communication (Weiss & Tschirhart 1994), a framework was designed based on five components: main message about the intervention approach, key benefits, context, positive outcomes, and patients' feelings after use. Evidence-based information for the five components was included in the framework for each intervention approach (Table 2). Film scripts were based on the communication framework.

Linked to the framework, a standardised design was used for each film: visual clips of the intervention approach with explanatory voice-over, followed by two actor-patients talking about the benefits. A ratio of 60:40 for these two sections was maintained across the films to restrict any bias in information presentation; communications in the first person, from the patients' perspective, are informative experientially and more influential than in the third person, but can restrain considered judgement of the information's personal relevance (Winterbottom *et al.* 2012). Film length was 2-3 minutes.

RECRUITMENT

Patients who have ESKD were recruited to the study from two NHS Hospital Trusts. Sampling aimed to be purposive, based on study inclusion criteria (Table 3), and to provide maximum diversity of age, gender, ethnicity, position along the ESKD pathway, and dialysis treatment type. However, the method employed resulted in recruitment of a convenience sample rather than the intended purposive sample. A study researcher in one site and a Renal Unit staff member in the second site each identified potential participants from anonymised patient lists. A total of 64 patients were selected, 32 in each site. These patients were sent a letter about the study by the lead consultant of their Renal Unit, with a Consent Form and Information Sheet outlining the study purpose and what participation would involve. The letter explained they would be contacted the following week by a renal staff member, asking whether they were interested in participating and willing to have their contact details passed to a researcher. Twenty patients (31%) expressed interest and were contacted by a researcher; seventeen agreed to be interviewed or participate in a mini-focus group. Two patients later withdrew due to ill-health. The interviews and focus groups took place during early to mid-December 2013.

PARTICIPANTS

A total of 15 patients participated, nine patients from one Trust and six from the second Trust. The mean age of participants was 58 years. There were six female and nine male participants. Seven patients were at the pre-dialysis stage, five patients were on peritoneal dialysis (PD) and three on haemodialysis (HD). The time patients had been on any dialysis therapy varied from less than 3 months to 12 months. Twelve patients were White British and three were Asian British. Nine patients participated in individual interviews and six patients in mini-focus groups (see Table 4).

None of the participants had been previously referred to a psychologist or had used any psychosocial support interventions. One patient reported having been offered formal peer support but had declined the offer.

DATA ANALYSIS

A framework approach was used to code and categorise the research data (Pope *et al.* 2000), guided by stress and coping theory (Folkman & Lazarus 1991). Transcripts from the first third of individual interviews and first mini-focus group were read and re-read by one researcher. Data were broken down using line-by-line coding; the codes were clustered to identify initial categories based on ideas, issues and themes. An initial framework was

developed from the emerging codes and categories after scrutiny and discussion with a second researcher, who had also read the transcripts.

Constant comparison was utilised with each data collection from further interviews compared with every other for similarities, differences and connections (Bryant & Chamaz 2007; Corbin & Strauss 2008). Categories included in the framework were refined and enhanced, some combined and others condensed or removed. This process was undertaken independently by one researcher and supplemented by continuous collaborative discussion with the second, to reach consensus and confirm categories and themes.

ETHICAL CONSIDERATIONS

Ethical approval was received from a local Committee of the National Research Ethics Service (13/LO/0443). The study was also approved by the Research Governance office of each Hospital Trust. All participants gave written informed consent.

RESULTS

Four main themes were identified: supporting mind and body together; different support needs at different times for different patients; accessibility of support; and, sensitivity around language and imagery.

SUPPORTING MIND AND BODY TOGETHER

Most participants recognised a close interrelationship between their physical and emotional wellbeing. With knowledge based on lived experience, they understood, especially if on dialysis, that negative feelings could impact their physical health. In turn, they appreciated that any improvements in wellbeing might have a corresponding positive effect on physical health outcomes.

Because of if you feel down, your body's going to feel down. So if you feel better in yourself, you should improve your condition. (P13)

It was generally acknowledged by participants that consultants could provide better quality care if given greater knowledge of their patients' emotional status. In this context, there was widespread comment on the benefits of clinic time being given to discussion of emotional concerns. Many respondents were attracted to the premise that talking about problems and feelings would offer insight into their overall wellbeing, allowing their consultant to provide more appropriate whole-person care.

It's a good idea, because the consultant then knows how you're feeling as well. It's not just for the medical part of it. (P11)

Analogous with these integrative care issues, many patients realised that improvements in physical health could have a positive effect on their wellbeing. Indeed, these perceived emotional as well as physical health benefits were the main reason cited for liking the physical activity programme, viewed by participants as the intervention approach they would be most interested in using personally. Patients liked the concept that through using a practical exercise programme they could lose weight and improve their blood pressure, and in turn achieve a better mood.

DIFFERENT SUPPORT NEEDS AT DIFFERENT TIMES FOR DIFFERENT PATIENTS
 Patients' perspectives of the different intervention approaches were highly individualistic, reflective of diverse coping methods and support needs. An example of this variability is found in the contrasting reactions of two female patients to the concept of peer support. A patient on PD for over 8 months expressed great enthusiasm about the opportunity to talk with a peer supporter in the same position as herself. Through sharing experiences, she anticipated learning helpful strategies for coping with her illness and treatment.

It's good to have that kind of person to talk to who's experiencing the same issues that you are. Some of the experiences that they've got might help me with mine. (P9)

Conversely a younger participant, who had been on HD for less than a month, felt no interest in accessing peer support. The focus on talking to a patient peer about negative thoughts and feelings was not appreciated, her preference being the functional approach of cycling while on dialysis. She wanted to live as normal a life as possible and thought concentrating on concerns about her treatment would be unhelpful.

Just not really in a place where I really feel like I want to sit and talk about it. It's just, I just want to get on and live my life really. (P11)

Mindfulness training also generated varied viewpoints. For example, one male participant was very negative, perceiving it a passive method of handling unhelpful thoughts. Although not yet a dialysis starter, he was motivated more by cycling while on dialysis, as a practical, activity-based way of coping with negative emotions. Whereas another male patient at the pre-dialysis stage who struggled with the uncertainty around his prognosis, felt mindfulness offered the opportunity to have greater control over his feelings.

Being able to control what you think...there's times when I do have some bad thoughts and you try and get rid of them and you can't. (P14)

Participants also expressed diverse views about the appropriate timing for intervention delivery. Some patients felt that interventions would be of particular value to help cope with the trauma of initial diagnosis, others wanted support timed to help dialysis starters adapt to the demands of treatment. Failures of dialysis treatment, such as the requirement to insert a new catheter, fistula failure, and a change to type of dialysis, were also discussed, and how negative reactions may need emotional support. However, several participants anticipated interventions being an added burden if offered at a time of difficult treatment experiences. Support needs at the pre-dialysis stage were reported less frequently, but some participants wanted interventions made available at this point in the pathway to handle stresses such as uncertainty about the future, fear, and a sense of unfairness.

Many participants recognised that their emotional wellbeing could fluctuate and they expected their need and receptiveness towards different interventions would likely vary over time. Having choice over when they might use an intervention was therefore important for some respondents. Others mentioned it would be reassuring just to know support was available if and when required.

ACCESSIBILITY OF SUPPORT

The attraction of an intervention approach was often closely linked to the perception of how easy it would be to access. Patients tended to weigh-up the communicated benefits against anticipated barriers to take-up. Lack of time was a recurrent access issue. Patients on HD in particular felt time-pressured having to spend so many hours of each week on dialysis. They wanted an intervention that would fit easily into a busy schedule and not add further time constraints. In this context, cycling while on dialysis was appealing because it presented an opportunity to use 'empty' time for positive benefit.

To do that while you're on dialysis is like... you're not wasting any time anywhere are you. You're doing it while you're there anyway. So to me that's brilliant. (P1)

Several participants, attracted to mindfulness by the anticipated benefit of being helped to handle negative thoughts and emotions, were nonetheless dissuaded because of the perceived difficulty of doing a course over several weeks. A female patient on HD who had been

dialysing for several months felt that the complexity of fitting the course into her time-constricted life would likely cause her more stress than benefit.

The challenge of learning new skills was mentioned as another barrier. Being perceived to require computer expertise was a key reason why computerised CBT was the least favoured intervention. Although it was stated in the audio-visual film that there was no necessity to be ‘*a computer whiz-kid*’, the abiding impression was of an intervention intended for people ‘*good at computers*,’ since a course of eight weekly sessions suggested fairly intense computer use.

No I'm not really a computer buff. I've no interest in it at all. (P6)

In contrast, an appealing attribute of walking as an intervention approach was that no specific skills or training were needed. It was immediately accessible to most patients, apart from those with certain physical disabilities.

SENSITIVITY AROUND LANGUAGE AND IMAGERY

A clear distinction was made by most respondents between their emotional difficulties and depression; they equated depression with more serious mental health problems. The descriptor was also associated with negative societal judgement and consequent shame. Some participants feared the medical repercussions of being labelled depressed; viewed as having another serious illness in addition to kidney disease, with a requirement to take anti-depressants.

You're being labelled then, aren't you? And that's what people might not want to be labelled. (P10)

‘Stress’, ‘anxiety’, ‘nervous’ and ‘feeling down’ or ‘low’ were considered more relevant and acceptable terms. These were the natural descriptors used by participants in relation to their emotional problems.

I do have my down days...but I'm not a depressive sort of person. (P5)

Any perceived relationship with depression could make an intervention approach appear less attractive and act as a potential barrier to take-up. For example, several participants were dissuaded from computerised CBT because of the impression given it was for depressed people; the word ‘depression’ having been shown in the film of the intervention approach.

I'm not a depressed person.....and so I don't think I'd use it, quite frankly. (P8)

On the other hand, intervention approaches seen as inclusive and suitable for any ESKD patient were more acceptable, and held greater appeal. Participants perceived no stigma attached to engaging in physical exercise since there was no explicit connection with depression. Similarly, the Patient Issues Sheet was liked for showing the kind of issues other patients with ESKD were concerned about and that it was normal to discuss with a consultant.

DISCUSSION

Although results cannot be generalized from this small-scale qualitative study, it has allowed an understanding of patients' attitudes to different intervention approaches that could be made available to help them cope with the psychosocial stressors of ESKD, and the potential acceptability of these approaches. This is useful learning since unlike for many other long-term condition populations, limited evidence exists on how renal patients' perceive different types of psychosocial support. Insights are also provided into how the intervention approaches could best be implemented.

Irrespective of their psychosocial needs, participants welcomed the potential availability and choice of interventions, as well as the prospect of improved wellbeing if additional support was made available for use. While some intervention approaches were more or less popular than others, there was an overall variable and individualistic response to each approach, seemingly influenced by participants' personal coping strategies for managing ESKD-related emotional stressors. A variety of strategies were evidenced that can be broadly grouped into the two approaches identified by Lazarus & Folkman (1984, 1991): problem-focussed, directed at modifying or eliminating the source of stress; and, emotion-focussed, directed at reducing distress generated by the stressful situation. The most popular intervention approach, physical activity programmes, for example, appeared to have particular appeal to some participants who favoured problem-focussed practical ways of coping. Whereas peer support and mindfulness seemed attractive to those participants more inclined to share and consider their feelings and emotions.

Although coping strategies were not formally assessed, these findings suggest congruence between the characteristics of an intervention, and patient coping style, could be an important determinant of its potential appeal and take-up. More research is needed on this inter-relationship; however, there may be benefits in identifying the most appropriate coping style for particular individuals, and offering them interventions that best match their approach.

This methodology would fit with the adjusting to chronic illness theory of Moss-Morris (2013), which suggests interventions be mapped onto building or maintaining existing cognitive and behavioural methods that facilitate coping, and reducing those that maintain a state of disequilibrium. Other relevant theories, that could be used in future research to understand the impact of interventions on adjustment to distress, include illness perceptions (Leventhal *et al.* 1997; Chilcot 2012) and cognitive adaptation (Taylor & Shelley 1983).

This study has shown that for most participants, any perceived connection to depression tended to make an intervention approach less attractive. Physical activity was more acceptable than some other approaches because there was no explicit association with depression. A key finding of the study by Taylor *et al.* (2016) was that fear of being judged overly needy could act as a barrier to take-up of peer support; to facilitate 'permission to engage', promotion of the intervention as suitable for anyone with ESKD was suggested. Similar findings on patients wanting to avoid stigma, and the identity of someone not coping, have been reported in the literature on other long-term conditions (Galway *et al.* 2012; Dennison *et al.* 2013). To maximise appeal, it will also be important to match the structure and duration of any intervention approach to the constrained time availability of patients who have ESKD. Hudson *et al.* (2016), for example, have considered patient burden in developing an online CBT treatment tailored specifically to the needs of people who have ESKD. Flexibility of intervention provision to accommodate variation in patients' receptivity across time and the disease trajectory may additionally enhance appeal (Taylor *et al.* 2016). In considering these findings, some limitations of the study sample should be borne in mind. Although the study endeavoured to employ a purposive sample to provide maximum diversity, there was limited ethnic variation and only a few of the recruited sample were on HD. This reflects the recruitment of a convenience sample rather than the intended purposive sample.

The use of audio-visual films has shown some promise as a methodology to assess patient attitudes and the acceptability of different intervention approaches. Employing both mini-focus groups and individual interviews enhanced understanding of patients' perspectives. The groups provided more breadth and contextual information, and the interviews greater depth and clarity in the data collected.

CONCLUSION

Each of the intervention approaches shown to participants has the potential to offer potentially attractive and acceptable psychosocial support to certain patients who have ESKD. Whether or not patients found an intervention approach particularly appealing seemed to be related to their individual coping strategy for managing stressors. Congruence between intervention features and patient coping style could therefore be influential in encouraging future take-up.

IMPLICATIONS FOR PRACTICE

Renal clinicians should understand that patients who have ESKD consider the provision of interventions to support their psychosocial needs as integral to good quality care. Given the individuality of patient responses to the different intervention approaches shown to them, there is value in clinicians making available a choice of appropriately timed and tailored interventions at key points of need across the dialysis and transplantation pathways.

ACKNOWLEDGEMENTS

This paper presents independent research funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care West Midlands (CLAHRC WM) initiative. The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

We thank Dr Johann Nicholas and Dr Kerry Tomlinson for their contributions to setting up the study; Dawn Child, Susan McGuire, Sara Simmons, Zoë Hancock and Pamela Nayyar for their assistance throughout the study; Floating Harbour Films for audio-visual film production; and, the volunteer actor-patients for their participation in the audio-visual films.

AUTHOR CONTRIBUTIONS

GC, Principal Project Leader, and FT conceived the research. All authors participated in the research design, development and refinement of the methodological approach. FT led on drafting the manuscript with input from GC and JH. All authors critically reviewed the manuscript, and have approved the final version.

REFERENCES

Barcellos F.C., Santos I.S., Umpierre D. *et al.* (2015). Effects of exercise in the whole spectrum of chronic kidney disease: a systematic review. *Clinical Kidney Journal* 1-13.

Bryant A. & K. Chamaz. (2007) Introduction. Grounded Theory Research: Methods and Practices. In *The Sage Handbook of Grounded Theory* (eds Bryant A. & Chamaz K.), Paperback edn, pp.1-28. London: Sage.

Bristowe K., Selman L. & Murtagh F.E.M. (2015). Qualitative research methods in renal medicine: an introduction. *Nephrology Dialysis Transplantation* **30**(9), 1424-1431.

Chilcot J. (2012). The Importance of Illness Perceptions in End-Stage Renal Disease: Associations with Psychosocial and Clinical Outcomes. *Seminars in Dialysis* **25** (1), 59-64. Chilcot J., Spencer

B.W., Maple H. *et al.* (2014). Depression and kidney transplantation. *Transplantation* **97**(7),717-721.

Clark S., Farrington K. & Chilcott J. (2014). Nonadherence in Dialysis Patients: Prevalence, Measurement, Outcome and Psychological Determinants. *Seminars in Dialysis* **27**(1), 42-49.

Combes G., Allen K., Sein K. *et al.* (2015). Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates. *Implementation Science* **10**, 148.

Corbin J. & Strauss A. (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. New York: Sage.

Dennison L., Moss-Morris R., Yardley L. *et al.* (2013) Change and processes of change within interventions to promote adjustment to multiple sclerosis: Learning from patient experiences. *Psychology & Health* **28**(9), 973-992.

Folkman S. & Lazarus R.S. (1991) Coping and emotion. In *Stress and Coping: An Anthology* (eds Monat A. & Lazarus R.S.), 3rd edn, pp.207-227. New York: Columbia University.

Foroushani P.S., Schnieder J. & Assareh N. (2011). Meta-review of the effectiveness of computerised CBT in treating depression. *BMC Psychiatry* **11**, 131-136.

Galway K., Black A., Cantwell M. *et al.* (2012) Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients. Review. *The Cochrane Library* **11**, CD007064. Chichester: Wiley.

Gill P. & Lowes L. (2014). Renal transplant failure and disenfranchised grief: Participants' experiences in the first year post-graft failure – a qualitative longitudinal study. *International Journal of Nursing Studies* **51**, 1271-1280.

Gotink R.A., Chu P, Busschbach J.J.V. *et al.* (2015) Standardised Mindfulness-Based Interventions in Healthcare: An Overview of Systematic Reviews and Meta-Analyses of RCTs. *PLoS One* **10**(4)

Gregory D.M., Way C.Y., Hutchinson T.A. *et al.* (1998). Patients' Perceptions of their Experiences with ESKD and Hemodialysis Treatment. *Qualitative Health Research* **8**(6), 764-783.

- Holloway I. & Wheeler S. (2010). *Qualitative Research in Nursing and Healthcare*, 3rd edn. Chichester: Wiley & Sons.
- Hudson J.L., Moss-Morris R., Game D. *et al.* (2016). Improving distress in dialysis (iDiD): a feasibility two-arm parallel randomised controlled trial of an online cognitive behavioural therapy intervention with and without therapist-led telephone support for psychological distress in patients undergoing haemodialysis. *BMJ Open* **6**, e011286.
- Hughes J., Wood E., Smith G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations* **12**, 396-406.
- Hutchinson T.A. (2005). Transitions in the lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing. *Palliative Medicine* **19**, 270-277.
- Khalil A.A., Frazier S.K., Lennie T.A. *et al.* (2011). Depressive symptoms and dietary adherence in patients with end-stage renal disease. *Journal of Renal Care* **37**(1), 30-39.
- Kimmel P.L. & Peterson R.A. (2005). Depression in End-Stage Renal Disease Patients Treated with Hemodialysis: Tools, Correlates, Outcomes and Needs. *Seminars in Dialysis* **18**(2), 91-97.
- Lawrence C., Sharma S., Da Silva-Gane. *et al.* (2013). Exploring the views of patients not on the transplant waiting list: a qualitative study. *Journal of Renal Care* **39**(2), 118-124.
- Lazarus R.S. & Folkman S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Leventhal H., Benyamini Y., Brownlee S. (1997). Illness representations: Theoretical foundations. In *Perceptions of health and illness: Current research and applications* (eds Petrie K.J. & Weinman J.), pp.19-45. London: Harwood.
- McDade-Montez E.A., Christensen A.J., Cvengros J.A. *et al.* (2006). The Role of Depression Symptoms in Dialysis Withdrawal. *Health Psychology*. **25**(2), 198-204.
- Morton R.L., Tong A., Howard K. *et al.* (2010). The views of patients and carers in treatment decision making for chronic kidney disease; systematic review and thematic synthesis of qualitative studies. *British Medical Journal* **340**, c112.
- Moss-Morris R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology* **18**, 681-686.
- National Institute for Health and Clinical Excellence. (2009). The treatment and management of depression in adults with chronic physical health problems: CG91 Depression with a chronic physical health problem, Manchester, National Institute for Health and Clinical Excellence.

Perry E., Swartz J., Brown S. *et al.* (2005). Peer mentoring: a culturally sensitive approach to end-of-life planning for long-term dialysis patients. *American Journal of Kidney Diseases* **46**(1), 111-119.

Pope C., Ziebland S., Mays N. (2000). Qualitative research in health care. Analysing qualitative data. *British Medical Journal* **320**, 114-116.

Pope C. & Mays N. (2006). Qualitative methods in health research. In *Qualitative Research in Health Care, Third Edition* (eds Pope C., Mays N.) pp.1-11. Malden/MA: Blackwell Publications/BMJ Books.

Ryan H., Schofield P., Cockburn J. *et al.* (2005). How to recognize and manage psychosocial distress in cancer patients. *European Journal of Cancer Care* **14**, 7-15.

Schell J.O., Patel U.D., Steinhauser P.D. *et al.* (2012). Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study. *American Journal of Kidney Diseases* **59**(4), 495-503.

Spitzer R.L., Kroenke K., Williams J.B. (1999). Patient Health Questionnaire Study Group. Validity and utility of a self-report version of PRIME-MD: the PHQ Primary Care Study. *Journal of the American Medical Association* **282**(18), 1737-1744.

Taylor S. & Shelley E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist* **38**(11), 1161-1173.

Taylor F., Gutteridge R., Willis C. (2016). Overcoming barriers and facilitating access to peer support for CKD patients and carers. *Health Expectations* **9**(3), 617-630.

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

Weiss J.A. & Tschirhart M. (1994). Public Information Campaigns as Policy Instruments, *Journal of Policy Analysis and Management* **13**(1), 82-119.

White C. & McDonnell H. (2014). Psychosocial distress in patients with end-stage kidney disease. *Journal of Renal Care* **40**(1), 74-81.

Winterbottom A.E., Bekker H.L., Conner M. *et al.* (2012). Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study. *Nephrology Dialysis Transplantation* **27**, 325-331.

Table 1 Exemplar interview and focus group questions*After each audio-visual film presented*

How do you feel about what you have just seen and heard?

Was there anything you particularly liked about the type of support shown?

Was there anything you particularly disliked about the type of support shown?

Would you personally be interested in using this type of support?

Who do you think would most benefit from this type of support?

When would it be most useful for this type of support to be provided?

Are there any ways you think the type of support that has been shown could be improved?

Overall, do you think it would be a good idea or not for your hospital to provide this type of support?

After all audio-visual films presented

Having seen these different ways that your hospital might provide support in future, which would you personally, be most interested in using?

Table 2 Communication framework for audio-films of intervention approaches

Intervention approach	Main message to capture the attention of patients	Key benefits of the intervention approach to generate interest in take-up	Context in which intervention approach can be used	Potential positive outcomes from intervention approach	How patients can feel after intervention approach
<p>Physical activity programmes managed and supported by the renal unit (Barcellos <i>et al.</i> 2015)</p>	<p>You could have your own personal activity programme designed for you by the hospital physiotherapist. There are two main choices of activity, cycling while on a dialysis machine, and walking in a small group with other patients.</p>	<p>The two physical activities are especially designed for kidney patients and can make you feel better in terms of mood and physical health.</p> <p>Cycling while on a dialysis machine is fun and easy to do, and makes good use of time while you are dialysing.</p> <p>Walking in a small group with other patients is also fun and easy to manage even if you are not feeling your best. You can fit the walks in around your personal life.</p>	<p>Based on your individual health, the hospital physiotherapist will work out what is the best for you and regularly check how your activity programme is going. Renal unit staff will also support and encourage you in doing your chosen activity.</p> <p>You do not have to be especially fit or active. Cycling while on a dialysis machine involves using a specially designed bike. You can cycle for as long as you want, but most patients will cycle for about 30 minutes during each dialysis session. Or you can join in regular walks with small groups of other patients. The walks have a trained leader and follow safe, easy routes. You can choose to walk as often as you like.</p>	<p>Doing these activities will help reduce any feelings of stress you have and improve your mood. You will also benefit from increased muscle strength and better blood pressure.</p>	<p>I was surprised how easy it was to cycle right there on the bed. You feel better because you've exercised. It helps you mentally. Also you've something to look forward to, to pass the time.</p> <p>Walking has been one of the best things I've done. I feel like I've found the real me again. I'm healthier, fitter, happier and more confident.</p>
<p>Clinic time to discuss emotional needs (Ryan <i>et al.</i> 2005)</p>	<p>When you attend a regular clinic appointment with your consultant at the hospital, as well as talking about your kidneys, you could be given some time to discuss how you are in general.</p>	<p>It's good to talk. Discussing any things you're worried about with your consultant can help reduce worry and stress. It gives your consultant a better idea of what is going on for you and what can be done to help.</p>	<p>During your regular appointment your consultant could simply ask, whether during the last few weeks you had been feeling down or miserable at all.</p> <p>To help you prepare for this discussion, while you wait in the renal unit before your appointment, you might like to look at a sheet of paper showing issues that other people with your illness have said they want to talk about. You could mark on this sheet of paper the issues that you would most like to talk about with your consultant. You could then take this sheet of paper with you into the appointment.</p> <p>It would be up to you whether or not you wanted to discuss such issues. You would have the choice.</p>	<p>Together you and your consultant can find solutions you may not have thought of before, to the things that are troubling you.</p>	<p>Talking to my consultant about how it was for me being on dialysis, how it was affecting my family life, has made a big difference. They really listened to how I was feeling.</p> <p>I didn't think I could talk about these sorts of things during my appointment, about what the future holds. But I'm glad we did. It helped me get it off my chest and I now feel less worried.</p>

Intervention approach	Main message to capture the attention of patients	Key benefits of the intervention approach to generate interest in take-up	Context in which intervention approach can be used	Potential positive outcomes from intervention approach	How patients can feel after intervention approach
Peer support (Perry <i>et al.</i> 2005; Hughes <i>et al.</i> 2009; Taylor <i>et al.</i> 2016)	You can have a friendly one-to-one chat and share thoughts and experiences with a kidney patient who is in a similar situation to you	<p>Although each patient's experience is unique, many kidney patients find it helpful to talk to someone who really understands what they are going through.</p> <p>Your nurse or consultant will try to make sure that you are matched to an appropriate person. You can choose to talk either over the telephone, face-to-face, or online.</p>	<p>The patient you can choose to talk to will have experience of kidney disease and dialysis treatment. They are also an unpaid volunteer, trained to provide support and guidance to other kidney patients. You can talk about anything you would like to.</p> <p>Often one session of talking is enough, but some patients choose to have further contact with their supporter.</p>	There are many benefits from talking with another, more experienced kidney patient. It can help reduce feelings of anxiety and isolation, increase confidence, and give you a greater sense of control.	<p>You feel you are not alone, less isolated. Somebody else has been through it. That is comforting. Emotional support from someone being there.</p> <p>I was able to ask anything - about relationships, sexual issues, managing with work. How you adapt your life to deal with the illness. It was really helpful listening to someone with the same experiences. It made me feel more positive.</p>
Training in Mindfulness (Gotink <i>et al.</i> 2015)	You can be given training in how to handle any negative thoughts and emotions you might have, so you feel calmer and more accepting of your situation. You will learn how to concentrate and how to focus your mind.	You will learn how to concentrate and how to focus your mind. This will help you deal with any unnecessary and unpleasant thoughts. As a result you will feel less worried.	<p>Anyone can learn the skills needed. The training can be done with other patients in a group or on your own, led by a professional teacher. Alternatively you can learn online using a CD. The training involves a one-hour session each week, over 6 to 8 weeks.</p> <p>Between each session, it is helpful to set aside some time each day to practice the skills you have been taught. This might, for example, involve doing a breathing exercise, or sitting in a certain way.</p>	You will be able to use the skills you've learnt to calm your mind and make it feel more at peace; whenever you need to. This can help reduce stress, help you sleep better and improve your general mood and wellbeing.	<p>After doing one of the exercises I feel refreshed and relaxed.</p> <p>The training has given me a handle on what causes stress and how to deal with it. I now feel more positive about things in my life. It has made me a much happier person than I ever felt I could be with my disease.</p>
Computerised cognitive behaviour theory (Foroushani <i>et al.</i> 2011)	You can do a training course online that will help you learn how to manage your feelings and mood.	<p>The course will teach you ways to deal with the problems that might be making you feel down.</p> <p>For example you can learn how to relax more or how to better plan all the tasks and activities you have to do.</p> <p>You do not have to be a computer expert to do the course.</p>	<p>The course consists of 8 weekly sessions. Each session lasts about 50 minutes. You can do the course anytime of the day you choose and go the speed that best suits you.</p> <p>It is helpful to practice the skills you have learnt between each weekly training session.</p> <p>You will need to be able to use a computer but do not have to be a computer expert.</p> <p>There is support available to help you. If you have any questions, you can contact a trained professional by phone.</p>	You can use the skills you have learnt whenever you need them. You will be able to continue using these skills to help you manage your feelings. This will make it less likely that any feelings of being anxious or downhearted will return.	<p>The course has given me the confidence to control my own feelings. It also helps you understand where these feelings are coming from.</p> <p>The skills learnt to change my behaviour have been the most helpful. They have had a positive effect on many areas of my life.</p>

Table 3 Participant eligibility criteria

Inclusion criteria

- Patient with ESKD receiving treatment in a Renal Unit at one of the study sites
 - Receiving haemodialysis (HD), peritoneal dialysis (PD) or home haemodialysis (HHD) for no more than 12 months or pre-dialysis with a dialysis plan
 - Aged 18-90 years
 - Willing to take part in an interview or mini-focus group
 - Clinically stable and well enough to participate in an interview or mini-focus group
 - Not participating in a parallel study conducted in a Renal Unit at one of the study sites
-

Exclusion criteria

- Currently accessing psychological support (counselling, psychologist, psychiatrist)
- Lacking capacity to give informed consent to participate in an interview or mini-focus group
- Participating in a parallel study conducted in a Renal Unit at one of the study sites

Table 4 Characteristics of patient participants (*n* =15)

Characteristic	<i>n</i> (%)
Mean age, years	58
Age	
18-49 years	3 (20)
50-64 years	8 (53)
65 years and over	4 (27)
Gender	
Male	9 (60)
Female	6 (40)
Race/ethnicity	
White British	12 (80)
Asian British	3 (20)
Current dialysis therapy	
Pre-dialysis	7 (47)
PD	5 (33)
HD	3 (20)
Time on dialysis therapy	
0 months	7 (47)
>3 months	1 (7)
3 - 6 months	2 (13)
7 - 9 months	4 (26)
10 - 12 months	1 (7)
Research method	
Interview	9 (60)
Mini-focus group	6 (40)