UNIVERSITY OF BIRMINGHAM

The prevalence, experience and management of mild to moderate distress in patients with end stage renal disease: results from a multi-centre, mixed methods research study

FINAL REPORT

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This study was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care West Midlands (CLAHRC-WM). The views expressed in this report are those of the authors and not necessarily those of the NHS, the NIHR of the Department of Health and Social Care.

March 2019

NHS
National Institute for
Health Research

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LIST OF ABBREVIATIONS

BDI	Beck Depression Inventory
BME	Black and Minority Ethnic
CKD	Chronic Kidney Disease
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
COPD	Chronic Obstructive Pulmonary Disease
DH	Department of Health
DT	Distress Thermometer
DTPL	Distress Thermometer Problem List
eGFR	Estimated Glomerular Filtration Rate
ESRD	End Stage Renal Disease
ET	Emotion Thermometers
HADS	Hospital Anxiety and Depression Score
HCA	Healthcare Assistant
HCP	Healthcare professional
HD	(Hospital or in-centre) Haemodialysis
HHD	Home Haemodialysis
HRA	Health Research Authority
IQR	Inter-Quartile Range
NCCN	National Comprehensive Cancer Network
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
PANAS	Positive and Negative Affect Schedule
PD	Peritoneal Dialysis
PIS	Participant Information Sheet
PPI	Patient and Public Involvement
RAG	Renal Advisory Group
RRT	Renal Replacement Therapy

EXECUTIVE SUMMARY

BACKGROUND

Patients with end stage renal disease (ESRD) typically experience frequent changes in health status, with significant impacts on employment, relationships and lifestyle. There is evidence of widespread lower-level emotional and psychological difficulties (‘mild to moderate distress’) in this patient group, which may be associated with decreased health-related quality of life, and poorer clinical outcomes. Although national renal guidelines mandate the provision of emotional and psychological support for patients with ESRD, there is evidence that there may be substantial unmet need for such support, with distress – defined as ‘difficulties adjusting to, and coping effectively with, renal failure, diagnosis, physical symptoms and treatment’ - often remaining unrecognised and untreated. There is little data about which patients may be distressed, or about the specific support that patients may need and want, and at which points in the ESRD pathway support may be targeted most effectively. We also have limited knowledge about the potential barriers and facilitators that may affect the ability of renal unit staff to identify and respond to patient distress.

AIMS AND OBJECTIVES

This study was designed to understand how the recognition and management of renal patients’ emotional and psychological difficulties can be integrated effectively into the ESRD pathway.

Specific objectives in relation to patients with ESRD were to:

- Identify any quantifiable differences in patient distress at different points in the ESRD pathway
- Explore patients’ needs, wants and expectations of support for distress
- Identify whether there are specific patient groups who may need or want more support than others
- Explore whether there are certain points along the ESRD pathway when it may be appropriate to screen patients for distress so that support can be offered
- Identify which potential interventions are likely to help most, for whom and in what circumstances.

Objectives for renal unit staff were to:

- Detail how distressed patients are currently identified and how support is provided
- Identify the factors that help or hinder staff in identifying and responding to patient distress
- Explore staff views about what support is required for patients and key points in the ESRD pathway when this support might be needed most
- Explore staff perceptions of the components of good support for distress and whose role it is to meet these needs
- Explore the interventions, tools, training and support that may be needed to improve how staff identify and respond to patient distress
- Identify and explain any differences and similarities between study sites.

METHODS

This mixed methods study combined quantitative data from renal patients and renal unit staff via cross-sectional surveys, and semi-structured interviews with a purposively sampled selection of patients and staff who had completed the survey.

Setting

Renal units at four NHS Trusts in the West Midlands were selected in order to achieve maximum geographical spread and ethnic diversity of the patient population, variation in Trust size, rural-urban mix, and in the organisation of emotional and psychological support services for renal patients. The patient survey and patient interviews were undertaken in all four study sites; the staff survey and interviews were undertaken in two study sites.

Patients

Eligible patients were aged 18 and over, with a diagnosis of Chronic Kidney Disease (CKD) stage 5, and at one of four stages of the ESRD pathway: i) diagnosed with CKD stage 5 and yet to begin RRT; ii) receiving hospital or home dialysis for less than two years; iii) receiving hospital or home dialysis for two or more years, or iv) with a functioning kidney transplant.

Patient data collection

Eligible patients were invited to complete a postal survey which incorporated a number of validated measures to assess different aspects of distress and emotional adjustment. Distress was measured using the Distress Thermometer (DT) and Emotion Thermometers (ET), which scored emotional upset across five domains: distress, anxiety, depression, anger and perceived need for help. The survey also included the Distress Thermometer Problem List which measured the recent experience of specific practical, family, emotional, spiritual and physical problems. Patient adjustment to emotional stressors was measured using the Positive and Negative Affect Schedule (PANAS), and information was also collected on recent events that had caused distress; patients' perceptions of their ability to cope with their illness and treatment; satisfaction with renal unit support, and views about the likely effectiveness of potential interventions to improve support. Semi-structured interviews were undertaken with a purposive, maximum diversity sample of patients who returned a survey. The topic guide explored issues relating to distress, coping, adjustment and support and patients' experience of emotional support offered by staff within their renal unit.

Staff

All renal unit staff in two participating sites working with patients at any stage of the ESRD pathway or who had a renal managerial role were invited to complete an electronic survey. The survey focused on respondents' perceptions of the prevalence of distress in patients with ESRD; the benefits of identifying and responding to distressed patients; the extent to which providing emotional and psychological support for distressed patients was considered part of the respondents' current role, and how skilled, confident and well-trained staff felt in identifying and responding to patient distress. Semi-structured interviews with a purposively selected sample of staff explored key issues relating to staff attitudes, perceptions and perspectives in relation to patient distress; how barriers to staff identifying and responding to patient distress could be overcome, and how appropriate changes could be implemented within renal units.

Analysis and synthesis

Patients were assigned to one of three distress groups (none to low, mild to moderate, severe) according to their scores on the DT and ET. Patients who scored between 4 and 7 on the DT or between 0 to 3 on the DT and between 4 to 7 on one or more of the ET were assigned to the mild to moderate distress group. All survey responses from patients and staff were analysed using descriptive statistics. Interview data were analysed thematically, and all findings were synthesised to triangulate themes across the multiple data sources, so that the key messages from the study could be determined.

RESULTS

Study participants - patients

The response rate to the patient survey was 27.9% (1040/3730 surveys returned), ranging from 23.0% to 30.4% across participating study sites. The majority of respondents were male (n=635; 60.9%) and in the white ethnic group (n=902; 86.7%). Patients aged between 51 and 69 years old constituted the largest age group (n=441; 42.9%). Nearly two fifths of respondents had received a transplant (n=404; 38.8%) and 28.8% had been on dialysis for two or more years (n=300). Of the 454 patients undergoing regular dialysis treatment, the most common modality was hospital haemodialysis (n=343; 75.6%). A total of 46 interviews were undertaken with patients.

Study participants - staff

The staff survey response rate was 35.2% (108/307 surveys returned). Nursing staff comprised almost 60% of respondents, with a further 14.8% of responses from doctors. Most respondents were female, and had been performing their current role for 10 or more years. Most respondents (64.8%) reported direct contact with renal patients every working day. Semi-structured interviews were carried out with 31 staff.

HEADLINE STUDY FINDINGS

Mild to moderate distress is common in patients with ESRD

The prevalence of patient distress was 33.3% (346/1040). Prevalence was highest in patients who had been on dialysis for less than two years (35.7%), and for those on dialysis for two or more years (36.3%). It was lowest in transplant patients (29.2%). Amongst dialysis patients, prevalence was highest in the home haemodialysis group (41.9%), although the absolute number of patients was small. Distress was strongly associated with sociodemographic characteristics – patients aged below 50, female patients, and patients from black and minority ethnic (BME) backgrounds were significantly more likely to experience distress than those in older age groups, males and patients of white ethnicity.

Distress impacts negatively on patient quality of life and wellbeing

As well as physical problems, emotional problems such as ‘worry’, ‘sadness’ and ‘depression’ were commonly reported. Interview participants frequently described the burden of ESRD, described a sense of losing their individuality, and noted the difficulties experienced in dealing with the need to modify their lifestyle to accommodate the restrictions imposed by their condition and its treatment.

Who will be distressed and when is unpredictable

The incidence and consequences of distress are determined by a complex interplay between sociodemographic, treatment-related and individual coping resources/resilience. Specific transitional points in the ESRD pathway may generate particular stressors, such as ESRD diagnosis or initiation of dialysis treatment, but adjustment to ESRD is a dynamic and constant process, and distress may affect any patient at any time. Most patients noted that they attempted to maintain a positive attitude towards their condition, yet in both the qualitative and quantitative data, many patients reported mixed feelings about their ability to cope, fear over the possibility that their condition and distress would worsen over time, and nervousness about the future. These fears were particularly pertinent for younger patients and those from BME groups.

Patients want help from the renal unit, and specific patient groups expressed a particular need for support

Not all patients with ESRD are distressed; not all distressed patients want support, and not all distressed patients who want support necessarily want this to be provided by their renal unit. However, younger patients, females, patients from BME groups and those who had recently begun dialysis treatment expressed a particular need for support.

Patients may be reluctant to disclose distress

Many patients reported that they avoided disclosing information about distress so as not to burden healthcare staff who were often perceived as being under stress themselves, too busy carrying out clinical tasks, or with limited time to discuss emotional issues. Some patients also felt that talking about emotions with staff was difficult due to a perception that staff may not understand their situation or may lack the relevant skills to handle the issues raised. Many believed that the culture of the renal unit, in which a positive, cheerful atmosphere was deliberately created by staff, inhibited discussions about distress, as the renal unit was seen as 'not the place' in which such discussions were appropriate.

Staff may find patient distress difficult to recognise

Staff respondents recognised that providing emotional support to patients should be part of high quality care and had intrinsic value. However, healthcare professionals may be relatively poor at recognising the signs of distress in their patients, especially when patients normalise their feelings or go out of their way to 'bottle them up'. Key barriers to renal staff being able to identify distress were related to:

- *Renal unit organisation*: Identifying distress often depended on individual staff members' skills, personality and individual approach to patients, rather than emotional support being considered an integral part of ESRD care.

- *Time*: Heavy workloads and the need to prioritise clinical rather than emotional issues were noted by some staff as barriers to discussing distress with patients.

- *Training and skills*: Staff who had received training in how to handle distressed patients were more likely to feel that this was part of their role, and these staff members typically reported a greater level of confidence in being able to manage patient distress effectively. Other staff members who had not developed key skills often described being less able to recognise and interpret non-verbal signs of distress; not knowing how to ask patients about their emotions, and feeling unable to 'contain' distress so that dealing with a distressed patient did not take up a disproportionate amount of time.

- *Perceptions of responsibility*: Although many staff considered identifying and responding to patient distress as being part of everyone's role in the renal unit (including non-clinical staff), they recognised that this was often not the case in practice. Some staff felt that dealing with distressed patients was the responsibility of staff members with specialist skills, or that it was optional, based on an individual's interests and personal inclination to include this in their role. Staff fell broadly into three groups:

    - '**Enthusiasts**' who thought that identifying and responding to patient distress was an intrinsic part of their role and who had developed the skills and confidence to do so through experience;
    - **'Equivocators**' who considered managing patient distress to be part of their role in theory, but in practice felt that they were lacking in skills and confidence to do this effectively, and
    - **'Avoiders'** who thought that dealing with patient distress was a key element of *care*, but who did not see this as part of their own *role*. These staff actively avoided the issue of distress with patients and prioritised clinical care over emotional wellbeing.

Staff may lack the capacity and capability to provide appropriate support

Even if renal unit staff do identify distress in their patients, they may lack the capacity and capability to provide appropriate support. Staff may feel that they lack the necessary training and skills to facilitate the provision of support, or that support services are not organised to allow immediate access.

- *Training and skills:* Some staff felt that emotional issues were often too complex, taking a significant amount of time to discuss and resolve. There was also a perception that a specialist skill set was required - some staff found it difficult to get to the root of the causes of patient distress, or to gauge the kind of response that should be offered. A lack of training and skills was often cited by staff as a reason for avoiding the proactive identification of patient distress for fear that the ‘floodgates would open’, without the possibility of providing acceptable or appropriate support. There was also a suggestion that patients and staff may differ in what they consider ‘support’ to entail: clinical staff are typically trained to offer a solution to a given problem, and many felt an expectation from patients that distress should be managed in the same way. However, patient interview data showed that those who disclose emotional issues to staff may not necessarily be seeking a solution, but simply want to be listened to by an empathetic and sympathetic member of renal unit staff.

- *Organisation of, and access to support services:* Onward referral to renal psychologists, counselling, or community services was seen as challenging given the need to wait for referrals to be processed and for appointments to become available. This was seen as particularly problematic given that many patients wanted immediate support at the time of need. The formality of support options was also seen as important: there was a sense from many patients that referral to formal psychological services could be stigmatising, since formalising support also formalises distress. Indeed, patients were most likely to report that discussing emotional issues during face-to-face meetings with renal doctors or nurses were their preferred support options. Thus, having a wider range of less formalised options for managing distress may be effective and acceptable to patients.

IMPLICATIONS AND RECOMMENDATIONS

A single intervention is unlikely to be effective: patient distress often has complex roots and influences, and staff experience numerous challenges in being able to identify distress and respond effectively. These complex and inter-related issues suggest that modifications to service organisation and delivery would need to be multi-faceted, and encompass changes at both the organisational (unit) and individual (staff) levels.

1. Patient education should be offered throughout the ESRD pathway: Participants frequently reported a desire for support to be available on an ongoing basis, and there is scope for improved education about the distress that patients may experience at different stages of the ESRD pathway. Patient education typically stops after the successful initiation of dialysis treatment, yet there may be scope for continuing patient education throughout the ESRD pathway, even after transplantation.

2. Patient education should fully explain the potential for patients to experience distress: Effective education may entail the provision of practical, factual information about treatments, prognosis etc. and signposting to the full range of support services that may be available. There is also scope for modifying patient education to become more effective in managing patients’ expectations about the distress they may experience as their condition and treatment progresses.

3. Building patient resilience and coping should be central to the support offered: In most cases, a key goal of support offered to patients should be to equip them better to cope with the distress they may experience. Building emotional resilience and coping mechanisms into pre-RRT education and into education at other stages of the pathway could help patients to develop coping skills, build healthy emotional responses and establish balance. Educational drop-in sessions on building resilience and coping could be offered periodically by renal psychologists, counsellors or specialist nurses and would offer the additional benefit of ‘normalising’ discussions about distress.

4. All renal staff should be given training in how to identify and manage patient distress: The overall goal of training would be to facilitate both the *proactive* identification of patient distress, and the appropriate *reactive* skills once distress was identified. Having visible senior leadership behind any changes to training and skills development would be beneficial, as would the formalisation of emotional support provision into the renal pathway at the renal unit level. The greatest potential for rapid progress may come through offering training interventions initially on a targeted basis to the ‘equivocators’, who feel that managing distress should be integral to their role, but who feel they lack the skills and confidence to do so effectively. A tailored approach to building communication skills may be particularly helpful, depending on staff role. For example, given consultants’ concerns that they do not routinely have time to respond to patient distress, it could be useful to prioritise training about how to time-limit distress-related conversations with patients so that clinical care is not compromised. For staff working in dialysis units, training which focuses on developing simple techniques for encouraging patients to open up about their distress may be useful.

5. Emotional support should be made available to renal staff: It is important to ensure that a greater emphasis on renal staff taking a proactive role in identifying and managing patient distress is not associated with a greater incidence of staff burnout or ‘compassion fatigue’. Evidence from oncology settings suggests some benefit to staff from the provision of emotional support based on regular group meetings or peer support groups to enhance personal coping resources, or the use of mindfulness approaches.

6. Immediately accessible support options should be made available to patients: Staff training in identifying and handling patient distress ‘in the moment’ through empathy and sympathetic listening may be effective in the short-term for many patients, particularly as patients often reported that they did not necessarily want a solution to their problems but may simply want to unburden themselves of their emotional issues. For patients who need further information or onward referral, it is important that a series of options are available and that renal units have appropriate pathways in place so that patients can be referred or signposted to additional support. This relies on staff members having clear, practical information about distress that they can pass on to patients. Renal units could provide drop-in sessions and in-house emotional support services that can be immediately accessed rather than requiring formal referral. Such services might comprise the provision of information emotional support to patients at the time of need, provided by embedded specialist nurses with counselling expertise.

7. Renal unit culture change: The recommendations described amount to a recommendation for a change to renal unit culture to ensure that distress is discussed routinely with patients, who are encouraged to seek help and to develop appropriate coping skills. Culture change is thus necessary both to support the introduction of other recommendations that make the identification and management of patient distress more central to renal unit activities, and to create an environment for patients and staff where talking about distress is normalised and emotional support valued.

CONCLUSIONS

This large, multi-site study is the first to explore the prevalence of mild to moderate distress in patients with ESRD. Our findings show that mild to moderate distress is common and there are potentially substantial unmet support needs within the ESRD patient population, with younger patients, females, and patients from BME communities particularly affected. Effectively identifying and responding to patient distress requires changes to renal unit organisation and to the way that individual staff manage their patients. There is unlikely to be any single intervention that can support patients with distress – its incidence is largely unpredictable and its duration uncertain. Further research must determine which combination of renal unit, renal staff and patient-focused interventions may be the most effective in optimising the identification and management of mild to moderate distress in patients with ESRD.

1. INTRODUCTION AND OVERVIEW

1.1 BACKGROUND

At the end of 2016, there were 51,672 patients with end stage renal disease (ESRD) receiving renal replacement therapy (RRT) in England.[1] Treatment is life-sustaining but not curative, and patients diagnosed with ESRD must undergo a constant process of adjustment as they face frequent changes to their health status and likelihood of survival.[2,3] Consequently, patients can experience numerous emotional and psychological stressors, related to acceptance of diagnosis, disease progression, choosing treatment options, coping with treatment, and the associated impacts on employment, relationships and lifestyle.[4-7]

The prevalence of depression and anxiety in patients with chronic conditions is known to be high,[7] and evidence suggests that patients with ESRD experience rates of depression and anxiety markedly higher than the general population.[8,9] Establishing prevalence is challenging, partly because uraemic symptoms can be misinterpreted as symptoms of depression,[10] and partly due to the variation in prevalence estimates obtained using different diagnostic tools, thresholds for identification and modes of assessment (e.g. self-reported vs. interview-based rating scales).[11,12] Consequently, depression and anxiety prevalence estimates reported in the ESRD literature range from around 6% to 71%,[13] but are generally considered to be between 20% to 30% for dialysis patients,[14] and around 25% for transplant patients.[15] This compares to estimates of 18 to 35% for patients with type 2 diabetes,[16] 20 to 50% for patients with cancer,[17,18] and 20% for patients with COPD.[19] This in turn compares with an estimated point prevalence of depression of between 2% and 9%,[20] and lifetime depression risk of around 7% in the general population.[21]

Untreated anxiety and depression in patients with ESRD are associated with decreased health-related quality of life and higher symptom burden.[12,22] These factors may raise the risk of poor outcomes, including increased healthcare resource use and impaired ability to adhere to diet and medication regimes.[23-25] There is some evidence of depression in renal patients being associated with non-adherence with dialysis treatment,[26] but the link is unclear and appears to be related to some aspects of non-adherent behaviour but not all.[20,27] Some studies have also found an association between depression and an increased likelihood of withdrawal from dialysis.[13,28,29] There is also evidence that depression status is associated with an elevated risk of all-cause mortality in renal patients, with meta-analysis suggesting an excess mortality risk attributable to depression higher than that observed in other chronic conditions such as cancer, diabetes and cardiovascular disease.[11,30]

Support for patients who experience emotional and psychological difficulties is central to the recommended management of long term conditions in general,[31] and for renal disease specifically.[32] National healthcare policy increasingly emphasises that mental health should have parity with physical health,[33,34] and both the Department of Health (DH) and National Institute for Health and Care Excellence (NICE) mandate the provision of emotional and psychological support within their national renal guidelines.[35,36] Patients with ESRD have also been found to regard support for emotional difficulties as an essential component of effective healthcare delivery.[37] However, whilst supportive services are relatively advanced for those with higher level needs that may require psychiatric or psychological intervention, there is a lack of robust information on the prevalence of lower-level support needs – defined as “difficulties adjusting to, and coping effectively with, renal failure, diagnosis, physical symptoms and treatment”.[38] These needs may consequently remain unrecognised and untreated.[39,40] This is particularly problematic given that lower-level problems may be associated with reduced ability to engage with pre-RRT education and treatment choices.[41,42]

It may also be useful to broaden focus beyond narrowly-defined anxiety and depression, to a consideration of the determinants and consequences of more general emotional and psychological difficulty encompassed by the term ‘distress’, which covers a range of issues related to physical and psychosocial wellbeing. The National Comprehensive Cancer Network (NCCN) define distress as “a multifactorial, unpleasant emotional experience of a psychosocial, social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling such as depression, anxiety, panic and social isolation”.[43] Although this definition was developed in relation to cancer patients, the concept of distress which underpins it is highly relevant to renal patients, and it has been argued that less severe forms of anxiety and depression covered by the term ‘distress’ may be associated with similar impacts to those seen in major depression.[44] There is also a lack of understanding about what support may be required, by whom, and when in the ESRD pathway. Whilst a linear progression from lower-level needs to more severe difficulty is not inevitable, timely identification of distress in renal patients may allow effective management to be put in place.

As well as a lack of information about the support that patients may require from renal services to manage distress, there is limited evidence about the factors that may help or hinder renal staff in identifying and responding to patient distress. Clearly, existing barriers at the renal unit or individual staff level that prevent staff from being able to identify and manage patient distress would need to be overcome if appropriate interventions are to be developed and targeted towards patients for whom support needs are greatest. There is some evidence that renal unit staff find it hard to recognise patient distress.[29,30,45] Studies with staff treating patients with cancer suggest that patients tend not to spontaneously express emotional concerns in clinics,[18,46] and with limited time for patient contact during consultations, doctors may be reluctant to raise emotional issues, focusing instead on biomedical and clinical concerns.[47,48]

Staff such as nurses and healthcare assistants (HCAs) may be particularly well placed to provide emotional and psychological support, as they may develop close relationships with patients, often over a number of years. This is particularly so for nurses and HCAs working with dialysis patients, where anecdotal evidence suggests that a focus on the technical aspects of dialysis may be an important barrier to identifying and managing patient distress.[49] It is likely that barriers and facilitators of renal unit/staff response to patient distress are affected by issues such as staff education and training in delivering emotional and psychological support,[50] perceived role and capacity, confidence, time, knowledge about options for onward referral of distressed patients, and the degree to which managing distress is considered by an individual to be their own responsibility, or primarily the responsibility of others.

Thus, there is strong evidence that there may be substantial unmet need for emotional and psychological support amongst patients with ESRD, which may give rise to a number of negative impacts on health and wellbeing. Building on the existing evidence, this study was designed to understand how the recognition and management of renal patients’ emotional and psychological difficulties can be integrated effectively into the ESRD pathway.[51]

1.2 AIM AND OBJECTIVES

The overarching aims of the study were to measure the prevalence of mild to moderate distress in patients with ESRD and understand how distress may differ for patients at different stages in the ESRD pathway; to develop an in-depth understanding of the support that patients with ESRD need, want and expect, and to understand the factors that may help or hinder renal staff in identifying and responding to patients with ESRD who have mild to moderate distress.

Specific objectives in relation to patients with ESRD were to:

- Identify whether there are quantifiable differences in the levels of distress experienced by patients at different points in the ESRD pathway
- Explore patients' needs, wants and expectations of support for distress
- Identify whether there are specific patient groups who may need or want more support than others
- Explore whether there are certain points along the ESRD pathway when it may be appropriate to screen patients for distress so that appropriate support can be offered
- Identify which potential support interventions are likely to help most, for whom and in what circumstances.

A further series of objectives was specified in relation to renal unit staff and the organisation of renal services, aiming to:

- Detail how patients with mild to moderate distress are currently identified and how support is provided (both within and outside of the renal unit)
- Identify the factors that help or hinder staff in identifying and responding to patient distress
- Explore staff views about what support is required for patients and key points in the ESRD pathway when this support might be needed most
- Explore what staff think are the components of good support for mild to moderate distress and whose role it is to meet these needs
- Explore the interventions, tools, training and support that may be needed to improve how staff identify and respond to patient distress
- Identify and explain any differences and similarities between study sites, including how local context influences practice.

1.3 STUDY MANAGEMENT AND OVERSIGHT

The research team undertaking the study met regularly to discuss progress and to resolve any issues that arose during data collection or analysis. A Renal Advisory Group (RAG) was also formed, bringing together relevant patient, clinical and academic expertise from a variety of disciplines. The role of the RAG was to ensure that the research delivered high quality outputs of relevance to the future support of patients with ESRD who have mild to moderate distress.

The RAG met regularly throughout the study period and provided feedback on interim research findings once analysis was complete. Group members included a patient and public involvement (PPI) representative; renal clinical leads from the four participating NHS Trusts; a renal clinical psychologist; a renal matron; a pre-dialysis nurse, and a Professor of Nursing. All study researchers attended each advisory group meeting.

1.4 PATIENT AND PUBLIC INVOLVEMENT

The study was driven from an early stage by patient views about the priority research areas for supporting the emotional wellbeing of patients with ESRD. A PPI reference group was set up at the start of the study, which met at key stages to contribute perspectives on study documentation (participant information sheets, consent forms, survey design and interview topic guides), and feedback on emerging and final research findings. The research team also worked closely with the PPI forum of the CLAHRC West Midlands chronic disease theme to obtain feedback about study design, data collection and collation of research results for wider dissemination.

1.5 REPORT STRUCTURE

The remainder of this report will outline the methodology for the study (Chapter 2), followed by three chapters outlining the quantitative findings. Chapter 3 reports the results from analysis of the patient survey, and Chapter 4 reports the results from analysis of the renal staff survey. Chapter 5 provides a brief summary of the overall findings from the quantitative element of the research. Chapters 6 and 7 report the qualitative findings: Chapter 6 outlines the results from analysis of the patient interviews, and Chapter 7 reports the results from the renal staff interviews. The report finishes with Chapter 8, which synthesises the findings from the quantitative and qualitative elements of the study, discusses the implications for healthcare providers and renal units, and outlines some potential areas for future research.

2. METHODS

2.1 OVERVIEW OF METHODS

This study used a mixed methods design combining qualitative and quantitative data collection. Quantitative data were collected from renal patients and renal unit staff via surveys; qualitative data collection focused on semi-structured interviews with a purposively sampled selection of patients and staff who had completed a survey. Once the qualitative and quantitative results had been analysed independently, interpretative synthesis allowed triangulation of findings across multiple data sources in order to identify key themes and their implications for the identification and management of mild to moderate distress in patients with ESRD.

2.2 STUDY SETTING

Two NHS Trusts in the West Midlands were initially selected to participate in both the patient and staff studies (sites 1 and 2). Interim analysis of the patient survey data from sites 1 and 2 showed a number of potentially important findings that the research team felt should be explored in greater depth. As the sample size (and study power) was not sufficient for this in-depth analysis using the surveys received from patients at sites 1 and 2, two additional NHS Trusts were recruited and the patient survey and semi-structured interviews were expanded to these sites. The work with renal unit staff was undertaken at sites 1 and 2 only. Sites were selected in order to achieve maximum geographical spread and ethnic diversity of the patient population, variation in Trust size and in how emotional and psychological support services were organised, and rural-urban mix (Table 2.1).

Table 2.1: Characteristics of participating study sites

Site	Psychological support	Catchment	Geography	Patient population
1	No renal psychologist	Large	Urban, inner city	Large BME* population
2	Renal psychologist	Small	Urban, inner city	Large BME population
3	No renal psychologist	Medium	Urban with surrounding rural districts	Predominantly white population
4	Renal psychologist	Large	Urban with surrounding rural districts	Predominantly white population

* BME – black and minority ethnic

2.3 ETHICAL APPROVALS

The study was sponsored by University of Birmingham. Ethical approval was obtained from the West Midlands (Coventry and Warwickshire) Research Ethics Committee in October 2015 (Ref: 15/WM/0288), and by the Health Research Authority (HRA) in August 2016. Approval was also obtained from the research governance office of each participating NHS Trust.

2.4 RENAL PATIENTS

2.4.1 Inclusion and exclusion criteria

Eligible patients were aged 18 and over, being treated at one of the participating study sites, with a diagnosis of Chronic Kidney Disease (CKD) stage 5 (eGFR <15), and at one of four stages of the ESRD pathway:

1. Diagnosed with CKD stage 5 and yet to begin renal replacement therapy (RRT)

2. On dialysis (hospital haemodialysis – HD, peritoneal dialysis – PD, home haemodialysis – HHD) for less than two years
3. On dialysis (HD, PD or HHD) for two or more years
4. With a functioning kidney transplant

Although distinguishing between patients on the basis of length of time on dialysis is not a recognised clinical distinction within the ESRD pathway, it was hypothesised that there may be differences in the prevalence of mild to moderate distress between patients who had begun dialysis more recently compared to those with a longer history of dialysis treatment, as patients in the latter group may have had more time to adjust to the transition.

Patients were excluded from participating in the study if they were cognitively impaired, were known to have had contact with psychiatric services (including seeing a psychiatrist) since their diagnosis with CKD stage 5, or were being managed conservatively.

2.4.2 Patient survey

Survey aims

The patient survey was cross-sectional, and aimed to assess the prevalence of mild to moderate distress across the patient cohort; to determine the association between distress and sociodemographic and clinical characteristics; to assess patient perceptions of the way that their distress is currently managed (by themselves and by staff in their renal unit), and to determine the extent to which each of a series of pre-specified interventions to manage distress were considered potentially acceptable to survey respondents.

Survey design and piloting

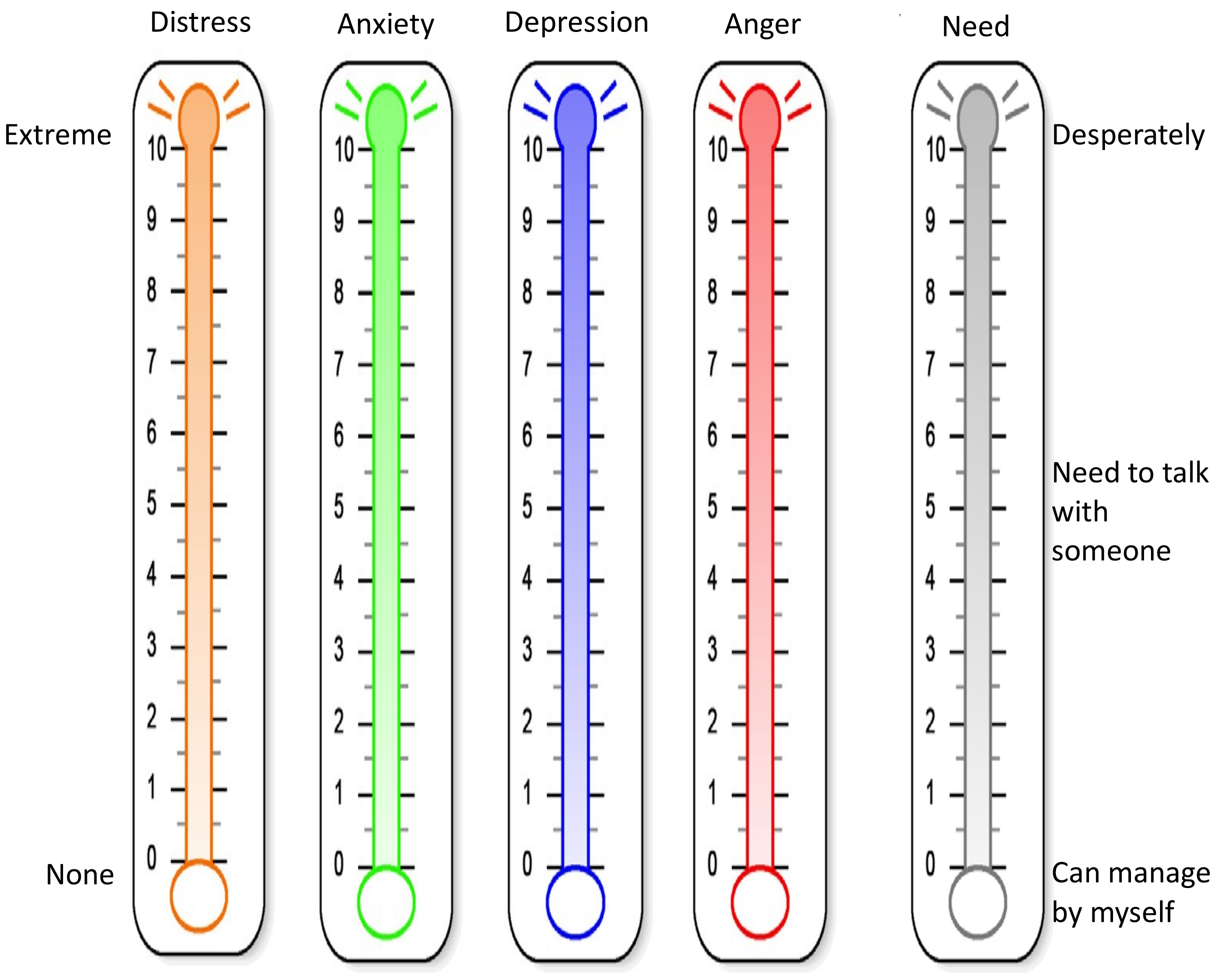
The survey was designed by study researchers, in consultation with the study RAG and patient representatives. The draft survey was piloted for readability and comprehension with five members of the renal PPI advisory group, and several CLAHRC chronic disease theme PPI advisors were also consulted. On the basis of their feedback, a number of changes were made to question order and wording.

Validated measures

The survey incorporated a number of validated measures to assess different aspects of emotional distress and adjustment to emotional stressors. The primary means of measuring distress was the Distress Thermometer (DT),[43] incorporated within the Emotion Thermometers (ET).[52,53] A literature review at the study design stage showed that few validated tools exist for measuring mild to moderate emotional and psychological difficulty, either among patients with ESRD or patients with chronic conditions in general. Existing studies have typically used validated instruments designed to measure anxiety and depression such as the Hospital Anxiety and Depression Score (HADS) or the Beck Depression Inventory (BDI), looking for scores below the thresholds set for detecting clinical anxiety or depression. HADS and the BDI are in widespread use and have been validated for use with renal patients, yet they were considered too limited in scope – restricting lower-level emotional issues only to those linked with lower-level anxiety and depression. In contrast, the ET allows the broader measurement of emotional and psychological difficulty deemed more appropriate to this study, and has the potential to identify a greater proportion of people with broadly defined emotional difficulties who may otherwise remain undetected with the application of tools like HADS or the BDI.[52]

The Emotion Thermometers use a visual analogue scale covering five domains: distress, anxiety, depression, anger and perceived need for help. Patients score each domain on an 11-point (0 to 10) Likert scale to rate how much emotional upset they have experienced during the preceding week, where ‘0’ corresponds to none and ‘10’ denotes extreme problems (Figure 2.1). In combining multiple dimensions of emotional and psychological difficulty, the ET has shown greater sensitivity in previous studies than the distress thermometer (DT) alone in identifying emotional concerns, since these may not be fully captured solely using the concept of distress.[52] For example, in a study with cancer patients, the DT alone was found to identify only 54% of cancer patients who recorded emotional difficulties using the ET, and 51% of patients who scored below the threshold for distress using the DT recorded emotional difficulties on the ET.[52] The ET typically has low non-completion rates (around 4%),[53] and the visual analogue scale is appropriate for people with language difficulties.

Figure 2.1: The Emotion Thermometers as used in the patient survey



Alongside the ET, the survey included the Distress Thermometer Problem List (DTPL).[54] This has been validated in the UK renal population,[55] and lists 36 problems across five domains: practical (n=5 e.g. childcare, transport), family (n=3 e.g. dealing with family/children), emotional (n=6 e.g. worry, sadness), spiritual (n=1) and physical (n=21 e.g. pain, fatigue). Patients were asked to indicate which (if any) of the 36 problems they had experienced in the previous week.

Patient adjustment to emotional stressors was measured using the Positive and Negative Affect Schedule (PANAS).[56] The PANAS is a 20-item self-report measure that has been widely used with patients with chronic diseases and in some renal populations[57] to measure positive and negative affect. Positive affect reflects the extent to which a patient feels enthusiastic, active and alert, whilst negative affect assesses subjective distress and discomfort. Each item on the PANAS represents a single emotion (e.g. ‘interested’, ‘upset’, ‘excited’), and respondents indicate on a 5-point scale (‘very slightly or not at all’, ‘a little’, ‘moderately’, ‘quite a bit’ or ‘extremely’) the extent to which they have felt that way during a specific time period – in this case, ‘during the last week’.

Other survey questions

In addition to the validated measures, the survey also collected information on recent events that had caused distress (in the last week and over the last two months); patients’ perceptions of their ability to cope with their illness and treatment; the extent to which they felt supported by renal staff; satisfaction with renal staff support, and perceptions about the degree to which patients felt that a series of potential interventions to improve support (e.g. online training courses, physical activity programmes, time to discuss emotional feelings with nurses/consultants) would be helpful. Most of these questions used an 11-point (0 to 10) Likert scale for responses. Closed questions recorded information on sociodemographic (age, gender, ethnic group) and clinical characteristics (dialysis modality – where relevant, time since diagnosis with CKD stage 5), and patients were given the opportunity to add any further comments by writing them in a free text box at the end of the survey. Finally, patients were asked if they were willing to participate in a further individual face-to-face or telephone interview, and if so, to provide their contact details. In total, survey completion was estimated to take around 20 minutes.

2.4.3 Patient recruitment for survey

All eligible patients across the four participating NHS Trusts were invited to complete a survey, which was sent by post to their home address. As far as possible, the patient identification and survey mailing process was consistent across sites, although there were some minor variations between sites due to local preferences for organising survey distribution.

Renal unit staff at each Trust identified eligible patients from hospital records. Lists were checked 24 hours before the survey mailing to ensure that recently deceased patients were not contacted, and survey packs were prepared on Trust premises by the University research team. Eligible patients received a letter of invitation from the lead consultant at their renal unit, a participant information sheet (PIS), and a survey, to be returned to University of Birmingham in a FREEPOST envelope. The PIS gave information about the study and explained to patients what participation would involve. As well as assuring patient confidentiality, the PIS provided contact details for appropriate clinical staff within their renal unit that patients could contact if they felt distressed or upset and would like support. In order to maintain patient anonymity, the research team marked each return envelope with a unique ID number when preparing survey packs for mailing. These ID numbers were recorded alongside each patient’s address details on the patient lists generated by renal unit staff at each site, and were kept securely at the renal unit throughout the period of data collection. Survey recipients who had not responded within 6-8 weeks of the initial mailing were sent one reminder survey pack. In order to increase the response rate, the study was promoted to patients through posters in the main renal unit and satellite units (at three study sites), and an article in the Kidney Patient Association newsletter (one study site).

Survey mailings were staggered across the participating Trusts, with the entire data collection period spanning a total of 17 months from January 2016 when the first mailing was undertaken for site 1, to May 2017 when the database was closed to new survey returns from the final two sites (Table 2.2).

Table 2.2: Timing of patient survey distribution by site

Site	Initial mailing	Reminder mailing	Database closure
1	January 2016	March 2016	May 2016
2	January 2016	March 2016	May 2016
3	November 2016	January 2017	May 2017
4	February 2017	March 2017	May 2017

2.4.4 Qualitative patient data

Sampling

In-depth, semi-structured interviews were undertaken with a purposive sample of patients who met the following inclusion criteria (additional to the survey inclusion criteria from section 2.4.1):

- Indicated willingness to be interviewed in their survey return
- Clinically stable and well enough to participate in an interview
- Capacity to give informed consent to participate in an interview
- Met the criteria for mild to moderate distress from their response to the emotion thermometers (scoring 4 to 7 on the DT regardless of scores in the other ET domains, or scoring from 0 to 3 on the DT and between 4 to 7 on one or more of the anxiety, depression and anger thermometers, with no individual thermometer exceeding a score of 7).

Patients who met the inclusion criteria were purposively sampled to provide maximum diversity by age, gender, ethnic group and ESRD pathway stage. The aim was to conduct ten interviews with patients at each pathway stage across sites 1 and 2 (n=40), or to continue until data saturation was achieved.

Recruitment

Patients selected following purposive sampling were contacted by a member of the research team to confirm their willingness to be interviewed and to record their preference for a face-to-face or telephone interview. After this initial contact, patients were sent a consent form and PIS which explained the purpose of the interview and what participation would involve. Patients were contacted again at least seven days after receiving the consent form and PIS so that a suitable date and time could be arranged for the interview to take place. Informed consent was taken over the telephone at the start of each telephone interview, or in person at the start of each face-to-face interview. Interviews followed a topic guide which allowed key issues to be explored without being too prescriptive about interview content and direction. All interviews were audio-recorded and independently transcribed by a professional transcriber, and transcripts were proof-read against the recordings to ensure reliability.

Topic guide

The interview topic guide was designed to explore issues related to distress, coping, adjustment and support:

- Experience of mild to moderate distress and support needs linked to patients' illness and/or treatment, when and for how long
- Whether and how emotional issues were recognised and supported by renal unit staff
- Views on how renal staff should support distressed patients
- What support had been offered, when and by whom
- Any support used, when and why and perceptions of the benefits/problems with this

- What support patients may want in future, when and from whom
- Views on key elements that could be included in an intervention.

The draft topic guide was reviewed by the renal PPI advisory group and the CLAHRC chronic disease theme PPI advisors. Following PPI feedback, changes were made to the question order and wording. The topic guide was further revised after the first eight interviews had been completed, to incorporated additional questions and prompts on key issues identified during early analysis of the data.

2.5 RENAL UNIT STAFF

All eligible renal unit staff at sites 1 and 2 were invited to complete a survey that focused on identifying and responding to distress in patients with ESRD and the degree to which they felt that this was part of their current role. Staff were eligible to receive the survey if they worked with patients at any stage of the ESRD pathway or had a renal managerial role, and had been employed by the Trust or a sub-contractor at one of the study sites for at least two months. Agency or bank staff were excluded.

2.5.1 Staff survey design

As with the patient survey, the survey for renal unit staff was designed following consultation with the study RAG and patient representatives. The draft questionnaire was piloted for readability and comprehension with four renal unit staff (two per site) and the CLAHRC chronic disease theme PPI group.

The survey aimed to gather staff views on a number of issues:

- The benefits of identifying and responding to renal patients with mild to moderate distress
- Perception of the proportion of patients with ESRD who are distressed
- Satisfaction with how the support needs of distressed patients are currently met
- The extent to which the identification of, and response to patient distress is considered part of the respondents' current role, and whether anybody else has/should have responsibility for this
- How skilled, confident and well trained staff feel in identifying and responding to patient distress
- Practical ideas about what would help in future to improve the identification and management of distress in patients with ESRD.

The survey took around 10 minutes to complete, with most questions using pre-specified answer options based on an 11-point (0 to 10) Likert scale. Open-ended questions towards the end of the survey allowed free-text responses to avoid missing any issues considered important by respondents that were not covered in the pre-specified answer options. Data were also collected on respondent age, gender, role, frequency of patient contact, length of time in post and since qualification, and receipt of training. Finally, respondents were asked to indicate on their survey return if they would be willing to participate in a subsequent telephone or face-to-face interview, and if so, to provide their contact details.

2.5.2 Staff recruitment for survey

The staff survey ran from February 2016 to May 2016 in both participating study sites (sites 1 and 2). Staff were invited to complete the survey in an email from their renal unit clinical lead. The email included a PIS explaining the reason for the study and what participation would involve, and an electronic web-link to access the questionnaire online. In addition to the email from the clinical lead, members of the research team attended staff meetings at each participating Trust and visited satellite units to publicise the study, answer questions and encourage participation. Two reminder emails were sent to staff by the clinical lead at each study site. Following initial low response rates to the electronic version of the survey, paper copies were distributed to renal staff working in hospital dialysis wards and satellite units who may have had limited access to computers. Survey packs included a PIS and reply-paid envelope to encourage survey return.

2.5.3 Qualitative staff data

Sampling and recruitment

Staff who met the inclusion criteria for the qualitative study and who expressed willingness to participate in an interview were purposively sampled to provide maximum variation in job roles and to ensure that similar numbers of staff would be interviewed at each site. Staff were contacted by a member of the research team to have their participation confirmed. They were asked whether they would prefer a face-to-face or telephone interview, and were sent a consent form and PIS explaining what the interview would involve. They were contacted again at least seven days after receiving the study documentation and a suitable date/time for the interview was arranged. Interviews were audio-recorded and independently transcribed by a professional transcriber, and transcripts were proof-read against the recordings to ensure reliability.

Topic guide

Interviews were in-depth and semi-structured, and followed a topic guide designed to explore key issues relating to staff attitudes, perceptions and perspectives of patient distress; to determine how barriers to staff identifying and responding to distress in patients with ESRD could be overcome, and how appropriate changes could be implemented. The topic guide covered the following areas:

- How distressed patients are identified and supported by the staff members/renal unit/Trust
- Perceptions of the individual/unit/Trust role in identifying and responding to distress
- What factors help or hinder support for distressed patients (perceived capacity, time available, referral options)
- Views on which patient groups need emotional and psychological support, at what points in the ESRD pathway and for how long
- Views on the components of good emotional and psychological support
- How skilled, confident and trained staff members feel in identifying and supporting distressed patients
- What needs to change or improve to enable better support for distressed patients (interventions, tools, resources, training)
- Views on how changes or improvements could best be facilitated and effectively implemented.

2.6 DATA ANALYSIS

2.6.1 Patient survey

Classifying patients by distress group

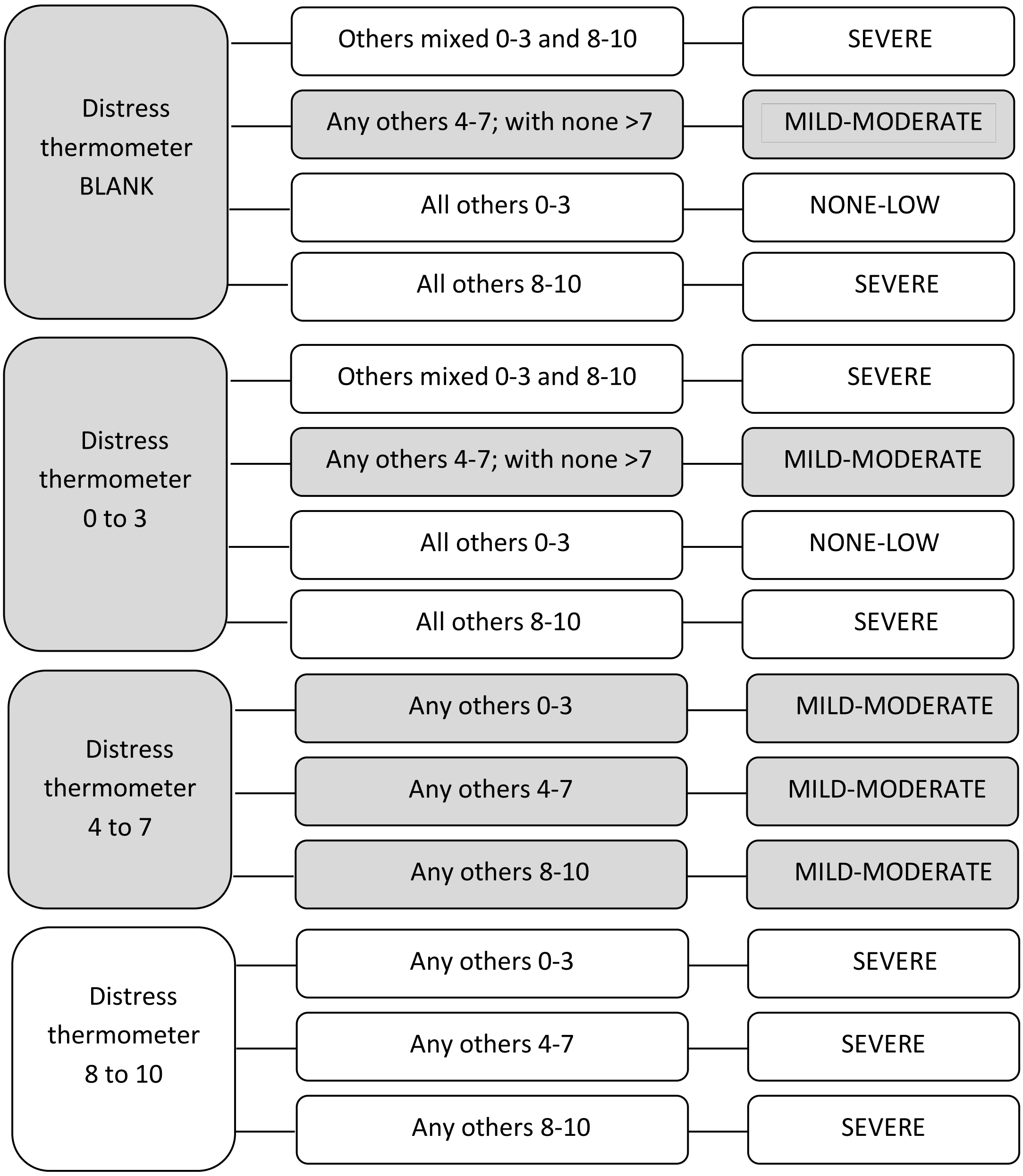
Thresholds for distress using the ET have been validated,[52,53,58] with a score of 4 to 5 denoting mild distress, and 6 to 7 denoting moderate distress. Patients were assigned to one of three distress groups (none to low, mild to moderate, severe) according to their scores on the distress, anxiety, depression and anger thermometers using a pre-specified algorithm (Figure 2.2). Patients were categorised as having mild to moderate distress if they:

a) Scored between 4 to 7 on the DT (regardless of scores in the other ET domains), or

b) Scored between 0 to 3 on the DT and between 4 to 7 on one or more of the anxiety, depression and anger thermometers, with no individual thermometer exceeding a score of 7.

The approach in point a) above will have classified a number of patients as having mild to moderate distress who scored above 7 on the anxiety, anger, and/or depression thermometers. This recognises that distress is the primary outcome measure for this study, so DT scores have been prioritised over those on the other thermometers. At the other end of the distress spectrum, it might be argued that the approach in point b) is biased towards capturing patients at the lower end of the distress scale. However, given the nature of the study, ensuring good sensitivity (the positive identification of patients with mild to moderate distress) was considered more important than good specificity (avoiding the misclassification of individuals with distress who do not actually have it). In this way, our method trades off the potential identification of false positives against the more important minimisation of false negatives. If patients had left the DT blank but had recorded a score on at least one of the other thermometers, they were assigned to the mild to moderate distress group if any of the ET domains were scored 4 to 7, with none exceeding 7.

Figure 2.2: Algorithm for determining patient distress group



The scoring algorithm omitted scores on the ‘need’ thermometer from the classification of distress group. It has been argued that need is a consequence of scores on the other thermometers, and therefore should be considered an outcome domain rather than a predictor domain.[52] By treating the need score separately in the analysis, this gave a standalone, objective measure of patients’ self-reported support needs. Analysis was descriptive and focused primarily on the patient group with mild to moderate distress, determining the association between mild to moderate distress and respondents’ sociodemographic characteristics and their stage on the ESRD pathway. Alongside analysis of the emotion thermometers, the prevalence of total and individual problems cited in the DT problem list was analysed descriptively, and medians and inter-quartile ranges (IQR) were calculated to compare the number of problems cited within each domain of the DT problem list (e.g. practical problems, physical problems).

PANAS

Positive and negative affect scores were calculated by scoring each of the ten positive emotions (attentive, interested, alert, excited, enthusiastic, inspired, proud, determined, strong, active) from 1 to 5 according to the degree to which respondents indicated these emotions had been felt in the previous week (1 = very slightly or not at all; 2 = a little; 3 = moderately; 4 = quite a bit, 5 = extremely), and giving a total positive affect score of between 10 to 50 for each patient, with higher scores denoting a more positive attitude. Each of the ten negative emotions (distressed, upset, hostile, irritable, scared, afraid, ashamed, guilty, nervous, jittery) were scored in the same way, giving a total negative affect score for each patient of between 10 and 50, with higher scores denoting a more negative attitude. Where one or more positive or negative emotions were left blank by a survey respondent, imputation was used to generate a score based on the answers that were given to the other emotions within the positive or negative domain, using the algorithm proposed by the instrument’s developers:[56]

10 / number of missing answers x the sum obtained from the answered items

Median positive and negative PANAS scores and inter-quartile ranges were calculated, and sub-group analysis compared medians across sociodemographic characteristics and for patients at each stage of the ESRD pathway.

Other analyses

Questions with answers based on Likert scales were analysed using medians and IQR, with comparison of medians tests assessing differences between sub-groups (e.g. gender, age group). The characteristics of respondents and non-respondents - for whom anonymised data were obtained from each study site’s hospital information systems – were compared using chi-squared tests. All data were analysed using SPSS (Version 21.0, Armonk, NY: IBM Corp).

Sample size

The primary outcome was the difference in the prevalence of mild to moderate distress for patients at different stages of the ESRD pathway. We anticipated an average prevalence of 25% across all patients,[14] but that patients in the pathway stages with the highest and lowest prevalence would be +/- 5 percentage points from this average (i.e. 20% for the stage with the lowest prevalence and 30% for the stage with the highest prevalence). This equated to a small effect size (w) of approximately 0.1. To detect this difference with 80% power and 5% significance, a total of 1090 survey responses was required (assuming approximately equal numbers of patients in each ESRD stage).

2.6.2 Staff survey

Analysis of survey returns from renal unit staff was descriptive given the comparatively small number of responses received (see Chapter 4). Response rates were calculated, along with chi-squared tests comparing respondents with non-respondents in terms of job role, for each study site separately and combined. Questions based on Likert scales were analysed using medians and IQR, with sub-group analyses (e.g. by study site, job role or training attainment) carried out where the sample size permitted this.

2.6.3 Qualitative data analysis

Thematic analysis[59] was used to analyse the data from both the patient and staff interviews. Two researchers independently analysed eight of the 46 patient transcripts and five of the 31 staff transcripts. Discussion of ordinate and subordinate nodes led to the development of a detailed coding structure that was then entered into NVivo software and the remaining transcripts were coded by one researcher. If any data did not fit into the coding structure, this was discussed among the researchers before any new nodes were added to the database. The first draft of the qualitative analysis was shared amongst all researchers and discussed to ensure that it accurately reflected the team’s understanding of the dataset.

After discussion, the research team decided to bolster some elements of the data analysis with a form of discourse analysis,[60] as some discursive elements of the data were found to be particularly interesting. In some instances, participants’ speech patterns changed when discussing themes that they were unsure about. To appropriately capture this data, elements of a discourse analysis methodology were integrated into the thematic analysis. It is important to note that this was a pragmatic choice of method derived from a data-driven analysis and not an epistemological comment on the data. Although it would have been interesting to subject the data to a full Foucauldian discourse analysis,[61] (particularly considering the intersectionality between patient and staff experience), this study was intended as a practical exploration of distress, its consequences and the implications for management.

2.7 DATA SYNTHESIS

Quantitative analysis of patient and staff surveys was carried out independently from qualitative analysis of patient and staff interviews, with different members of the research team conducting quantitative and qualitative analyses, each blinded to the other’s findings. After the separate quantitative and qualitative analyses were complete, a further stage of analysis interpreted and synthesised the findings in order to triangulate themes from multiple data sources, identify patterns, and determine plausible explanations for the observed findings. Synthesis was based on a series of detailed discussions within the research team, and was carried out iteratively, with additional analysis of specific elements of the survey or interview data carried out to clarify, discount or explain concordant or discordant findings so that the overall key messages from the research could be distilled.

3. RESULTS: PATIENT SURVEY

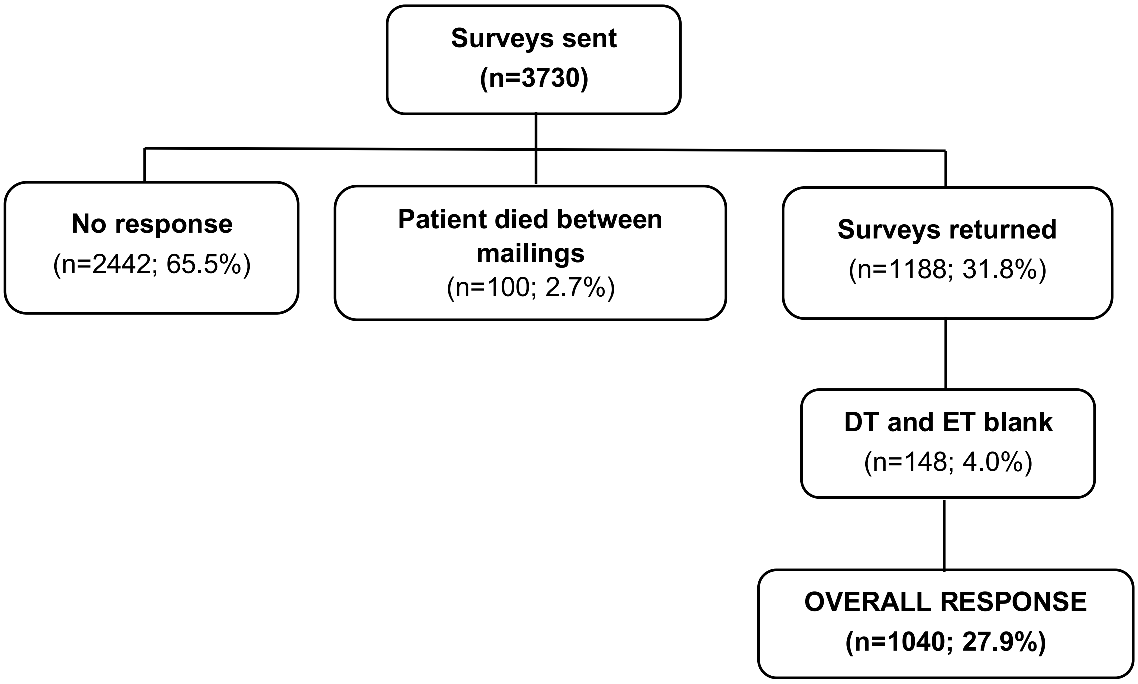
3.1 PATIENT SURVEY RESPONSE RATE

A total of 3730 surveys were sent across the four participating study sites. One hundred patients died between the initial and reminder mailings (2.7%) and a further 2442 recipients (65.5%) did not respond to either the initial or reminder mailing. Of the 1188 responses received (31.8%), 148 were removed from the sample due to non-completion of the ET (4.0%), giving a total of 1040 valid responses (27.9%) (Figure 3.1). Rates of valid responses ranged from 23.0% at site 1 to 30.4% at site 4 (Table 3.1).

Table 3.1: Patient survey responses by Trust

Site	Surveys sent	No response (%)	Patient died (%)	Returned (%)	Invalid return (%)	Valid response (%)
1	812	566 (69.7)	33 (4.1)	213 (26.2)	26 (3.2)	187 (23.0)
2	632	410 (64.9)	18 (2.8)	204 (32.3)	27 (4.3)	177 (28.0)
3	1123	714 (63.6)	40 (3.6)	369 (32.9)	46 (4.1)	323 (28.8)
4	1163	752 (64.7)	9 (0.8)	402 (34.6)	49 (4.2)	353 (30.4)

Figure 3.1: Patient survey response rate



Representativeness of sample

Comparison of proportions tests compared the characteristics of survey responders (according to age group, group, gender, ethnicity, ESRD stage and hospital site) against those who did not respond. Younger patients (<65 years old) were significantly less likely to respond than those aged 65 and over (X^2=20.19; p<0.0001), as were those from black and ethnic minority (BME) groups compared to those in the white ethnic group (X^2=60.24; p<0.0001). For ESRD stage, patients yet to begin RRT and those who had been on dialysis for less than two years were significantly less likely to respond than patients who had been undergoing dialysis for two or more years, or who had received a transplant (X^2=9.96; p=0.019). Patients from sites 3 and 4 were significantly more likely to respond than those in sites 1 and 2. There was no significant difference between responders and non-responders on the basis of gender (X^2=0.02; p=0.888) (Table 3.2).

Table 3.2: Characteristics of respondents vs. non-respondents

Characteristic	**Responders**	**Non-responders**	**Comparison of proportions**
Study site			
Site 1	187	625	**X^2=13.48; p=0.004**
Site 2	177	455	
Site 3	323	800	
Site 4	353	810	
ESRD stage			
Pre-RRT	183	560	**X^2=9.96; p=0.019**
Dialysis <2 years	162	481	
Dialysis 2+ years	293	684	
Transplant	402	965	
Gender			
Male	635	1636	X^2=0.02; p=0.888
Female	405	1054	
*Age group**			
<65 years old	503	1537	**X^2=20.19; p<0.0001**
65+ years old	524	1151	
*Ethnicity***			
White	596	1244	**X^2=60.24; p<0.0001**
BME	121	591	

* Age unknown for 13 responders and 2 non-responders; ** Ethnicity unknown for 280 patients at site 3 – analysis based on data from sites 1, 2 and 4 only. Bold text indicates statistical significance at p<0.05

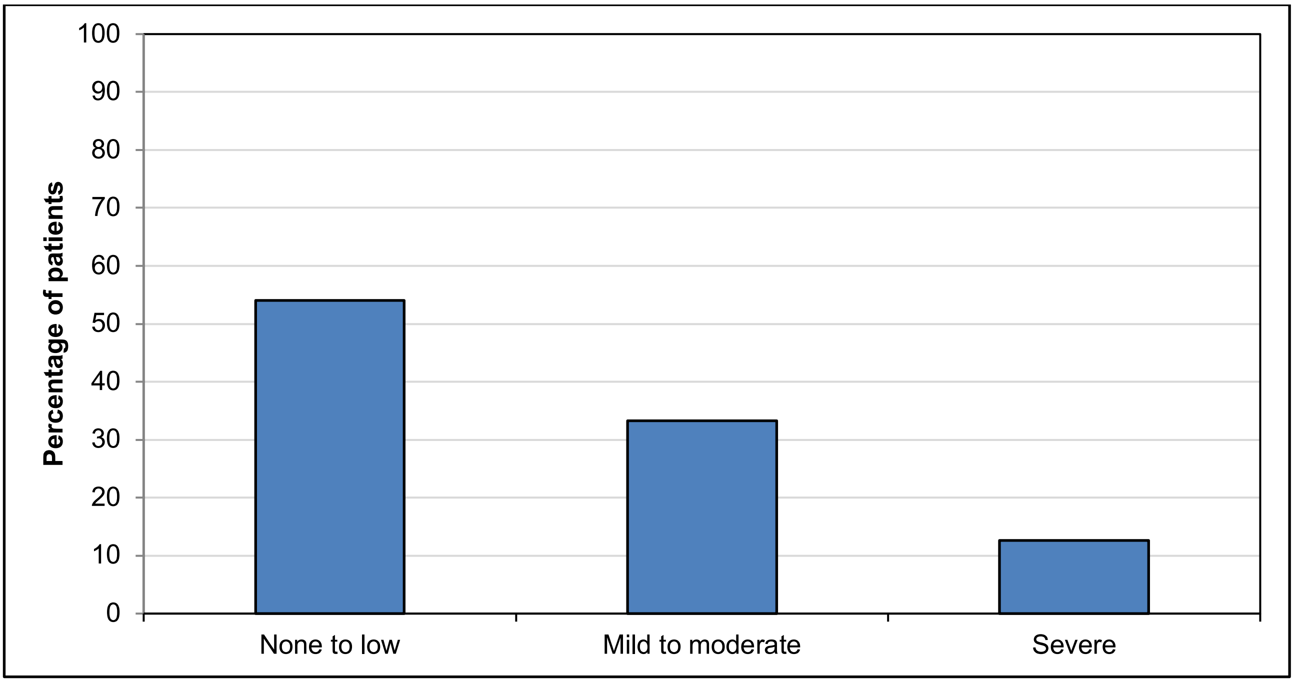
Characteristics of respondents

The majority of respondents were male (n=635; 60.9%) and in the white ethnic group (n=902; 86.7%). Patients aged between 51 and 69 years old constituted the largest age group (n=441; 42.9%), with those aged under 50 comprising 16.9% of the total (n=174). Nearly two fifths of respondents had received a transplant (n=404; 38.8%) and 28.8% had been on dialysis for two or more years (n=300). Of the 454 patients undergoing regular dialysis treatment, the most common modality was HD (n=343; 75.6%).

3.2 PATIENT DISTRESS GROUPS

Of the 1040 respondents who returned valid surveys, 33.3% (n=346) met the criteria for mild to moderate distress. In the other distress groups, 561 patients were categorised has having none to low levels of distress (53.9%), and 133 patients were grouped into the severe distress category (12.8%) (Figure 3.2).

Figure 3.2: Patient distress groups (all respondents)



Comparison across distress groups
Table 3.3 compares the proportion of patients in each of the three distress groups against key characteristics: study site, ESRD pathway stage, dialysis type, age group, gender and ethnicity (with graphical representations given in Appendix 1).

There was no difference across sites in the proportion of patients reporting mild to moderate or severe distress, although patients in site 1 were significantly less likely than those in the other three sites to fall into the none to low distress group (48.1% of patients; $p<0.0001$). In terms of ESRD pathway stage, there was little difference in the proportion of patients at each stage who were allocated to the three distress groups. However, transplant patients were significantly more likely than those at other ESRD stages to be in the none to low distress group (61.6% of patients; $p=0.0009$), and significantly less likely to be in the severe distress group (9.2% of patients; $p=0.023$). For the sub-group of patients undergoing dialysis ($n=454$), the proportion of patients assigned to each distress group who were treated with each of the three modalities assessed was similar.

There were some differences in the distribution of patients across distress groups for age, gender and ethnicity: patients aged 70 and older were significantly more likely than younger patients to be in the none to low distress group (60.9% of patients; $p<0.0001$), whereas patients aged less than 50 were significantly more likely than other patients to be in either the mild to moderate distress group (44.8% of patients; $p=0.0008$) or the severe distress group (19.5%; $p=0.010$). Females were significantly less likely than males to be in the none to low distress group (47.7% vs. 58.0%), with a significantly increased likelihood of being in the mild to moderate distress group (38.1% vs. 30.2%; $p=0.01$). Finally, patients of white ethnicity were significantly more likely than patients from BME groups to be in the none to low distress group (57.4% vs. 31.2%). Conversely, BME patients were significantly more likely than white patients to be in either the mild to moderate distress group (45.7% vs. 31.4%; $p=0.0013$), or the severe distress group (23.2% vs. 11.2%; $p=0.0002$).

Table 3.3: Respondent characteristics and proportion by sub-group in each distress category

Characteristic	None to low distress (%)	Mild to moderate distress (%)	Severe distress (%)	Total
Study site				
Site 1	**90 (48.1)**	72 (38.5)	25 (13.4)	187
Site 2	93 (52.5)	58 (32.8)	26 (14.7)	177
Site 3	184 (57.0)	107 (33.1)	32 (9.9)	323
Site 4	194 (55.0)	109 (30.9)	50 (14.2)	353
Stage on ESRD pathway				
Pre-RRT	93 (51.1)	64 (35.2)	25 (13.7)	182
Dialysis <2 years	71 (46.1)	55 (25.7)	28 (18.2)	154
Dialysis 2+ years	148 (49.3)	109 (36.3)	43 (14.3)	300
Transplant	**249 (61.6)**	118 (29.2)	**37 (9.2)**	404
Dialysis type (n=454)				
HD	160 (46.6)	129 (37.6)	54 (15.7)	343
HHD	13 (41.9)	13 (41.9)	5 (16.1)	31
PD	46 (57.5)	22 (27.5)	12 (15.0)	80
Age group				
Aged <50	62 (35.6)	**78 (44.8)**	**34 (19.5)**	174
Aged 50 to 69	240 (54.4)	145 (32.9)	56 (12.7)	441
Aged 70+	**252 (60.9)**	179 (28.7)	43 (10.4)	414
Gender				
Male	367 (58.0)	191 (30.2)	75 (11.8)	633
Female	**194 (47.7)**	**155 (38.1)**	58 (14.3)	407
Ethnicity				
White	**518 (57.4)**	283 (31.4)	101 (11.2)	902
BME	63 (31.2)	**63 (45.7)**	**32 (23.2)**	138

Bold text indicates a statistically significant difference for a given sub-group in relation to the proportion within a specific distress group

3.3 MILD TO MODERATE DISTRESS GROUP

Mild to moderate distress was identified in 208 patients (60.1%) on the basis of their DT score alone, with the remaining 138 (39.9%) identified from their scores on the anxiety, depression or anger thermometers. For the 346 patients reporting distress, median scores for each of the emotion thermometers were similar: distress: 4 (IQR 2 to 6), anxiety: 5 (IQR 4 to 7), depression: 4 (IQR 2 to 7), anger: 4 (IQR 1 to 6).

Across the participating study sites, the prevalence of mild to moderate distress was lowest in site 4 (30.9%; n=109) and highest in site 1 (38.5%; n=72). On the basis of ESRD pathway stage, mild to moderate distress rates were highest in patients who had been on dialysis for 2 or more years (n=109/300; 36.3%) and lowest in transplant patients (n=118/404; 29.2%). Amongst dialysis patients, mild to moderate distress was highest in the home haemodialysis group (n=13/31; 41.9%) and lowest in the peritoneal dialysis group (n=22/80; 27.5%), although numbers of patients on home haemodialysis and peritoneal dialysis were very small compared to those on HD. There was no significant difference in rates of distress on the basis of ESRD stage or dialysis type when groups were compared (Table 3.4).

Table 3.4: Prevalence of mild to moderate distress by sub-group

Variable	Group	Patients	Prevalence (%)	Comparison of proportions
ESRD pathway stage	Pre-RRT	64/182	35.2	X^2=4.89; p=0.183
	Dialysis <2 years	55/154	35.7	
	Dialysis 2+ years	109/300	36.3	
	Transplant	118/404	29.2	
Dialysis type (n=454)	HD	129/343	37.6	X^2=3.36; p=0.186
	HHD	13/31	41.9	
	PD	22/80	27.5	
Hospital site	Site 1	72/187	38.5	X^2=3.24; p=0.356
	Site 2	58/177	32.8	
	Site 3	107/323	33.1	
	Site 4	119/353	30.9	
Age group	<50 years	78/174	44.8	**X^2=14.33; p=0.0008**
	50 to 69 years	145/441	32.9	
	70+ years	119/414	28.7	
Gender	Male	191/633	30.2	**X^2=6.63; p=0.01**
	Female	155/407	38.1	
Ethnicity	White	283/902	31.4	**X^2=10.36; p=0.0013**
	BME	63/138	45.7	

In contrast, all sociodemographic characteristics showed significant differences in the prevalence of mild to moderate distress between groups. Patients younger than 50 were significantly more likely to report distress than those in the older age groups (n=78/174; 44.8%; X^2=14.33; p=0.0008). The prevalence of mild to moderate distress was significantly higher for females than males and for BME patients compared to patients of white ethnicity.

3.4 PROBLEMS EXPERIENCED

The distress thermometer problem list asked patients whether or not they had experienced specific problems (from a total of 36) in the previous week. Analysis of the problem list first considers problems cited across the patient cohort as a whole (section 3.4.1), then sub-group analysis examines problems reported by specific sub-groups of patients within the group with mild to moderate distress (n=346).

3.4.1 Problems experienced: all patients

Taking the cohort of respondents as a whole, 943 patients (90.7%) had experienced at least one problem in the preceding week (Table 3.5), with a mean of 8.4 problems each. Physical problems were the most commonly reported, with 88.2% of patients (n=917) having experienced one or more of the listed physical problems in the previous week. This was followed by emotional problems (66.1%; n=687), practical problems (32.1%; n=334), and family problems (22.7%; n=236). Few patients reported spiritual problems (40/1040; 3.8%). As the proportion of patients reporting spiritual problems was so low, the remainder of this analysis focuses solely on problems reported in the practical, family, emotional and physical domains.

Table 3.5: All respondents – experience of problems in each problem domain

Problem domain	Patients reporting at least 1 problem (%)	Mean percentage of problems reported*
Practical	334 (32.1)	9.8
Family	236 (22.7)	9.3
Emotional	687 (66.1)	33.3
Spiritual	40 (3.8)	N/A
Physical	917 (88.2)	28.7
ANY problems	943 (90.7)	24.6

* Mean percentage of problems is calculated to control for the differing number of problems that could be reported in each domain. For example, if the mean number of problems reported in the practical domain is 2, the mean percentage will be 2/5 i.e. 40% of problems within the domain

Experience of specific problems

For the entire group of respondents, four of the top five most frequently reported problems overall were in the physical domain: fatigue, dry/itchy skin, sleep and pain. The six emotional domain problems were all cited amongst the top 15 problems, with worry expressed most frequently (47.9% of patients; n=498). The most commonly experienced practical problem was related to transport, although this ranked only 26/36 overall (16.1% of patients; n=167). The most commonly experienced family problem concerned dealing with a close friend/relative (rank 28/36 overall; 12.7% of patients; n=132) (Table 3.6).

Physical and emotional problems accounted for all of the 25 most frequently reported problems, with those on the practical and family domains all in the bottom 11 when problems were ranked. The most commonly experienced problem in the previous week was fatigue, with 60.7% of patients (n=631) reporting this problem. This was followed by dry/itchy skin (54.8%; n=570) and sleep problems (48.8%; n=508).

Table 3.6: Frequency and rank of DT problems experienced in the previous week (all patients)

Domain	Problem	Number of patients (%)	Rank within domain*	Overall rank**
Practical problems (n=5)	Childcare	21 (2.0)	5	35
	Housing	61 (5.9)	4	32
	Insurance/financial	156 (15.0)	2	27
	Transportation	167 (16.1)	1	26
	Work/school	106 (10.2)	3	29
Family problems (n=3)	Dealing with children	55 (5.3)	3	33
	Dealing with partner	109 (10.5)	2	36
	Dealing with friend/relative	132 (12.7)	1	28
Emotional problems (n=6)	Depression	289 (27.8)	5	13
	Fears	288 (27.7)	6	14
	Nervousness	293 (28.2)	4	12
	Sadness	328 (31.5)	3	10
	Worry	498 (47.9)	1	4
	Loss of interest in usual activities	389 (37.4)	2	8
Physical problems (n=21)	Appearance	230 (22.1)	14	20
	Bathing/dressing	247 (23.8)	10	16
	Breathing	310 (29.8)	8	11
	Changes in urination	236 (22.7)	12	18
	Constipation	225 (21.6)	15	21
	Diarrhoea	179 (17.2)	19	25
	Eating	235 (22.6)	13	19
	Fatigue	631 (60.7)	1	1
	Feeling swollen	262 (25.2)	9	15
	Fevers	66 (6.3)	21	31
	Getting around	401 (38.6)	6	7
	Indigestion	217 (20.9)	17	23
	Memory/concentration	405 (38.9)	5	6
	Mouth sores	97 (9.3)	20	30
	Nausea	221 (21.3)	16	22
	Nose dry/congested	244 (23.5)	11	17
	Pain	405 (38.9)	4	5
	Sexual	207 (19.9)	18	24
	Skin dry/itchy	570 (54.8)	2	2
	Sleep	508 (48.8)	3	3
	Tingling in hands/feet	366 (35.2)	7	9

* The most frequently cited problem in each domain is highlighted in green; ** The top five problems overall (regardless of domain) highlighted in green

Problems experienced by distress group

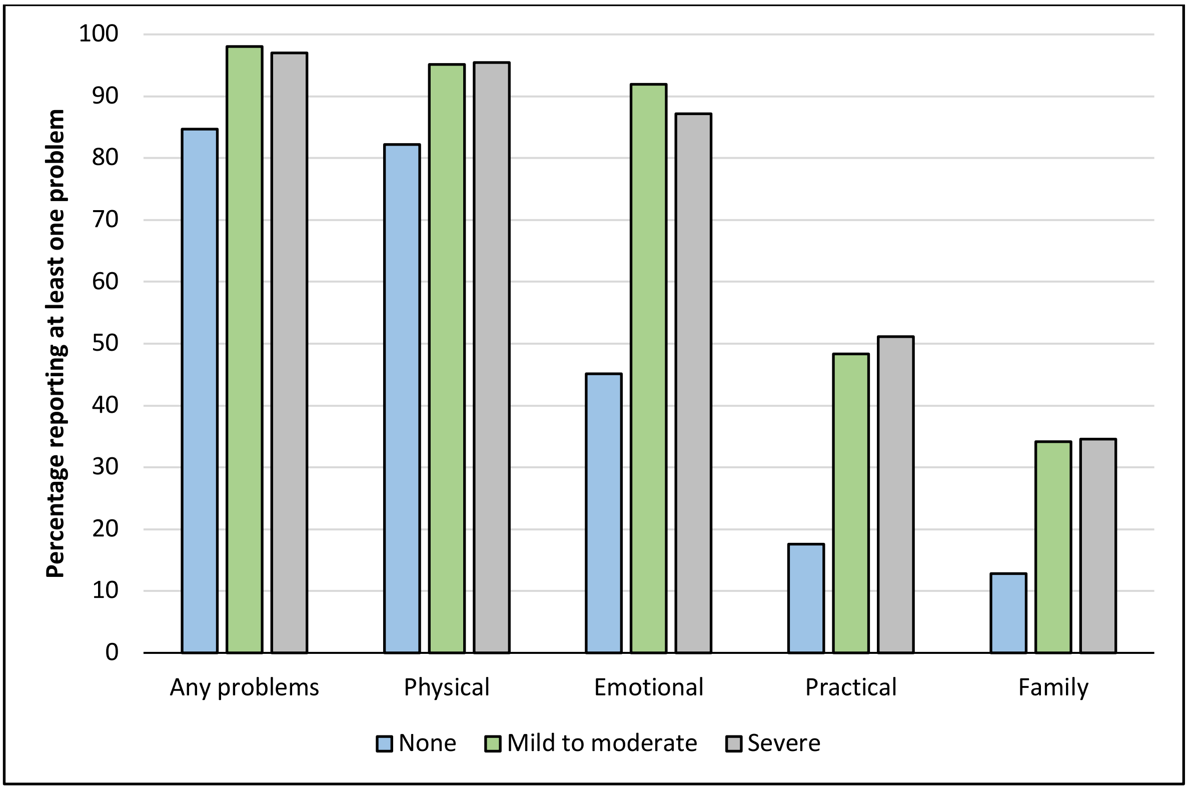
For patients in all distress groups, physical problems were the most frequently cited, and the proportion of patients reporting at least one physical problem was high across all groups – even those who reported no distress on the distress thermometer (Table 3.7). Patients with mild to moderate or severe distress had a mean percentage of problems more than double that of the none to low distress group (33.8% and 38.8% vs. 15.5%). Rates of reporting emotional, practical and family problems were typically 3 to 4 times higher for the mild to moderate or severe groups compared to the none to low distress group.

Table 3.7: Experience of problems in each domain, by distress group

Problem domain	**Patients reporting at least 1 problem (%)**			**Mean percentage of problems reported**		
Distress group:	None (n=561)	Mild to moderate (n=346)	Severe (n=133)	None	Mild to moderate	Severe
Practical	99 (17.6)	167 (48.3)	68 (51.1)	4.8	14.8	17.8
Family	72 (12.8)	118 (34.1)	46 (34.6)	5.0	14.7	14.7
Emotional	253 (45.1)	318 (91.9)	116 (87.2)	15.3	51.3	62.8
Physical	461 (82.2)	329 (95.1)	127 (95.5)	20.2	37.2	42.0
ANY problems	475 (84.7)	339 (98.0)	129 (97.0)	15.5	33.8	38.8

Emotional problems were also frequently experienced in all distress groups, followed by practical and lastly family problems. The similarity in proportions of respondents reporting problems in the mild to moderate and severe distress groups is striking. In the case of emotional problems, patients in the mild to moderate distress group were more likely to report problems than those in the severe distress group (Figure 3.3).

Figure 3.3: Proportion of patients reporting at least one problem in DT domains, by distress group



There was a positive and statistically significant relationship between distress group and experience of problems in all domains i.e. patients with higher levels of distress reported more problems (Table 3.8), although it is clear from Figure 3.3 that the differences were between patients with no distress and the other two groups, rather than between the mild to moderate and severe distress groups.

Table 3.8: Relationship between distress group and number of problems cited

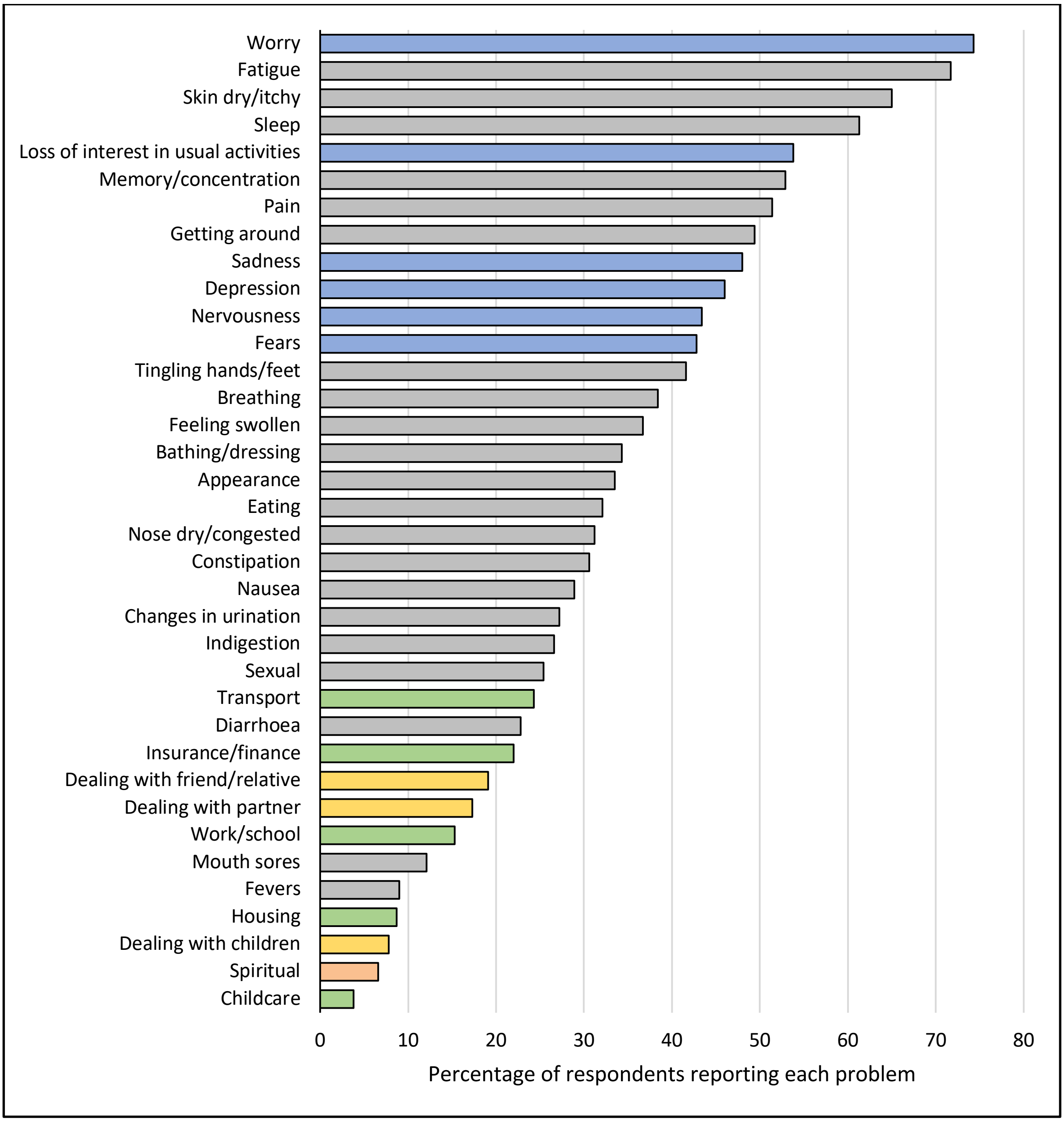
Domain	**Kendall's tau-b; p value**
Any problems	0.456; **p<0.0001**
Practical problems	0.326; **p<0.0001**
Family problems	0.247; **p<0.0001**
Emotional problems	0.543; **p<0.0001**
Physical problems	0.366; **p<0.0001**

3.4.2 Problems experienced – mild to moderate distress group

Figure 3.4 ranks the most to least frequently reported problems amongst the patients with mild to moderate distress (n=346). All but six patients in this group reported experiencing at least one problem on the DT in the preceding week (98.0%). The most frequently reported problems were all in the emotional and physical domains, with 91.9% of patients reporting at least one emotional problem, and 95.1% reporting at least one physical problem. Worry was the most common problem reported (74.3%; n=247). The median number of problems reported for the mild to moderate distress group was 12/36 (IQR: 7 to 16).

There were some significant differences in the distribution of responses across sociodemographic and clinical sub-groups by problem list domain: transplant patients reported significantly fewer physical problems and total problems than pre-RRT or dialysis patients (median physical problems 6/21, IQR 3 to 10, p=0.019; median total problems 10/36, IQR 5 to 16; p=0.023) (Table 3.9). Patients aged 70 and older reported significantly fewer problems on the practical, family and emotional domains than younger patients. They also reported significantly fewer total problems. Females reported significantly more physical problems than males (median 8/21, IQR 5 to 12 vs. 7/21, IQR 5 to 11; p=0.043). There were no significant differences in the median number of problems reported for any domain on the basis of dialysis type or patient ethnicity.

Figure 3.4: Rank of problems experienced in the previous week (mild to moderate distress group)



Shading: blue = emotional domain; grey = physical domain; green = practical domain; yellow = family domain; orange = spiritual domain

Table 3.9: Median number of problems reported in each DT problem domain, by patient sub-group

Characteristic	Practical	Family	Emotional	Physical	Total problems
Stage on ESRD pathway	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
Pre-RRT	1 (0 to 1)	0 (0 to 1)	3 (1 to 4)	**8 (4 to 12)**	**12 (7 to 17)**
Dialysis <2 years	1 (0 to 2)	0 (0 to 1)	3 (2 to 5)	**8 (6 to 12)**	**13 (9 to 17)**
Dialysis 2+ years	1 (0 to 1)	0 (0 to 1)	3 (2 to 5)	**9 (6 to 11)**	**13 (9 to 16)**
Transplant	0 (0 to 1)	0 (0 to 1)	3 (1 to 4)	**6 (3 to 10)**	**10 (5 to 16)**
				p=0.019	**p=0.023**
Dialysis type (n=164)					
HD	1 (0 to 1)	0 (0 to 1)	3 (2 to 5)	8 (5 to 11)	13 (8 to 16)
HHD	1 (0 to 2)	0 (0 to 1)	4 (2 to 5)	10 (8 to 13)	16 (11 to 19)
PD	0 (0 to 1)	0 (0 to 1)	3 (2 to 4)	8 (6 to 11)	12 (9 to 16)
Age group					
Less than 50	**1 (0 to 2)**	**0 (0 to 1)**	**3 (2 to 5)**	7 (4 to 11)	**13 (8 to 17)**
50 to 69	**1 (0 to 2)**	**0 (0 to 1)**	**3 (2 to 5)**	8 (5 to 11)	**12 (8 to 18)**
70 and above	**0 (0 to 1)**	**0 (0 to 0)**	**3 (1 to 4)**	7 (4 to 10)	**11 (7 to 15)**
	p<0.0001	**p=0.001**	**p=0.038**		**p=0.033**
Gender					
Male	1 (0 to 1)	0 (0 to 1)	3 (2 to 4)	**7 (4 to 10)**	12 (7 to 16)
Female	0 (0 to 1)	0 (0 to 1)	3 (2 to 5)	**8 (5 to 12)**	12 (8 to 17)
				p=0.043	
Ethnicity					
White	0 (0 to 1)	0 (0 to 1)	3 (2 to 4)	8 (5 to 11)	12 (7 to 16)
BME	0 (0 to 2)	0 (0 to 1)	4 (1 to 5)	7 (4 to 10)	11 (7 to 17)
All respondents (n=346)	0 (0 to 1)	0 (0 to 1)	3 (2 to 5)	8 (5 to 11)	12 (7 to 16)

3.5 EVENTS CAUSING DISTRESS

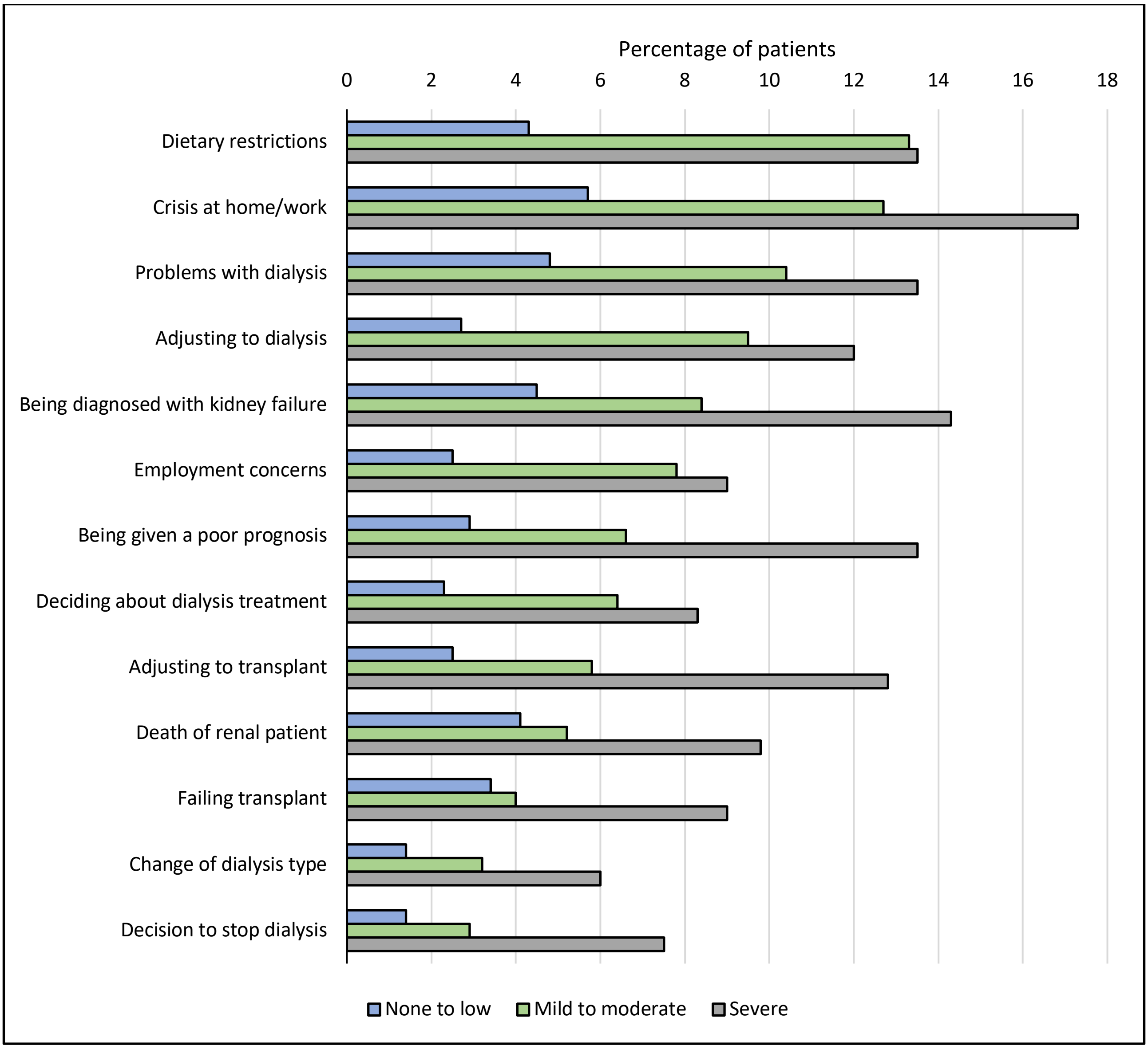
Survey recipients were asked to indicate whether any of a series of pre-specified events had caused them distress in the previous week. A full analysis of the data is challenging, as the total number of patients who had experienced each event is not known – only whether a particular event caused distress. Events did not have to take place in the past week, but could have been events that happened a long time previously that were the cause of current distress at the time respondents completed the survey.

Analysis compares the incidence of distressing events across patients in the different distress groups (all survey respondents), then by sociodemographic and clinical sub-group for the patients with mild to moderate distress.

3.5.1 Distressing events, by distress group

Patients in the none to low distress group were the least likely to report distress from specific events, with 96/561 patients (17.1%) reporting distress from 1 or more events in the previous week (Figure 3.5).

Figure 3.5: Proportion of patients in different distress groups experiencing distress from events



Distressing events were reported more than twice as frequently for patients in the mild to moderate distress group (137/346; 39.6%). Rates of problem reporting were highest for patients in the severe distress group, where nearly half of all patients experienced recent distress from a specific event (64/133; 48.1%). For both the none to low group and the severe group, ‘crisis in home or work life’ was the most frequently reported individual event; for the mild to moderate distress group, ‘dietary restrictions’ had caused distress for 13.3% of patients (n=46). For patients in all groups, the least distressing events were related to ‘decision to stop dialysis’ or ‘change of dialysis type’, although this is likely to be due to the small number of patients to whom occurrence of these events would be relevant, whereas other events such as dietary restrictions or crises in personal or work life may have the potential to affect all renal patients since they are not necessarily related to a particular point in the disease pathway.

Table 3.10 shows the number and proportion of survey respondents with mild to moderate distress who indicated at least one event that had caused distress in the previous week, along with the most frequently reported event, by sub-group. Dialysis type is not reported due to numbers of patients reporting specific events being too small within the HHD and PD sub-groups.

Table 3.10: Number and proportion of respondents experiencing distress (mild to moderate patients)

Variable	Respondents reporting at least 1 event (%)	Most frequently reported event (n;%)
Study site		
Site 1	26/72 (36.1)	Dietary restrictions (11; 15.3)
Site 2	25/58 (43.1)	Being diagnosed with renal failure (8; 13.8)
Site 3	42/107 (39.3)	Dietary restrictions (15; 14.0)
Site 4	44/109 (40.4)	Crisis in home or work life (17; 15.6)
Stage on ESRD pathway		
Pre-RRT	28/64 (43.8)	Being given a poor prognosis (11; 17.2)
Dialysis <2 years	25/55 (45.5)	Problems with dialysis (13; 23.6)
Dialysis 2+ years	48/109 (44.0)	Dietary restrictions (19; 17.4)
Transplant	36/118 (30.5)	Crisis in home or work life (16; 13.6)
Age group		
Aged <50	32/78 (41.0)	Failing transplant (17; 21.8)
Aged 50 to 69	60/145 (41.4)	Dietary restrictions (21; 14.5)
Aged 70+	44/119 (37.0)	Dietary restrictions (15; 12.6)
Gender		
Male	76/191 (39.8)	Dietary restrictions (27; 14.1)
Female	61/155 (39.4)	Crisis in home or work life (24; 15.5)
Ethnicity		
White	106/283 (37.5)	Dietary restrictions (35; 12.4)
BME	31/63 (49.2)	Crisis in home or work life (14; 22.2)

Although there was some variability in responses from patients treated at the different participating study sites, none of the differences was statistically significant. Patients from sites 1 and 3 were most likely to report distress caused by dietary restrictions, whereas patients in site 2 reported that diagnosis with renal failure was particularly distressing. Patients in site 4 were most likely to report distress from crises in home or work life. When considering ESRD stage, being given a poor prognosis was most frequently cited as a reason for recent distress amongst pre-RRT patients. Patients who had been on dialysis for less than 2 years were most likely to mention problems with dialysis as causing distress, whereas those who had been on dialysis for longer than 2 years had experienced distress from dietary restrictions. Crises in home or work life were most likely to have adversely affected transplant patients.

Comparison of proportion tests for specific events showed some significant differences in the proportion of patients at various points on the ESRD pathway who reported distress from those events:

- Decisions about choice of dialysis treatment were significantly more likely to have caused distress to pre-RRT patients and those who had been on dialysis for less than two years, than for those in the other groups (X^2=14.16; p=0.003)

- The impact of dietary restrictions was prominent for the pre-RRT and both groups of dialysis patients in comparison to transplant patients where concern over this issue was significantly lower (X^2=13.00; p=0.005)

- Pre-RRT patients and those on dialysis for less than two years were most likely to experience distress caused by considering a change to dialysis type (X^2=12.80; p=0.005)

- Distress caused by the decision (or potential decision) to stop dialysis was most pronounced in the group of patients who had been on dialysis for less than two years compared to patients at other ESRD stages (X^2=9.73; p=0.021).

For patients in the youngest age group, distress caused by a failing (or potentially failing) transplant was the event most likely to have caused distress. For patients aged 50-69 or 70+, the impact of dietary restriction was distressing to the greatest proportion of patients. Comparison of proportion tests found differences between observed and expected responses for two of the events listed: patients in the 50 to 69 age group were significantly more likely than patients in the other two age groups to have experienced a crisis in their home/work life that caused distress (X^2=9.74; p=0.008), and to have concerns over employment (X^2=17.18; p<0.0001).

The proportion of males and females reporting distress from at least one event in the previous week was very similar (39.8% vs. 39.4%). None of the comparisons for rates of reporting of specific events showed statistically significant difference except for the proportion of patients indicating distress over being diagnosed with kidney failure. Males were more than twice as likely as females to report distress over their diagnosis (11.5% vs. 4.5%; X^2=5.46; p=0.019).

In terms of ethnic group, nearly 50% of BME patients had suffered distress caused by one or more events in the previous week, compared to 37.5% of white patients. Several of the potentially distressing events showed statistically significant differences in the proportion of BME vs. white patients reporting them. BME patients were significantly more likely than white patients to report recent distress caused by:

- Being given a poor prognosis (X^2=4.55; p=0.033)
- Difficulties adjusting to dialysis (X^2=10.99; p=0.001)
- Distress related to a failing transplant (X^2=5.95; p=0.015)
- Crisis in home or work life (X^2=6.27; p=0.012)
- Decision to stop dialysis treatment (X^2=6.99; p=0.008).

3.6 ADJUSTMENT AND COPING

This analysis assesses positive and negative affect scores (PANAS measure) for the entire cohort of survey respondents, and for the sub-group with mild to moderate distress. The analysis reports medians and IQR for PANAS scores, as these were not normally distributed.

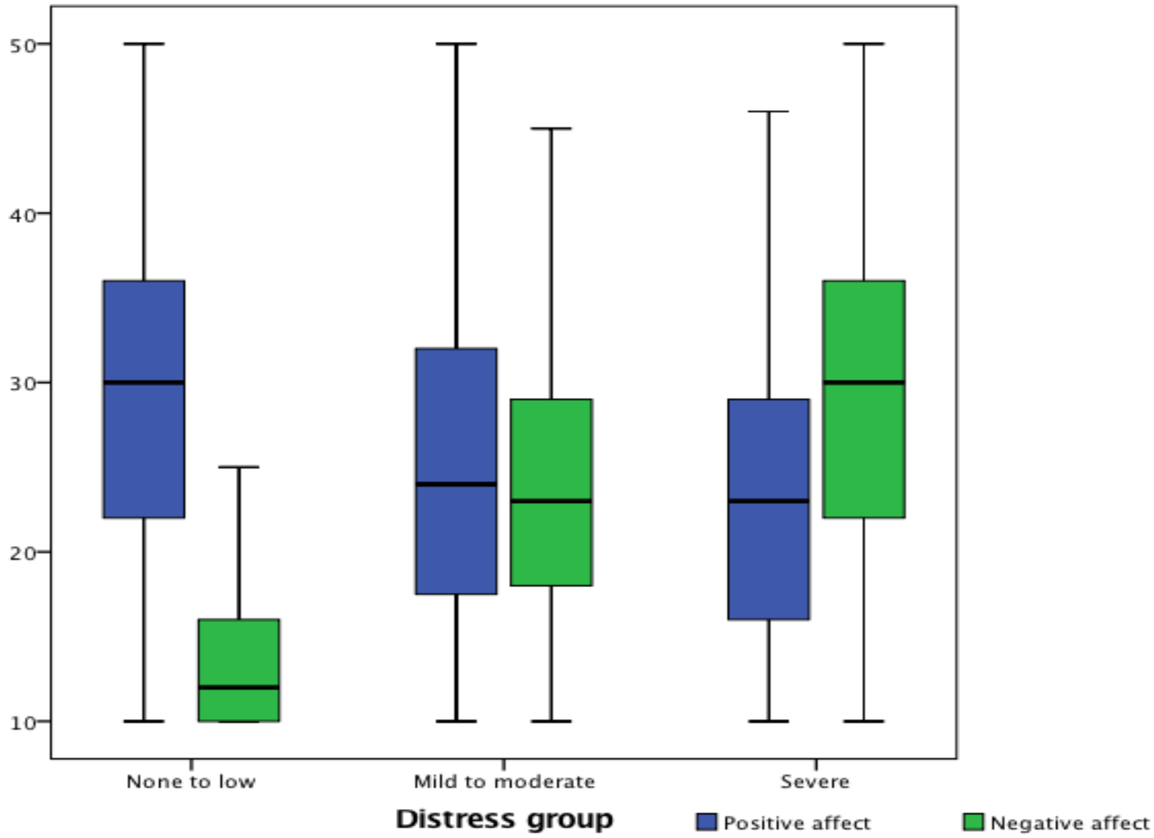
Table 3.11 shows median positive and negative affect scores for each distress group.

Table 3.11: PANAS scores by distress group

Distress category	**Number of respondents**	**Median positive affect score (IQR)**	**Median negative affect score (IQR)**
All respondents	987	27.3 (20 to 35)	19.1 (11 to 24)
No distress	531	30.0 (22 to 36)	12.0 (10 to 16)
Mild to moderate	332	24.0 (17.3 to 32)	23.0 (18 to 29)
Severe	124	23.0 (16 to 27.5)	30.0 (21 to 36)
Non-parametric trend test		**p<0.0001**	**p<0.0001**

For patients categorised as having none to low levels of distress, median positive affect scores were substantially higher than negative affect scores (30.0: IQR 22 to 36 vs. 12.0: IQR 10 to 16). For the group with mild to moderate distress, positive and negative affect scores were similar (24.0: IQR 17.3 to 32 vs. 23.0: IQR 18 to 29). For the group with severe distress, negative affect scores were higher than positive affect scores (Figure 3.6). For both positive and negative affect, a non-parametric trend test was highly significant (p<0.0001) i.e. as distress increased, positive affect significantly reduced, and negative affect significantly increased.

Figure 3.6: Comparison of PANAS scores by distress category



3.6.1 PANAS scores by sub-group for patients with mild to moderate distress

A total of 332 survey respondents within the mild to moderate distress group reported enough PANAS data to be included in the analysis. Table 3.12 shows median PANAS scores by sub-group. Appendix 2 represents the results graphically (Figures A2.1 to A2.6).

Table 3.12: Median PANAS scores by sub-group (patients with mild to moderate distress)

Variable	Number of respondents	Median positive affect score (IQR)	Median negative affect score (IQR)	Comparison of medians
Study site				
Site 1	67	25.0 (18 to 31)	24.0 (18 to 29)	Positive affect: p=0.909 Negative affect: p=0.502
Site 2	55	23.0 (17 to 32)	23.0 (19 to 27)	
Site 3	106	24.0 (17 to 32.3)	23.0 (17 to 30)	
Site 4	104	25.5 (17.3 to 31.8)	22 (15.3 to 29)	
Stage on ESRD pathway				
Pre-RRT	59	21.0 (17 to 31)	24.0 (17 to 28)	**+ve: p=0.017** -ve: p=0.869
Dialysis <2 years	52	23.0 (17.3 to 28.8)	22.0 (18.3 to 29)	
Dialysis 2+ years	106	25.5 (17 to 31)	24.0 (18 to 30)	
Transplant	115	27.0 (20 to 35)	22.0 (16 to 29)	
Dialysis type				
HD	124	24.0 (17 to 30)	24.0 (18 to 30)	+ve: p=0.823 -ve: p=0.120
HHD	13	26.0 (18 to 31)	22.0 (18.5 to 31)	
PD	21	23.0 (17 to 32)	20.0 (14.5 to 24)	
Age group				
Aged <50	75	26.0 (20 to 34)	24.0 (18 to 30)	+ve: p=0.284 **-ve: p=0.014**
Aged 50 to 69	143	24.0 (17 to 31)	24.0 (19 to 30)	
Aged 70+	110	23.0 (18 to 31)	21.0 (16 to 27.3)	
Gender				
Male	181	25.0 (17 to 32.5)	22.0 (17 to 27)	+ve: p=0.892 **-ve: p=0.048**
Female	151	23.0 (18 to 31)	24.0 (18 to 30)	
Ethnicity				
White	271	24.0 (17 to 32)	22.0 (17 to 28)	+ve: p=0.134 **-ve: p=0.003**
BME	61	28.0 (21 to 31)	26.0 (20 to 30.5)	

When positive and negative affect scores were compared for patients treated at the four study sites, there was no statistically significant difference between sites in terms of median positive or negative affect scores. In terms of stage on the ESRD pathway, median positive affect scores showed some significant differences (lowest in pre-RRT patients and highest in transplant patients). Negative affect scores were significantly higher for younger patients compared to older patients; for female patients compared to male patients, and for BME patients compared to patients of white ethnicity. There was no difference in median positive or negative affect scores between groups on the basis of dialysis type, although median positive affect scores were highest for HHD patients and lowest for HD patients. However, numbers of patients in the home haemodialysis and peritoneal dialysis groups were very small.

All three sociodemographic characteristics assessed in the analysis showed some statistically significant differences in median PANAS scores across sub-groups. Median negative affect scores were significantly lower in the oldest age group compared to those aged below 70. Although there was no difference in positive affect scores by gender, female patients were significantly more likely to have a higher negative affect score than male patients. Similarly, BME patients had significantly higher negative affect scores than white patients.

3.6.2 Adjustment and coping over time

As this study was cross-sectional, it is difficult to determine the extent to which adjustment and coping may change over time. Unfortunately, data were not available for patients on the length of time since (for example) they began dialysis or received a transplant. Length of time since diagnosis is used in the following analysis as a proxy for assessing trends in PANAS scores over time, although this must be interpreted with caution: some patients may have been diagnosed with CKD stage 5 many years previously and received a transplant soon afterwards, whereas others may have been diagnosed many years ago and have received a transplant recently or still be undergoing dialysis treatment.

The analysis compares PANAS scores against time since diagnosis first for the entire cohort of patients (Figure 3.7), then for the cohort with mild to moderate distress (Figure 3.8).

Figure 3.7: Trends in PANAS scores with increasing time since diagnosis (all patients)

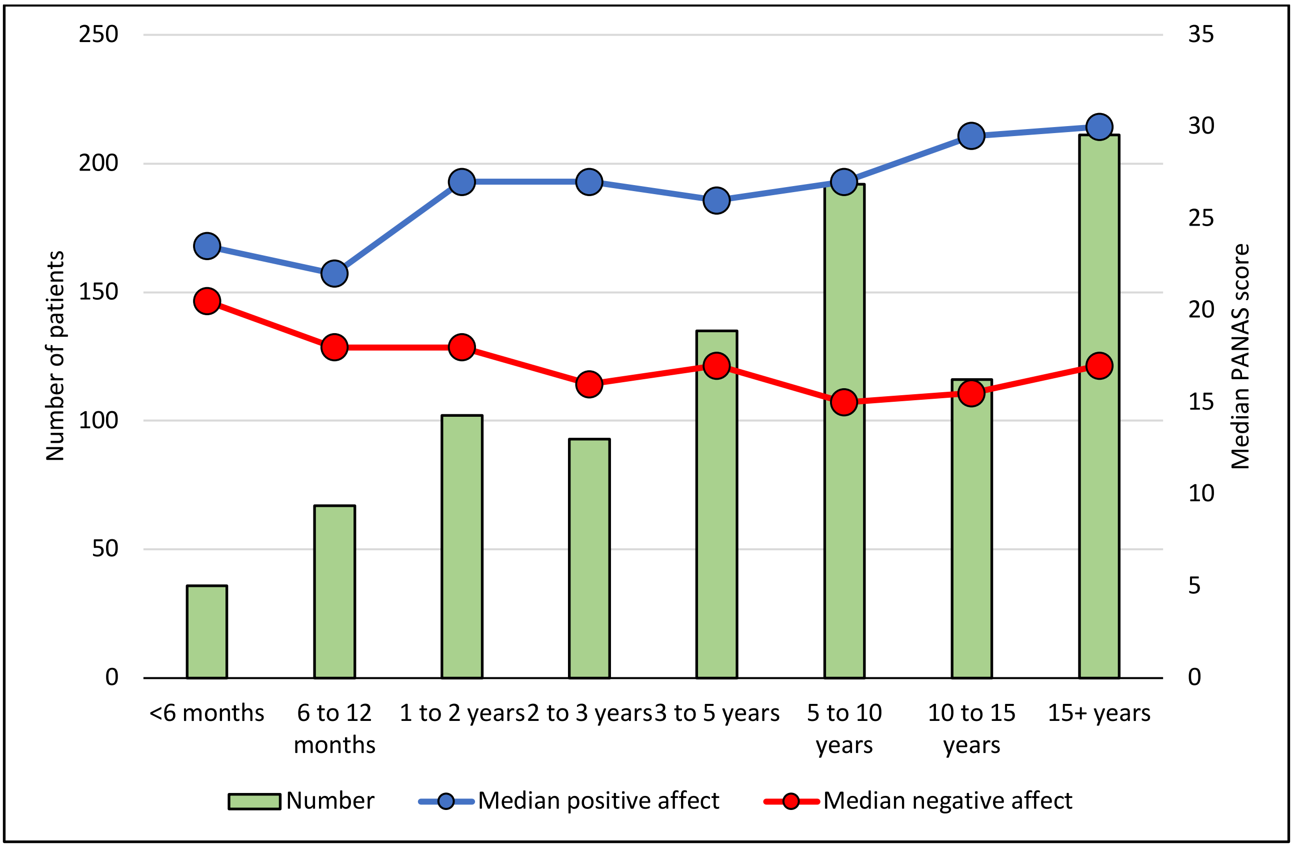
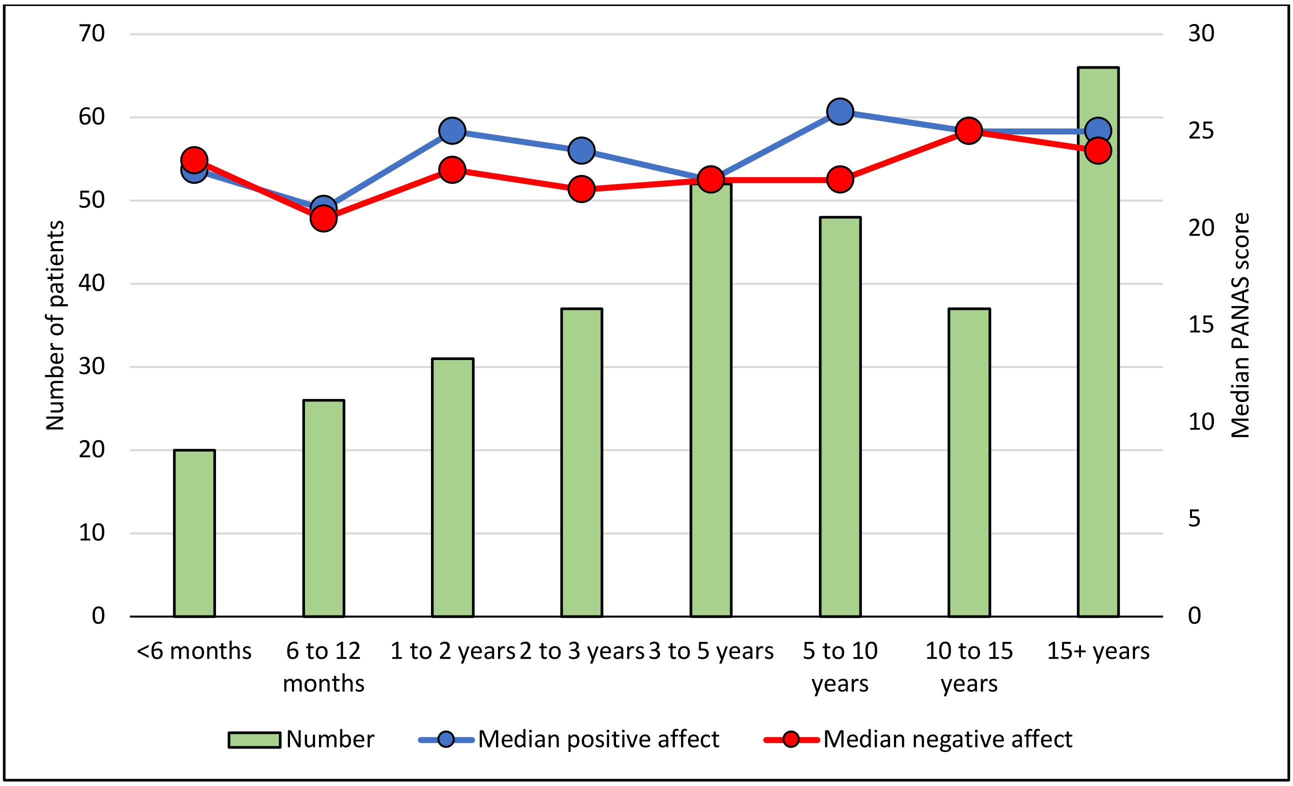


Figure 3.7 shows a trend (for all 952 patients for which PANAS scores and time since diagnosis were available) towards increasing positive affect scores as time since diagnosis increases, and a corresponding trend towards reduction in negative affect score. This may suggest that patients become increasingly able to adjust to their condition the longer they live with it.

Figure 3.8: Trends in PANAS scores with increasing time since diagnosis (mild to moderate distress)



In contrast to Figure 3.7, Figure 3.8 shows that when only the group of patients meeting the criteria for mild to moderate distress is selected, the trend for changes in median positive and negative affect scores is not evident. This suggests that patients with mild to moderate distress may not experience a significant improvement in their ability to cope with their condition over time.

3.7 PERCEIVED NEED FOR HELP

Scores on the need thermometer of the ET were assessed as an outcome measure indicating patients' perceived need for help with their distress (Table 3.13). Scores of 4 and above on the need thermometer were considered to indicate unmet support needs.[52]

Table 3.13: Median need thermometer scores for patients in each distress group

Distress group	Patients scoring 4 and over for need (%)	Median need score for group (IQR)	Comparison of proportions
None to low	12/561 (0.2)	0 (0 to 1)	**X^2=303.40; p<0.0001**
Mild to moderate	141/346 (40.8)	3 (1 to 5)	
Severe	86/133 (64.7)	6 (2 to 8)	

Only 0.2% of patients in the none to low distress group reported a need score of 4 or more in the emotion thermometers. For the patients in the mild to moderate distress group, 40.8% of patients (n=141/346) scored 4 and above on the need thermometer. Nearly two thirds of patients in the severe distress group (86/133; 64.7%) reported support needs. A comparison of proportions test was strongly statistically significant (p<0.0001), showing that the proportion of patients reporting a need for support increased significantly as distress increased.

Amongst the 346 patients in the mild to moderate distress group, there were significant differences by sub-group relation to support needs according to ESRD pathway stage: 66.0% of patients on dialysis for less than two years reported that they required support (n=35), as did 55.7% of patients on dialysis for two or more years (n=59). Perceived support needs in the pre-RRT and transplant groups were significantly lower, at 34.9% and 29.9% respectively (X^2=27.71; p<0.0001). There was no difference on the basis of dialysis type, although this is probably due to small patient numbers in the home haemodialysis and peritoneal dialysis groups: 28.6% of PD patients reported support needs, compared with 53.8% of HHD and 56.0% of HD patients.

Support needs were also significantly higher in BME compared to white patients, at 57.6% vs. 37.9% (X^2=7.06; p=0.008) (Table 3.14), and when hospital sites were compared, patients in site 1 reported significantly higher support needs than those in the other sites (29.4%; X^2=9.49; p=0.02).

Table 3.14: Perceived need for help with distress by sub-group with mild to moderate distress

Characteristic	**Median 'need' score (IQR)**	**Patients scoring 4 or more on need thermometer (%)**	**Comparison of proportions**
All respondents	3 (1 to 5)	141 (40.8)	
Study site			
Site 1	1 (0 to 4)	55 (29.4)	**X^2=9.49; p=0.02**
Site 2	1 (0 to 3)	38 (21.5)	
Site 3	1 (0 to 3)	74 (22.9)	
Site 4	0 (0 to 3)	71 (20.1)	
ESRD pathway stage			
Pre-RRT	2 (0 to 4)	22 (34.9)	**X^2=27.71; p<0.0001**
Dialysis <2 years	3 (2 to 6)	35 (66.0)	
Dialysis 2+ years	4 (2 to 6)	59 (55.7)	
Transplant	2 (0 to 4)	35 (29.9)	
Dialysis type (n=454)			
HD	4 (2 to 6)	70 (56.0)	X^2=5.44; p=0.07
HHD	4 (2 to 8)	7 (53.8)	
PD	3 (0 to 5)	6 (28.6)	
Age group			
Less than 50	3 (2 to 5)	35 (44.9)	X^2=0.85; p=0.654
50 to 69	3 (1 to 5)	55 (39.0)	
70 and above	3 (1 to 5)	48 (41.4)	
Gender			
Male	3 (1 to 5)	73 (39.2)	X^2=0.54; p=0.462
Female	3 (1 to 5)	67 (43.8)	
Ethnicity			
White	3 (1 to 5)	106 (37.9)	**X^2=7.06; p=0.008**
BME	5 (2 to 7)	34 (57.6)	

3.8 PATIENT PERCEPTIONS OF SUPPORT FROM RENAL STAFF

Analysis in this section focuses on patients' response to eight statements about support from renal staff which were scored on a Likert scale from 0 (strongly disagree) to 10 (strongly agree). Responses were not normally distributed, as answers tended to be skewed either towards the 'strongly agree' or 'strongly disagree' ends of the scale, so analysis reports comparisons of medians and IQR. All analysis focuses on the group of patients with mild to moderate distress only.

Of the eight statements in the survey, four were negatively worded (i.e. disagreement with the statement indicates the 'positive' response) and four were negatively worded (i.e. agreement indicates the 'positive' response). For ease of interpreting the results, positively and negatively worded statements have been grouped together when presented.

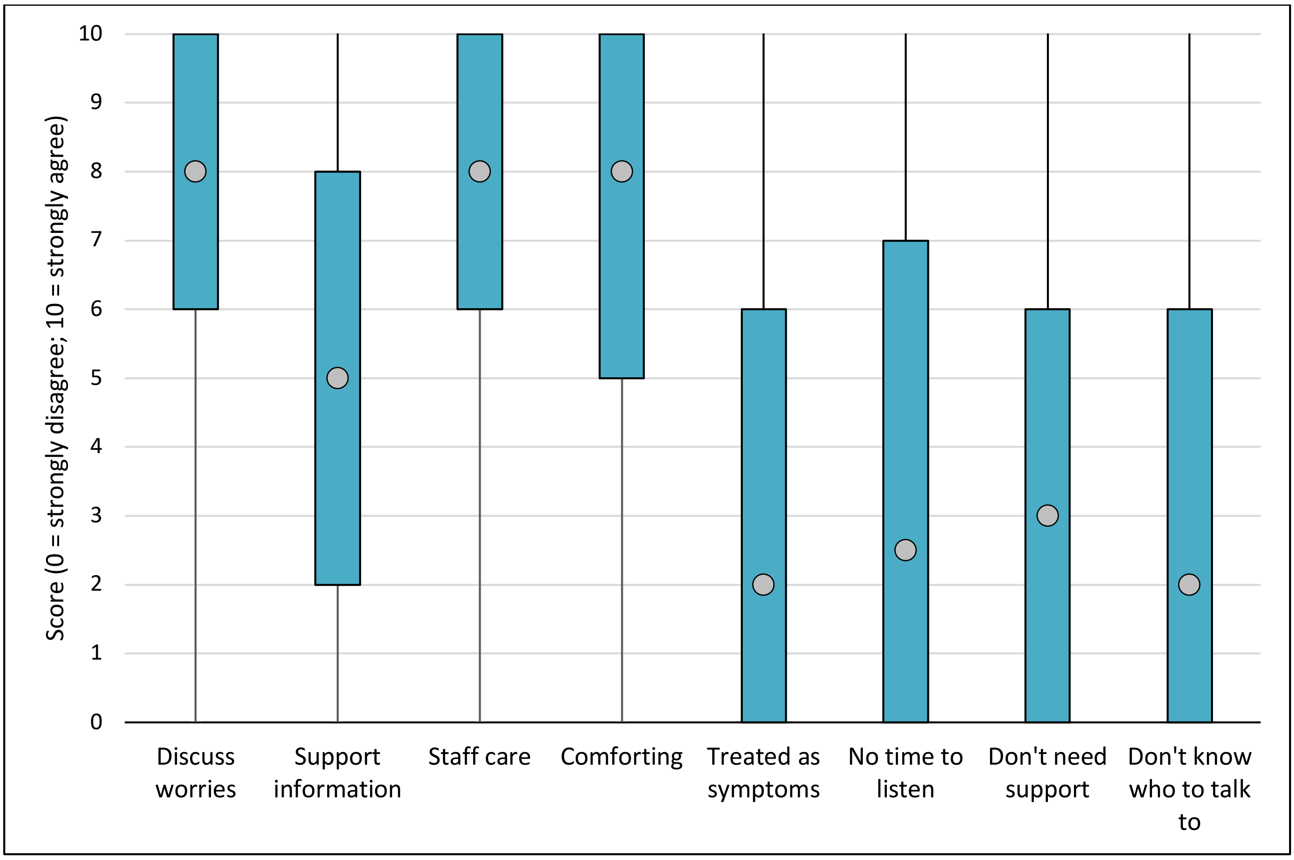
Table 3.15 shows the distribution of responses to support statements amongst patients in the mild to moderate distress group.

Table 3.15: Responses to support statements

Statement type	Statement	Median score (IQR)
Positive	I can discuss worries or fears with renal staff	8.0 (6 to 10)
	Renal staff tell me about support available	5.0 (2 to 8)
	I feel the renal staff really care	8.0 (6 to 10)
	It's comforting the way renal staff treat me	8.0 (5 to 10)
Negative	I feel I am treated as a set of symptoms	2.0 (0 to 6)
	Renal staff do not have time to listen	2.5 (0 to 7)
	I don't need renal staff support	3.0 (0 to 6)
	I don't know who to talk to	2.0 (0 to 6)

Median scores for statements relating to being able to discuss worries with staff, feeling that renal staff care, and feeling comforted by the way they are treated by renal staff were all high, at 8 out of 10. The lowest scoring positive statement related to whether or not patients felt that renal staff told them about different types of support that may be available. For the negative statements, medians were low, showing that patients tended to disagree with the statements, although the inter-quartile range was fairly broad, showing a wide range of answers across the 0 to 10 Likert scale (Figure 3.9).

Figure 3.9: Distribution of responses to statements about staff support



3.8.1 Sub-group analysis of patient perceptions about staff support

Sub-group analysis of patient responses to the survey statements about support received from renal staff showed several areas where median scores on the Likert scale differed significantly.

On the basis of ESRD pathway stage, there were significant differences in median scores for two statements. For the statement ‘I feel I am treated as a set of symptoms’, median scores were very low for pre-RRT patients (median 0.5; IQR 0 to 5) (i.e. strong disagreement with the statement), whereas for patients on dialysis for two or more years, median scores indicated higher levels of agreement with the statement (median 4; IQR 0 to 6). A comparison of medians test gave a p value of 0.025 for the difference.

For the statement ‘renal staff do not have time to listen’, responses were similar, with pre-RRT patients tending to disagree with the statement (median 0.5; IQR 0 to 3), and patients who had been on dialysis for two or more years having a significantly higher level of agreement with the statement (median 5; IQR 1 to 7) (p=0.001). (Figures 3.10 and 3.11).

Figure 3.10 I feel I am treated as a set of symptoms

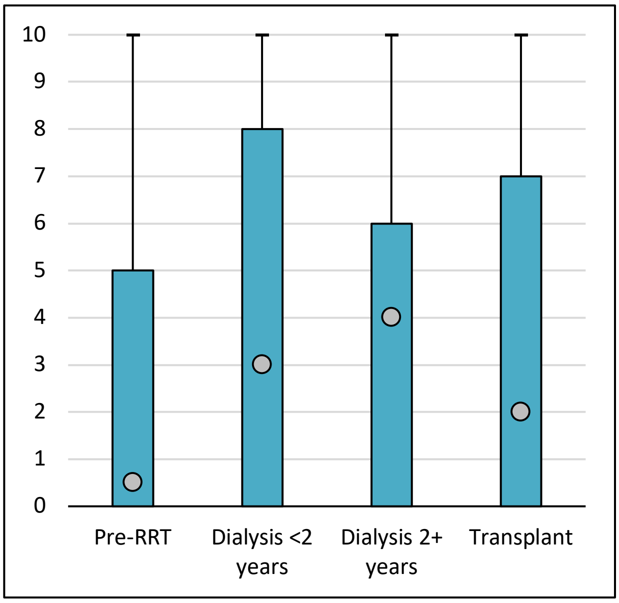
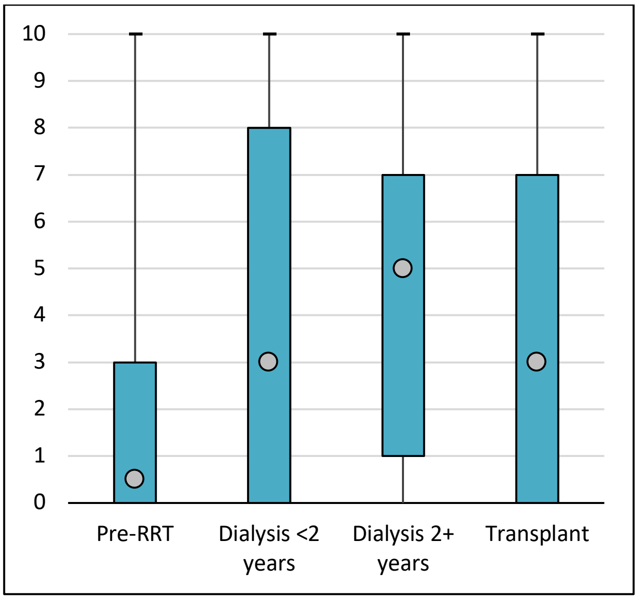


Figure 3.11 Staff do not have time to listen



0 = strongly disagree; 10 = strongly agree

In terms of hospital site, responses to all support statements were similar, with high median scores for the four positive statements (indicating agreement) and low median scores for the four negative statements (indicating disagreement). Median responses differed significantly for one statement: ‘renal staff do not have time to listen’. For this statement, medians were low for sites 1 and 2 (median 2; IQR 0 to 6 and median 1; IQR 0 to 5 respectively, and significantly higher for sites 3 and 4 (median 5; IQR 0 to 8 and median 4; IQR 0 to 7). This suggests that patients at sites 3 and 4 were significantly more likely than those in sites 1 and 2 to feel that staff did not have the time to listen to them (p=0.008).

For patient age, there were significant differences in median scores for four support statements across the patient cohort with mild to moderate distress following comparison of median tests (Figures 3.12 to 3.15). Differences were largely driven by patients in the oldest age group being significantly more likely both to agree with positive statements and disagree with negative statements than those in the two younger groups. For the statement ‘I can discuss worries or fears with renal staff’, patients aged 70 and over were significantly more likely to agree than patients aged below 50 or between 50 to 69 (70+ median 10; IQR 7 to 7 vs. under 50 median 8; 5.5 to 10 and 50 to 69 median 8; 5 to 10 respectively; p=0.007). Similarly, older patients were significantly more likely to agree that ‘it is comforting the way renal staff treat me’ (70+ median 9; 6 to 10 vs. under 50 median: 7; 5 to 9, and 50 to 69 median: 8; 5 to 10; p=0.017).

In contrast, older patients were significantly less likely to agree that they feel as though they are treated as a set of symptoms (70+ median 1; 0 to 6 vs. under 50 median 4; 0 to 7 and 50 to 69 median 2; 0 to 5.5; p=0.022), or that renal staff do not have time to listen (70+ median 1; 0 to 6 vs. under 50 median 2; 0 to 7 and 50 to 69 median 4; 0 to 7; p=0.027).

Figure 3.12: I can discuss worries with renal staff

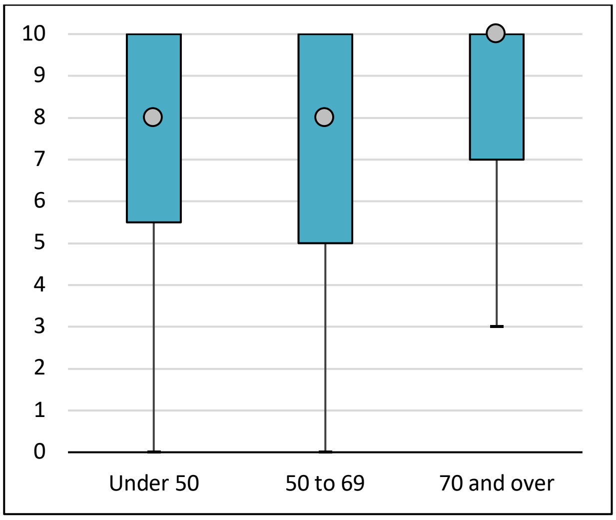
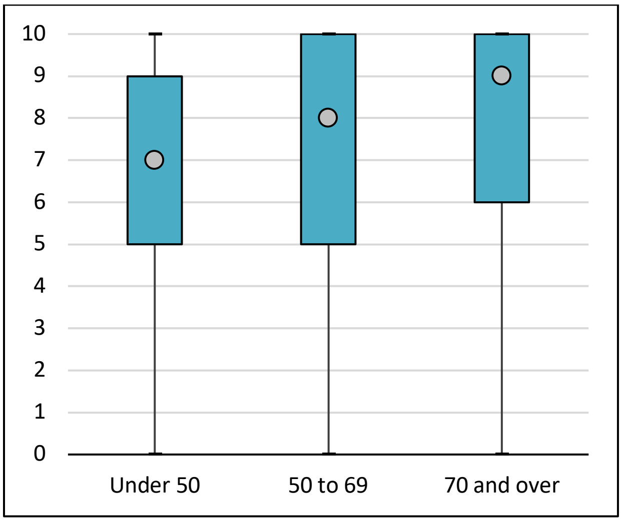


Figure 3.13: It's comforting the way staff treat me



0 = strongly disagree; 10 = strongly agree

Figure 3.14: I feel I am treated as a set of symptoms

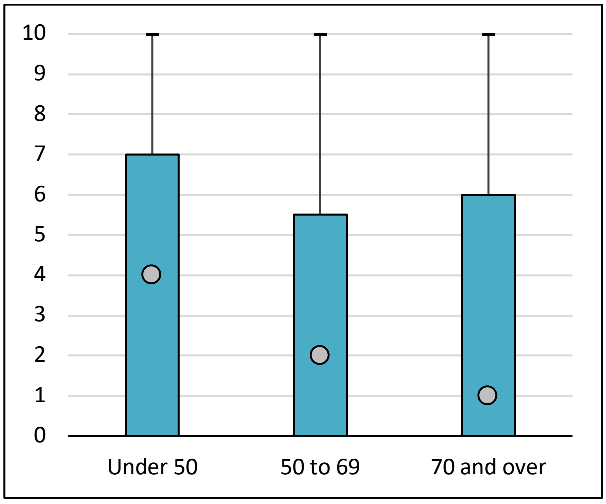
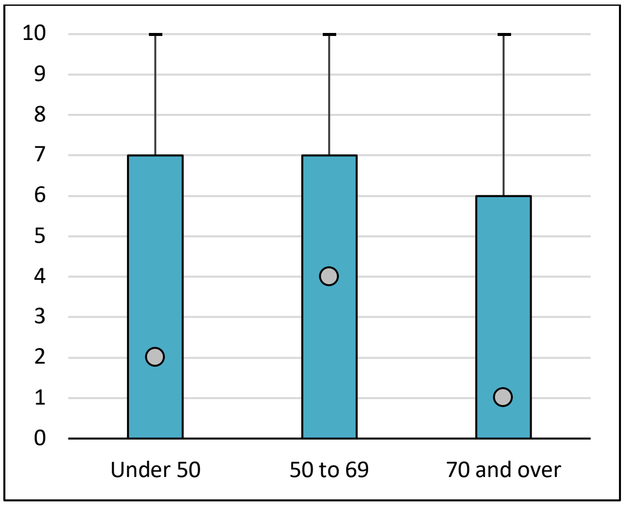


Figure 3.15: Staff do not have time to listen



0 = strongly disagree; 10 = strongly agree

There were no significant differences in median scores for patient responses to the support statements on the basis of gender, with both male and female patients having a similar distribution of responses in which positively worded statements were agreed with, and negatively worded statements were largely disagreed with. Female patients were more likely than male patients to feel that renal staff do not have time and that they 'don't know who to talk to', but the differences were not statistically significant.

In terms of ethnicity, whilst responses to the positively worded statements were similar between white and BME patients, two of the negatively worded statements showed a significant difference in median score by sub-group. BME patients were significantly more likely than white patients to feel that they were treated as a set of symptoms (median 4, IQR 0 to 7 vs. median 2, IQR 0 to 6; p=0.020). BME patients were also significantly more likely to agree with the statement 'I don't know who to talk to' (median 4, IQR 0.5 to 7 vs. median 1, IQR 0 to 5; p=0.037) (Figures 3.16 and 3.17).

Figure 3.16: I feel I am treated as a set of symptoms

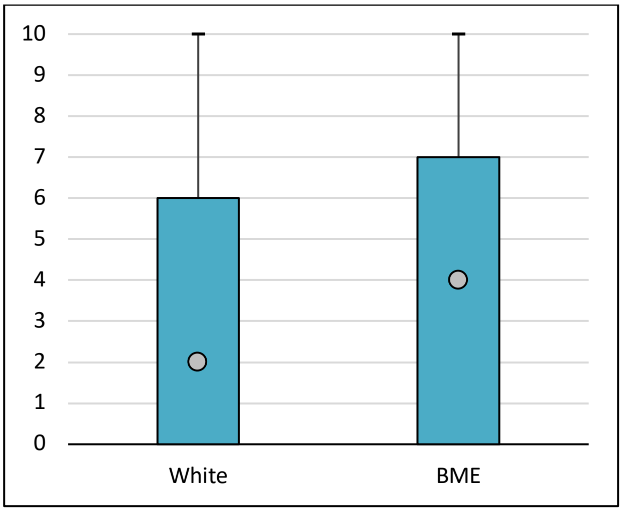
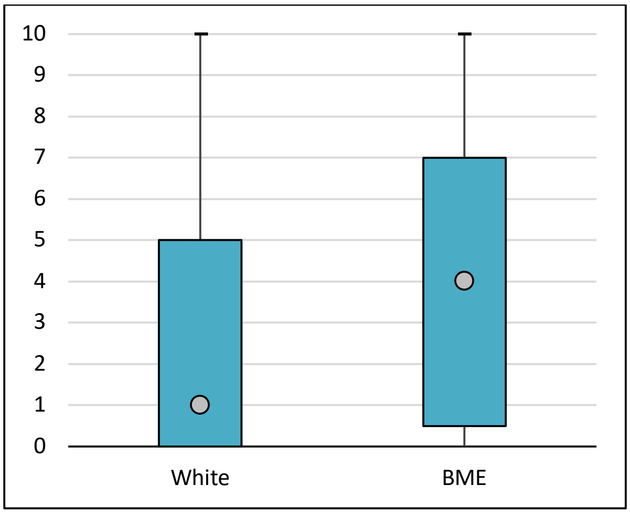


Figure 3.17: I don't know who to talk to



0 = strongly disagree; 10 = strongly agree

3.9 PATIENTS' ABILITY TO COPE WITH THEIR ILLNESS AND TREATMENT

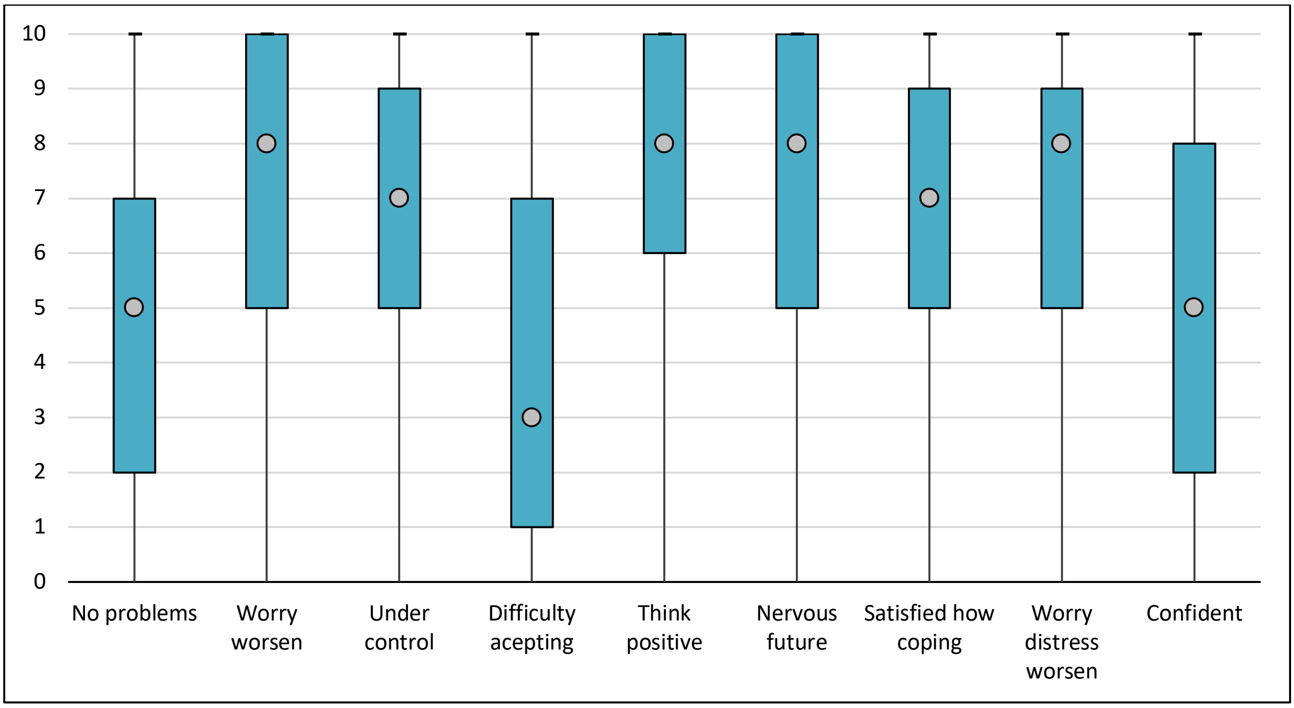
In addition to being asked about their perceptions of support received from renal staff, survey respondents were asked to indicate the degree to which they felt able to cope with their illness and its treatment, by responding to a series of pre-specified statements on a Likert scale. Table 3.16 shows median scores for each statement, and IQR for the whole cohort of patients with mild to moderate distress.

Table 3.16: Patient responses to coping statements

Statement	Median score (IQR)
I have no difficulties coping with my illness	5 (2 to 7)
I worry that my condition will worsen	8 (5 to 10)
I manage to keep bad feelings under control	7 (5 to 9)
I have difficulty accepting my illness	3 (1 to 7)
I try to think positively about my illness and treatment	8 (6 to 10)
I feel nervous about what will happen in the future	8 (5 to 10)
I'm satisfied with how I'm coping	7 (5 to 9)
I worry I might become more distressed in the future	8 (5 to 9)
I feel confident I can handle anything upsetting about my illness and treatment	5 (2 to 8)

Across the group with mild to moderate distress, there was some variability in responses to the coping statements. Although median scores were high for statements relating to positive thinking and being able to keep bad feelings under control (8.0 and 7.0 respectively), patients were often worried that their condition (and distress) would worsen and expressed nervousness about what may happen in the future. Median scores for the statement 'I have difficulty accepting my illness' were low, indicating fairly high levels of acceptance, but for this statement, the IQR was also the widest (ranging from 1 to 7), suggesting variability in responses. Agreement with the statements was most equivocal for the two statements 'I have no difficulties coping with my illness' (median 5; IQR 2 to 7), and 'I feel confident that I can handle anything upsetting about my illness and treatment (median 5; IQR 2 to 8) (Figure 3.18).

Figure 3.18: Distribution of responses to coping statements



0 = strongly disagree; 10 = strongly agree

3.9.1 Responses to coping statements by sub-group

Responses to the coping statements by ESRD pathway stage followed a similar pattern to those expressed by the group of patients with mild to moderate distress as a whole, although there were statistically significant differences in median scores for two statements. Pre-RRT and transplant patients were significantly more likely to agree that they were satisfied with how they were coping (median 9; IQR 7 to 10 and median 8; IQR 5 to 9 respectively) in comparison to those on dialysis for less than or more than two years (median 8; IQR 5.8 to 10 and median 7; IQR 6 to 9.5; p=0.035). Similarly, patients in the pre-RRT and transplant groups were significantly more likely to agree that they were able to think positively about their illness and treatment (pre-RRT median 8; IQR 5 to 10; transplant median 8; IQR 5 to 9 vs. dialysis <2 years median 6; IQR 4 to 8.3, dialysis 2+ years median 7; IQR 5 to 8; p=0.026) (Figures 3.19 and 3.20).

Figure 3.19: I am satisfied with how I am coping

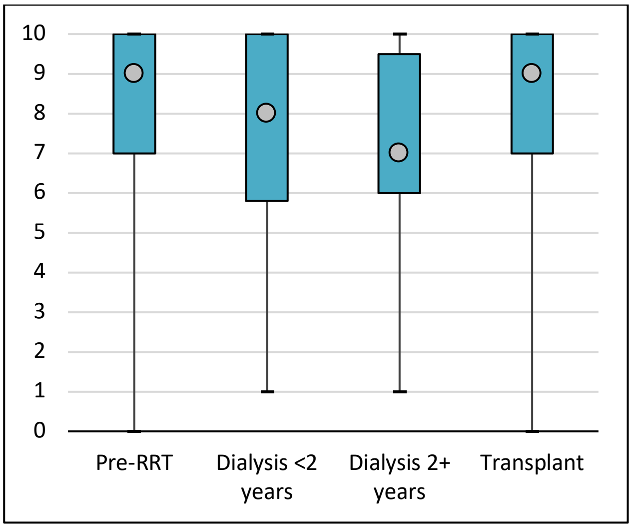
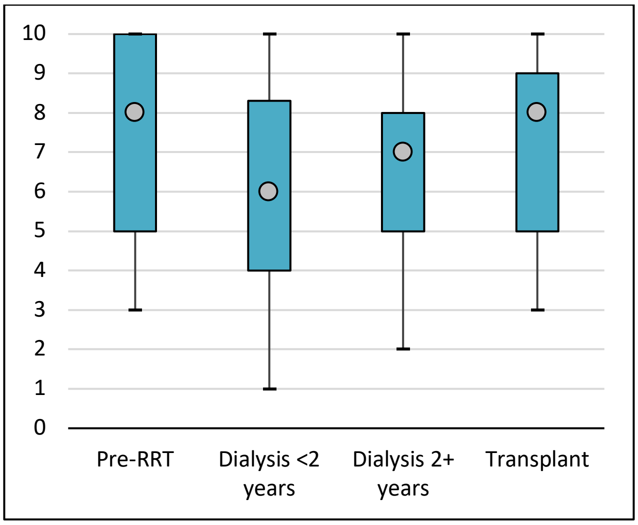


Figure 3.20: I am able to think positive



0 = strongly disagree; 10 = strongly agree

For patients being treated at the participating study sites, there were no significant differences in median scores for the coping statements, and the general pattern of answers for each site followed that of the group as a whole shown in Figure 3.18 above.

For age, younger patients (aged below 50) were significantly less likely than those in the other two groups to feel that they were able to keep bad feelings under control (median 3; IQR 1 to 7 vs. 50 to 69 median 5; IQR 2 to 7, 70+ median 5; IQR 3 to 8; p=0.018). Similarly, there was a highly significant difference in median scores for the statement ‘I have no difficulties coping with my illness’. Patients in the youngest age group were significantly more likely than other patients to agree with the statement (median 5; IQR 3 to 9 vs. 50 to 69 median 7; IQR 5 to 9, 70+ median 8; IQR 5 to 10; p<0.0001) (Figures 3.21 and 3.22).

Figure 3.21: I manage to keep bad feelings under control

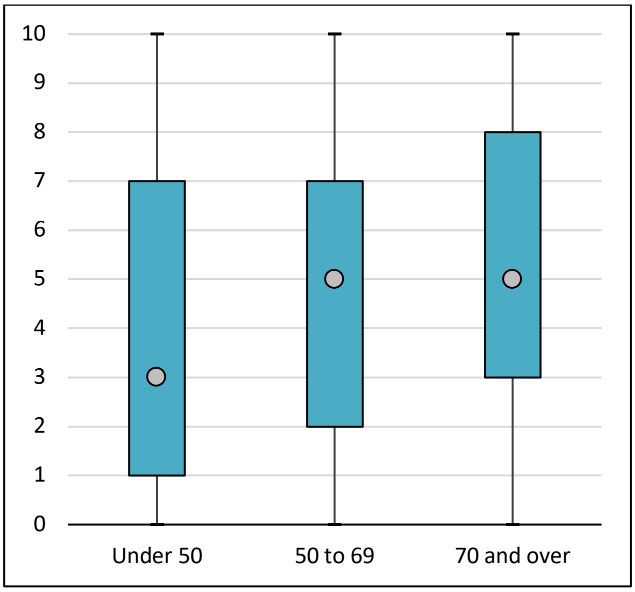
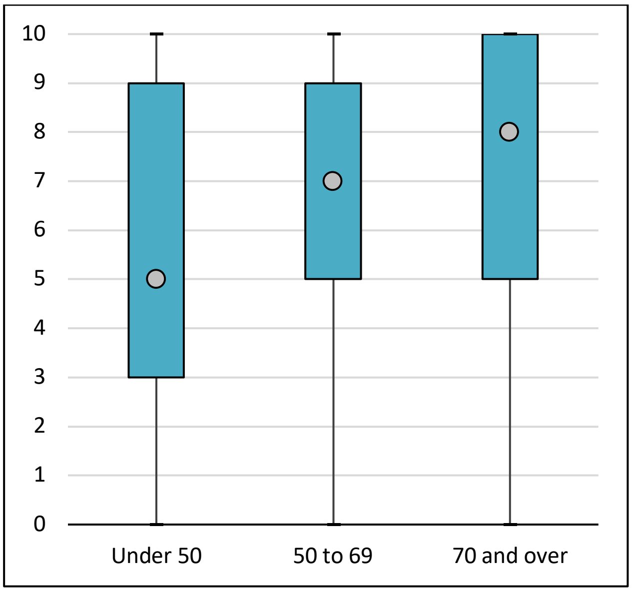


Figure 3.22: I have no difficulties coping



0 = strongly disagree; 10 = strongly agree

There were no significant differences in responses to the coping statements from male and female patients. Female patients were more likely than male patients to express difficulties coping and to express nervousness about the future than male patients, but the differences were not statistically significant.

For ethnicity, responses to the coping statements were similar for all but one statement: BME patients were significantly more likely than white patients to agree with the statement ‘I worry that I might become more distressed in the future’ (median 7; IQR 5 to 9 vs. median 9; IQR 6 to 10; p=0.005).

3.10 PATIENT PERCEPTIONS OF SUPPORT THAT MAY BE HELPFUL

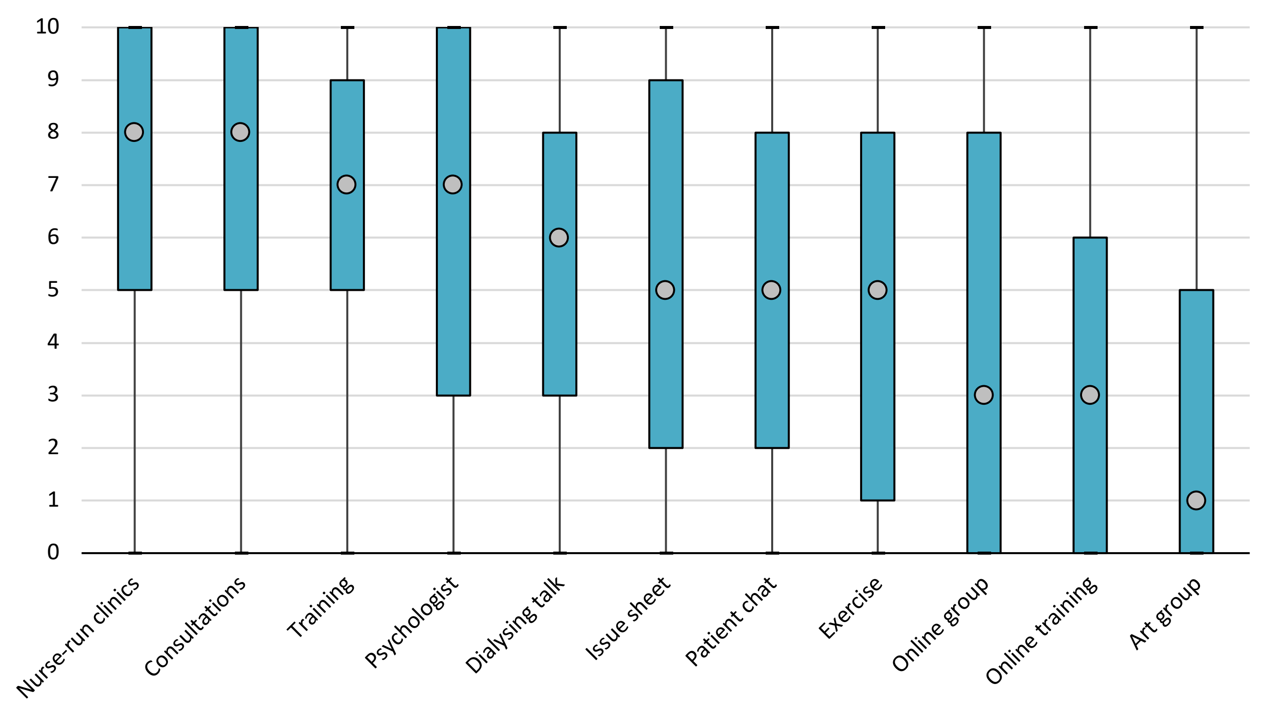
Patients were asked to indicate which of a series of pre-specified support interventions they felt might be helpful to them. Responses were again scored on a Likert scale from 0 (not at all helpful) to 10 (extremely helpful). As responses were not normally distributed, analysis focuses on descriptive statistics and a comparison of medians across sub-groups within the group of patients with mild to moderate distress. Table 3.17 and Figure 3.23 show the response to each support statement for the entire mild to moderate distress group, ordered from those with the highest median score (i.e. interventions considered most helpful) to those with the lowest score (i.e. interventions considered least helpful).

Table 3.17: Patient responses to statements about supportive interventions

Statement	Number answering	Median score (IQR)
Time to discuss emotional feelings during nurse-run clinics	325	8 (5 to 10)
Time to discuss emotional feelings during consultations with a doctor	331	8 (5 to 10)
Training in how to handle negative feelings	316	7 (5 to 9)
Talking about distress with a renal psychologist/counsellor	313	7 (3 to 10)
Talking with a nurse whilst dialysing*	149	6 (3 to 8)
Marking on a sheet the issues I want to discuss in my clinic/consultation	312	5 (2 to 9)
One-to-one chat with another renal patient	321	5 (2 to 8)
Personal physical activity programme	310	5 (1 to 8)
Online support group with other renal patients	295	3 (0 to 8)
Online training course in managing feelings and moods	309	3 (0 to 6)
Art or drawing group	308	1 (0 to 5)

* Responses restricted to the group of patients currently on dialysis

Figure 3.23: Patient responses to statements about supportive interventions



0 = not at all helpful; 10 = extremely helpful

When all patients with mild to moderate distress were considered together, the two highest scoring statements related to having more time to discuss emotional feelings during nurse-run clinics, or with a doctor in consultations. This was followed by the opportunity to receive training in how to handle negative feelings, and being able to talk about distress with a renal psychologist or counsellor.

Patients were least likely to perceive online support groups, online training in managing moods/feelings and art/drawing groups as being potentially helpful supportive interventions.

Further analysis explored the ranking of interventions from most to least helpful based on the proportion of the ‘ceiling score’ given to each intervention based on the number of individuals who answered the question. For example, if 100 patients responded to the statement about the perceived helpfulness of exercise classes, and all 100 considered this intervention to be extremely helpful, the maximum total score from summing the Likert scale responses for that intervention would be 1000 (100x10=1000). In summing the actual Likert scale responses for that intervention (e.g. 50 patients scored it as a 1; 20 patients scored it as a 2 etc.) and expressing this total as a percentage of the potential ceiling score, this gives an indication of the interventions that were considered more or less helpful by patients giving a score for each intervention.

Table 3.18 shows the ranking of most to least helpful intervention on the basis of the proportion of ceiling score it achieved (higher percentages represent more helpful interventions).

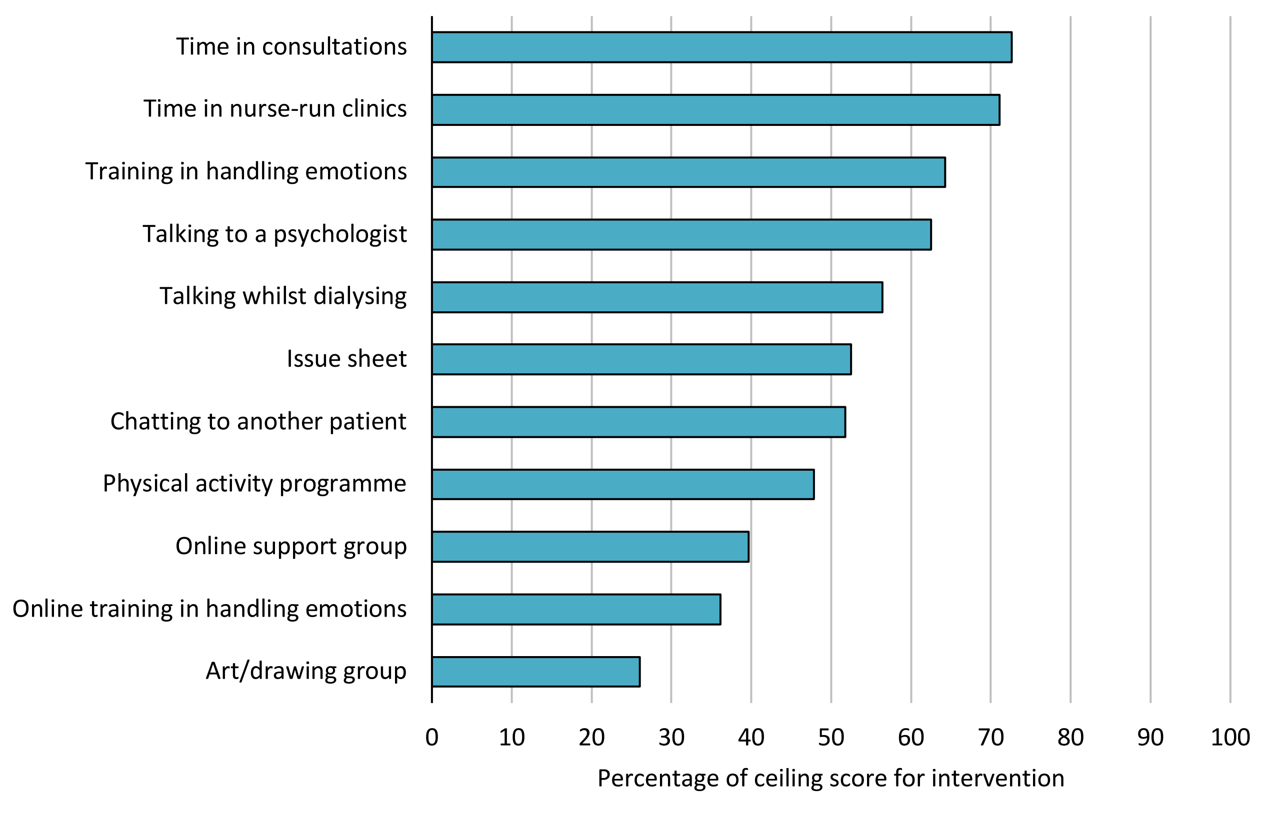
Table 3.18: Patient ranking of supportive interventions

Statement	Ceiling score	Actual score	% of ceiling score	Rank
Time to discuss emotional feelings during consultations with a doctor	3310	2404/3310	72.6	1
Time to discuss emotional feelings during nurse-run clinics	3250	2312/3250	71.1	2
Training in how to handle negative feelings	3160	2033/3160	64.3	3
Talking about distress with a renal psychologist/counsellor	3130	1955/3130	62.5	4
Talking with a nurse whilst dialysing*	1490	841/1490	56.4	5
Marking on a sheet the issues I want to discuss in my clinic/consultation	3120	1639/3120	52.5	6
One-to-one chat with another renal patient	3210	1662/3210	51.8	7
Personal physical activity programme	3100	1482/3100	47.8	8
Online support group with other renal patients	2950	1172/2950	39.7	9
Online training course in managing feelings and moods	3090	1117/3090	36.1	10
Art or drawing group	3080	802/3080	26.0	11

* Restricted to patients currently on dialysis

The ranking of interventions is similar to that presented in Figure 3.23. The top three potentially most helpful interventions were reported as time to discuss emotional feelings during consultations with a doctor (72.6% of ceiling score) or during nurse-run clinics (71.1%), and training in how to handle negative feelings (64.3%). The three potentially least helpful interventions were considered to be an online patient support group (39.7%), an online training course (36.1%) and art/drawing group (26.0%). It is clear from this list that the interventions that patients may value the most are based on face-to-face interaction with healthcare professionals in which emotions can be discussed in person, or face-to-face training. Online support options, which may have similar aims in allowing patients to express any issues they may be facing, were the least popular of the inter-personal options offered. Figure 3.24 presents the ranking of interventions graphically, ordered from most to least helpful.

Figure 3.24: Ranking of potentially helpful supportive interventions



3.10.1 Differences in perceived helpfulness of supportive interventions by sub-group

Table 3.19 shows the ranking of potential supportive interventions according to the proportion of the ceiling score each achieved, on the basis of ESRD pathway stage. Rankings were remarkably similar across groups: the top four interventions were the same for all patients, with discussing feelings in nurse-run clinics and discussing feelings in consultations the top two options for all patients (nurse-run clinics were top for pre-dialysis and transplant patients, and second for the two dialysis groups). This suggests that dialysis patients may value talking to their consultant about their distress more than talking to a nurse about it. Similarly, 'training to handle negative feelings' and 'talking with a psychologist' were ranked 3 or 4 by each group of patients. Transplant patients ranked talking with a psychologist 3rd, whereas the other groups ranked this option 4th, and cited training in how to handle negative feelings as 3rd.

All patients, regardless of stage, had the same four interventions ranked in the lowest positions of 8, 9, 10 and 11 (physical activity programme, online training course, online patient support group and art or drawing group). The latter was ranked lowest by all patients, reaching less than 30% of its ceiling score across the board. The (comparative) lack of support for online training and support options suggests that all patients value talking face-to-face with specific individuals (particularly doctors or nurses) in preference to the more impersonal option of online distress management. Nevertheless, despite ranking online patient support as 9th out of 11 possible interventions, for transplant patients this still reached 51% of its ceiling score, suggesting that half of all transplant patients would still find the option of online support useful. Indeed, transplant patients achieved a greater percentage of the ceiling score for every intervention than patients at other stages. All patients ranked the remaining interventions in places 5 to 7, although the specific order varied according to ESRD pathway stage.

Table 3.19: Ranking of interventions for patients at each stage of the ESRD pathway

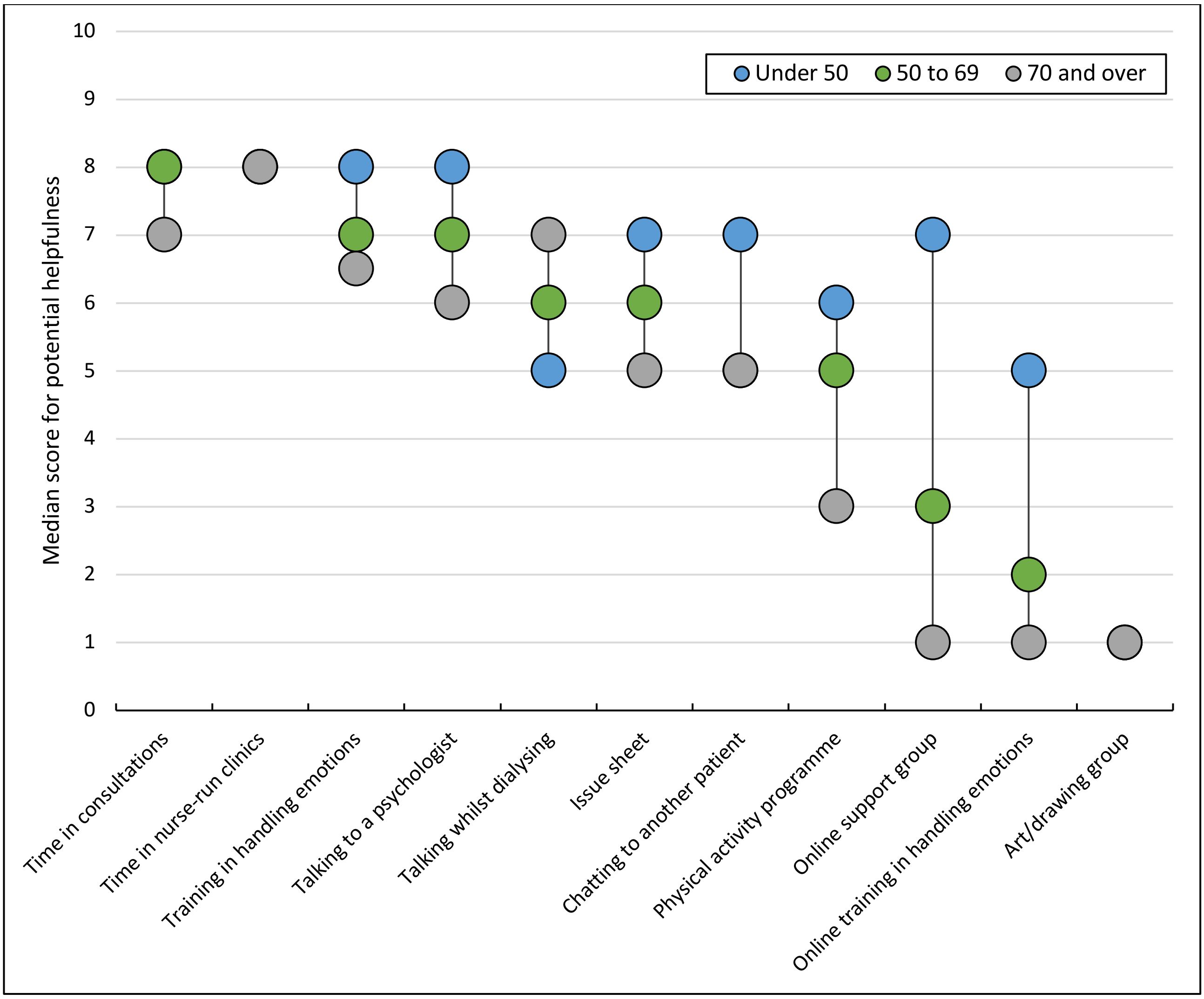
	Pre-RRT		Dialysis <2 years		Dialysis 2+ years		Transplant	
Intervention	% of ceiling score	Rank	% of ceiling score	Rank	% of ceiling score	Rank	% of ceiling score	Rank
Discuss feelings in nurse-run clinics	74.8	1	69.4	2	67.7	2	74.7	1
Discuss feelings in consultations	72.3	2	74.5	1	71.0	1	74.0	2
Training to handle negative feelings	64.5	3	68.2	3	60.4	3	68.5	4
Talking with psychologist	57.1	4	63.3	4	57.8	4	69.0	3
Chat with another patient	52.8	5	49.4	7	49.0	6	57.3	6
Online training course	31.6	10	34.5	9	28.7	10	45.9	10
Issue sheet to mark issues	51.4	6	50.4	6	45.3	7	57.2	7
Physical activity programme	49.3	8	47.0	8	39.4	8	54.6	8
Art or drawing group	26.8	11	26.9	11	21.8	11	28.8	11
Talking with nurse whilst dialysing	51.3	7	56.0	5	56.7	5	62.0	5
Online patient support group	35.7	9	34.2	10	33.4	9	51.0	9

It is less instructive to assess whether or not patients in particular sociodemographic sub-groups had different preferences for support interventions, given that any such interventions are likely to be offered to all patients, or tailored to patients at specific stages of the ESRD pathway rather than offered e.g. to younger patients or females. Nevertheless, there were some significant differences in median scores given by patients in specific sub-groups in relation to perceptions about the helpfulness of particular interventions.

There were no differences between groups according to hospital site. Perhaps surprisingly, there were also no significant differences in the perceived helpfulness of specific interventions when the data were assessed on the basis of ethnic group. Both white and BME patients had a similar profile of responses to each potential intervention, with time to discuss feelings with nurse/doctor scored highest by both groups of patients. BME patients were more likely to find taking with a nurse whilst dialysing helpful (median 7; IQR 3.8 to 9 vs. median 5; IQR 3 to 8), and white patients were more likely to consider talking to a renal psychologist to be helpful (median 7.5; IQR 4 to 10 vs. median 6; IQR 2 to 9), but these differences were not statistically significant.

In terms of age group, there were some significant differences in the perceived helpfulness of potential interventions (Figure 3.25). Patients in all three age groups rated time to discuss emotional feelings with doctors or in nurse-run clinics as potentially the most helpful. Patients aged below 50 were significantly more likely to regard talking to a renal psychologist as helpful, with patients aged 70 and over rating this as the 5th most useful intervention according to median score ($p=0.030$). The largest differences in median intervention scores for patients in different age groups came in relation to perceptions of the helpfulness of physical activity programmes and the utility of online training. The difference for physical activity programmes was largely driven by patients aged 70+ finding this particularly unhelpful in comparison to patients in the other two age groups (p=0.015). In contrast, patients aged below 50 were significantly more likely than patients in the other age groups to value participation in either an online patient support group (p<0.0001), or an online training course about emotion management (p=0.002).

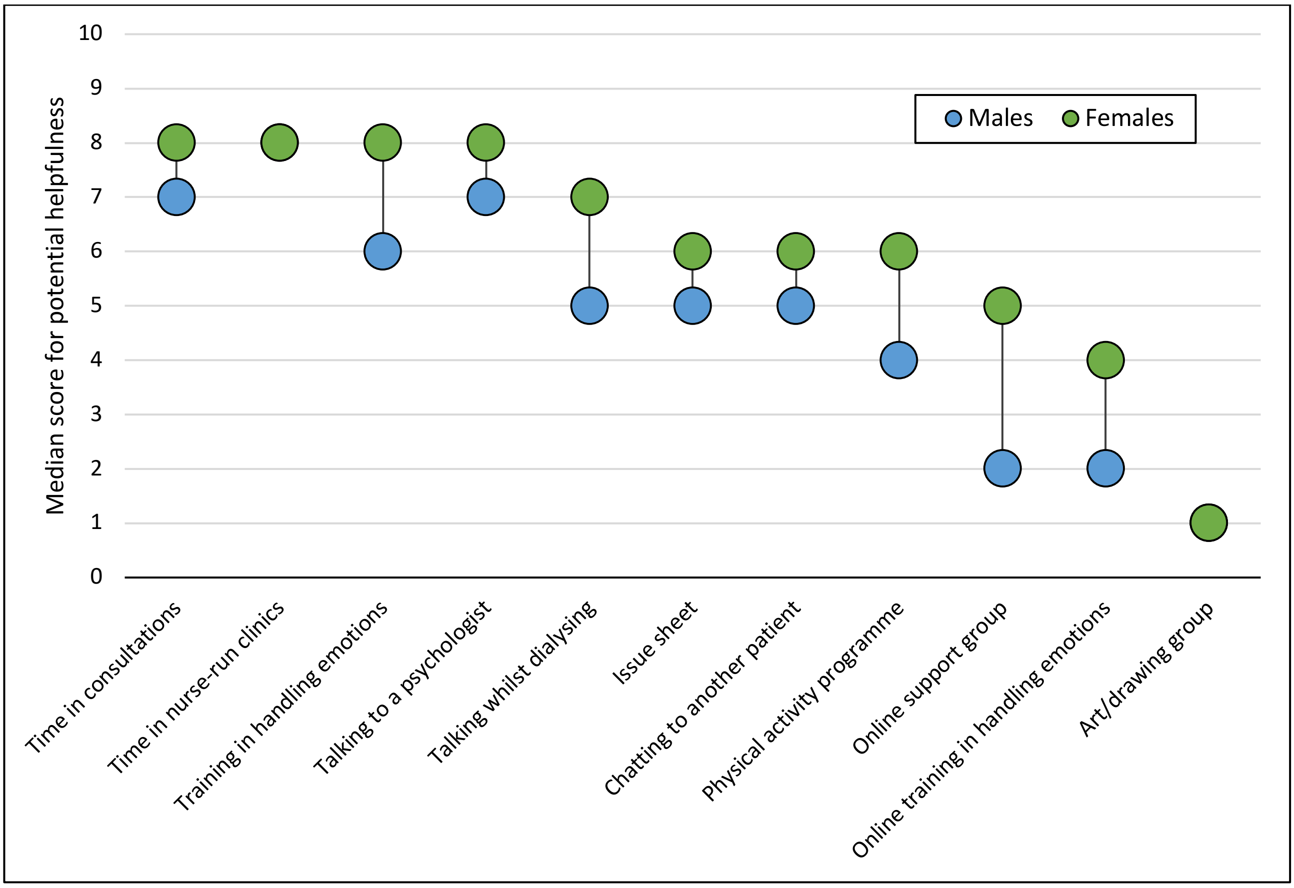
Figure 3.25: Median scores for perceived helpfulness of interventions, by age group



There were also some significant differences in the perceived usefulness of specific interventions for female vs. male patients, with 4 out of the 11 interventions showing significantly differing median scores (Figure 3.26). Apart from perceptions of the utility of talking about emotions during nurse-run clinics, for which median scores for both groups were the same, females reported higher median scores than males for all other interventions. This suggests that female patients may be more receptive than male patients to any support intervention.

The largest differences in medians for females and males related to perceptions of the usefulness of training in how to handle emotions (female median 8; IQR 5 to 10 vs. male median 6; IQR 4 to 9; p=0.035); talking to a nurse whilst dialysing (female median 7; IQR 3.5 to 9 vs. male median 5; IQR 3 to 8; p=0.018), and both of the online support options. Male patients were significantly less likely than females to perceive an online patient support group or online handling in how to handle emotions as being useful (median 2; IQR 0 to 7 vs. median 5; IQR 0 to 9; p=0.014) and (median 2; IQR 0 to 5 vs. median 4; IQR 0 to 8; p=0.011 respectively).

Figure 3.26: Median scores for perceived helpfulness of interventions, by gender



4. RESULTS: STAFF SURVEY

This chapter presents the findings from the survey of renal unit staff undertaken at study sites 1 and 2. The broad aims of this survey were to assess the factors that help or hinder staff in identifying and responding to patients who may have emotional and psychological support needs, and to consider how these barriers might be overcome. The number of survey responses was comparatively small (Section 4.1), so analysis focuses on descriptive statistics rather than detailed sub-group analyses, although results are broken down by hospital site to assess whether there may be any organisational or staff factors operating at the local context that influence the extent to which staff can identify and respond to patient distress. Sub-group analysis has been carried out where appropriate to assess whether there was any association between survey responses and whether or not staff members had received any training in how to deal with patient distress.

4.1 STAFF SURVEY RESPONSE RATE

In total, 307 surveys were sent to staff across the two sites (172 at site 1, and 135 at site 2). The overall response rate was 35.2%, with 108/307 surveys returned (Table 4.1). Seventy two surveys were returned electronically (66.7%), and 36 were returned in paper format (33.3%). Response rates by site were similar from staff in the two Trusts surveyed: at site 1, 64/172 surveys were returned (37.2%), compared with 44/135 from site 2 (32.6%). The highest response rates at each site were from managers, doctors (registrars or consultants) and allied health professionals (dieticians, social workers etc.), with the lowest rate of return in both sites being from healthcare assistants. A comparison of proportions test to assess non-response bias showed no significant differences in the proportion of responses received from staff at each site (X^2=0.62; p=0.43).

Table 4.1: Staff survey responses by role and site

	Site 1		**Site 2**	
Job role	**Survey returns**	**Response (%)**	**Survey returns**	**Response (%)**
Nurse	37/113	32.7	26/95	27.4
Healthcare assistant	4/33	12.1	2/13	15.4
Doctor	8/13	61.5	8/13	61.5
Allied Health Professional	4/7	57.1	3/4	75.0
Manager	2/2	100.0	2/2	100.0
Administration	9/12	75.0	3/8	37.5
Total	**64/172**	**37.2**	**44/135**	**32.6**

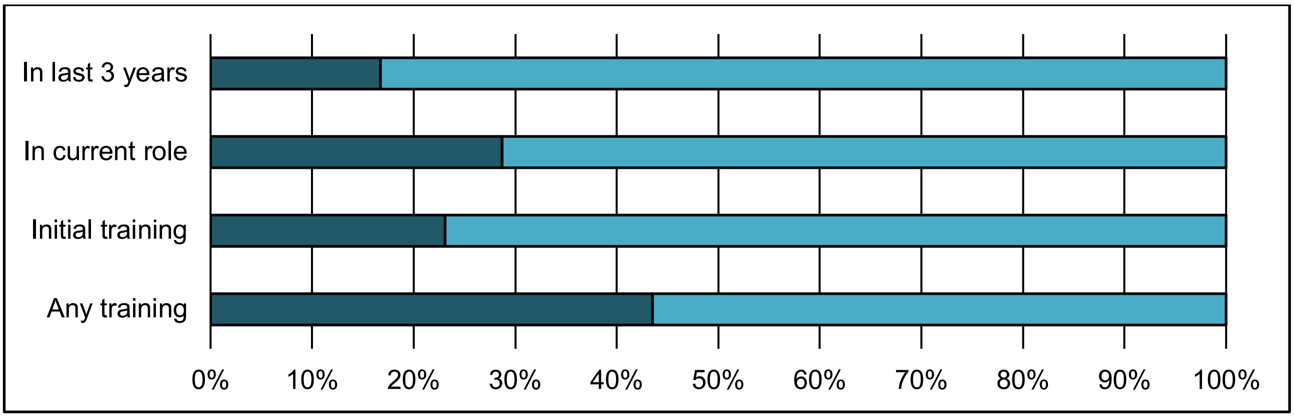
Characteristics of respondents

Table 4.2 shows the characteristics of the sample who returned a survey, for each site and overall, on the basis of key sociodemographic, employment and training-related characteristics. Staff in nursing roles comprised almost 60% of all respondents, with a further 14.8% classed as doctors. Around three quarters of the sample were female, and the mean age across respondents was 46. The majority of respondents had been performing their current role for a substantial period of time: over half had been in their current role for 10 or more years. Most respondents (64.8%) stated that they had direct contact with renal patients every working day. Despite this, 56.5% of respondents (57.8% at site 1, 54.5% at site 2) had not received any training in working with distressed renal patients, whether this was part of their initial professional training, in their current role or in the past three years (Figure 4.1).

Table 4.2: Characteristics of respondents to renal staff survey

Variable	Sub-groups	Site 1 (%)	Site 2 (%)	Total
Age (years)	Mean (SD); Range	46 (10.5); 21 to 70	47 (9.8); 25 to 64	46 (10.1); 21 to 70
Gender	Male	17 (26.6)	9 (20.5)	26 (24.1)
	Female	47 (73.4)	35 (79.5)	82 (75.9)
Role	Nurse	37 (57.8)	26 (59.1)	63 (58.3)
	Healthcare Assistant	4 (6.3)	2 (4.5)	6 (5.6)
	Doctor	8 (12.5)	8 (18.2)	16 (14.8)
	Allied Health Professional	4 (6.3)	3 (6.8)	7 (6.5)
	Renal manager	2 (3.1)	2 (4.5)	4 (3.7)
	Administration/other	9 (14.1)	3 (6.8)	12 (11.1)
Time in current role	< 6 months	4 (6.3)	2 (4.5)	6 (5.6)
	7 to 12 months	4 (6.3)	2 (4.5)	6 (5.6)
	12 months to 2 years	3 (4.7)	5 (11.4)	8 (7.4)
	2 to 3 years	2 (3.1)	3 (6.8)	5 (4.6)
	3 to 5 years	2 (3.1)	6 (13.6)	8 (7.4)
	5 to 10 years	13 (20.3)	6 (13.6)	19 (17.6)
	10 to 20 years	27 (42.2)	14 (31.8)	41 (37.9)
	20 to 30 years	8 (12.5)	6 (13.8)	14 (13.0)
	30+ years	1 (1.6)	0 (0.0)	1 (0.9)
Time since qualifying	< 6 months	1 (1.6)	1 (2.3)	2 (1.9)
	7 to 12 months	2 (3.1)	3 (6.8)	5 (4.6)
	12 months to 2 years	2 (3.1)	2 (4.5)	4 (3.7)
	2 to 3 years	2 (3.1)	4 (9.0)	6 (5.6)
	3 to 5 years	3 (4.7)	3 (6.8)	6 (5.6)
	5 to 10 years	7 (10.9)	18 (40.9)	25 (23.1)
	10 to 20 years	26 (40.6)	11 (25.0)	37 (34.3)
	20 to 30 years	18 (28.1)	2 (4.5)	20 (18.5)
	30+ years	3 (4.7)	0 (0.0)	3 (2.8)
Frequency of contact with renal patients	Less than monthly	1 (1.6)	0 (0.0)	1 (0.9)
	Monthly	1 (1.6)	0 (0.0)	1 (0.9)
	Every 2 to 3 weeks	0 (0.0)	2 (4.5)	2 (1.9)
	Weekly	5 (7.8)	1 (2.3)	6 (5.6)
	3 to 4 days per week	7 (10.9)	3 (6.8)	10 (9.3)
	Most working days	8 (12.5)	10 (22.7)	18 (16.7)
	Every working day	42 (65.6)	28 (63.6)	70 (64.8)
ANY training	Yes	27 (42.2)	20 (45.5)	47 (43.5)
	No	37 (57.8)	24 (54.5)	61 (56.5)
Initial training	Yes	16 (25.0)	9 (20.5)	25 (23.1)
	No	48 (75.0)	35 (79.5)	83 (76.9)
As part of current role	Yes	10 (15.6)	8 (18.2)	18 (16.7)
	No	54 (89.4)	36 (81.8)	90 (83.3)
Whilst in current role	Yes	14 (21.9)	17 (38.6)	31 (28.7)
	No	50 (78.1)	27 (61.4)	77 (71.3)
In the last 3 years	Yes	7 (10.9)	11 (25.0)	18 (16.7)
	No	57 (89.1)	33 (75.0)	90 (83.3)

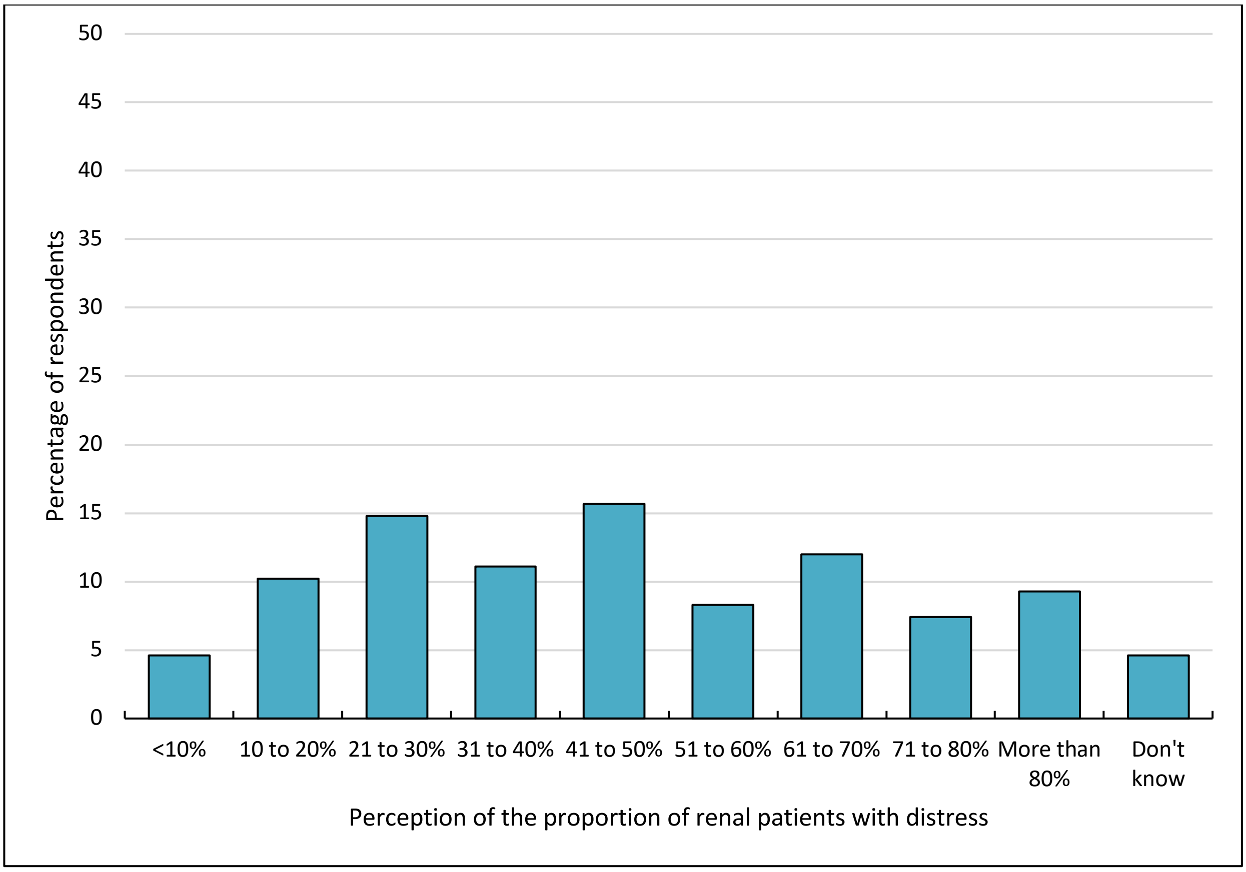
Figure 4.1: Staff training in dealing with distressed renal patients



4.2 STAFF PERCEPTIONS OF PATIENT DISTRESS AND SUPPORT OFFERED

Staff were asked to estimate the proportion of patients with ESRD in their renal unit who were distressed (Figure 4.2). Responses were wide-ranging across the full set of answer categories. Data from the patient survey for this study suggest that between 30 to 40% of renal patients may have mild to moderate distress. Around 30% of renal unit staff perceived the proportion of distressed patients to be lower than this; 11.1% (n=12) believed the true proportion to be between 30 to 40%; 4.6% of respondents (n=5) returned a ‘don’t know’ answer, and the remaining 57 respondents (52.8%) believed the prevalence of distress to be greater than 40%. The median response group (both overall and when data from each study site were assessed separately) was 41 to 50%.

Figure 4.2: Renal unit staff perceptions of the proportion of ESRD patients with distress



Respondents were also asked whether they considered support for renal patients with distress to be beneficial. Staff overwhelmingly considered support to be very beneficial, with 63.9% of staff agreeing very strongly with the survey statement (Figure 4.3). Proportions were similar across the two study sites (p=0.517), with 67.2% of staff in site 1 (n=43) and 59.1% (n=26) in site 2 strongly agreeing with the statement. Despite the large proportion of renal unit staff who considered support for renal patients with distress to be very beneficial, reported levels of satisfaction with the support provided within the two renal units were far lower. On the Likert scale for satisfaction with support offered (Figure 4.4), the median response from staff in both study sites was 6 out of 10, indicating a moderate level of satisfaction with support. A comparison of median test for responses from each site again showed no significant differences between Trusts (p=0.581).

Figure 4.3: Is support to distressed patients beneficial?

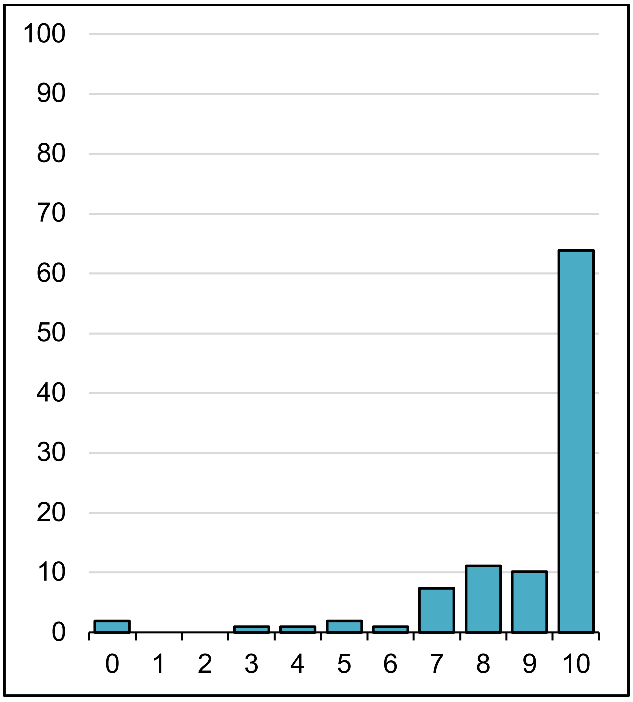
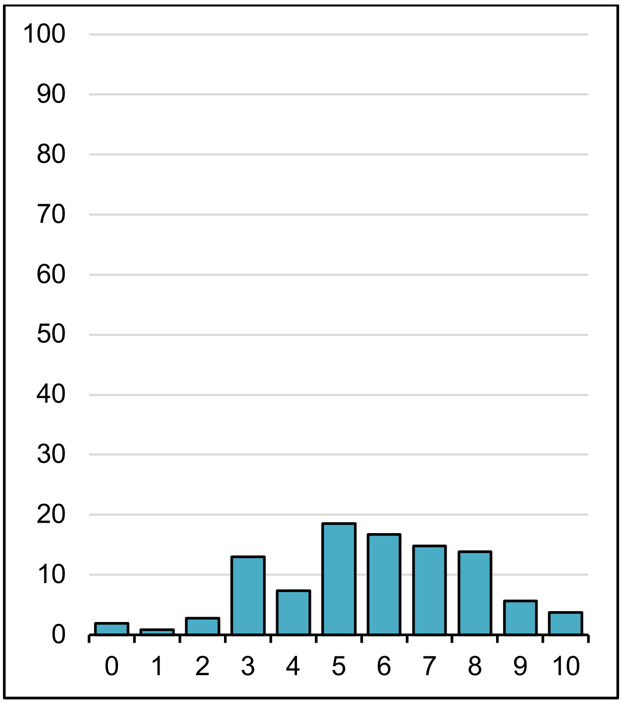


Figure 4.4: How satisfied are you with the support your renal unit provides?



0 = strongly disagree; 10 = strongly agree

4.3 STAFF PERCEPTIONS OF THEIR ROLE IN IDENTIFYING AND RESPONDING TO DISTRESS

Staff were asked to respond to a series of eight statements relating to their perception of their role in both identifying and responding to distress in patients with ESRD within their renal unit. All statements were scored on a Likert scale, with 0 indicating strong disagreement with the statement, and 10 indicating strong agreement. Four of the statements were positively worded e.g. 'I find this a fulfilling role', and four were negatively worded e.g. 'there is little point in taking responsibility without reward or promotion'.

4.3.1 Staff response to 'role' statements, overall and by study site

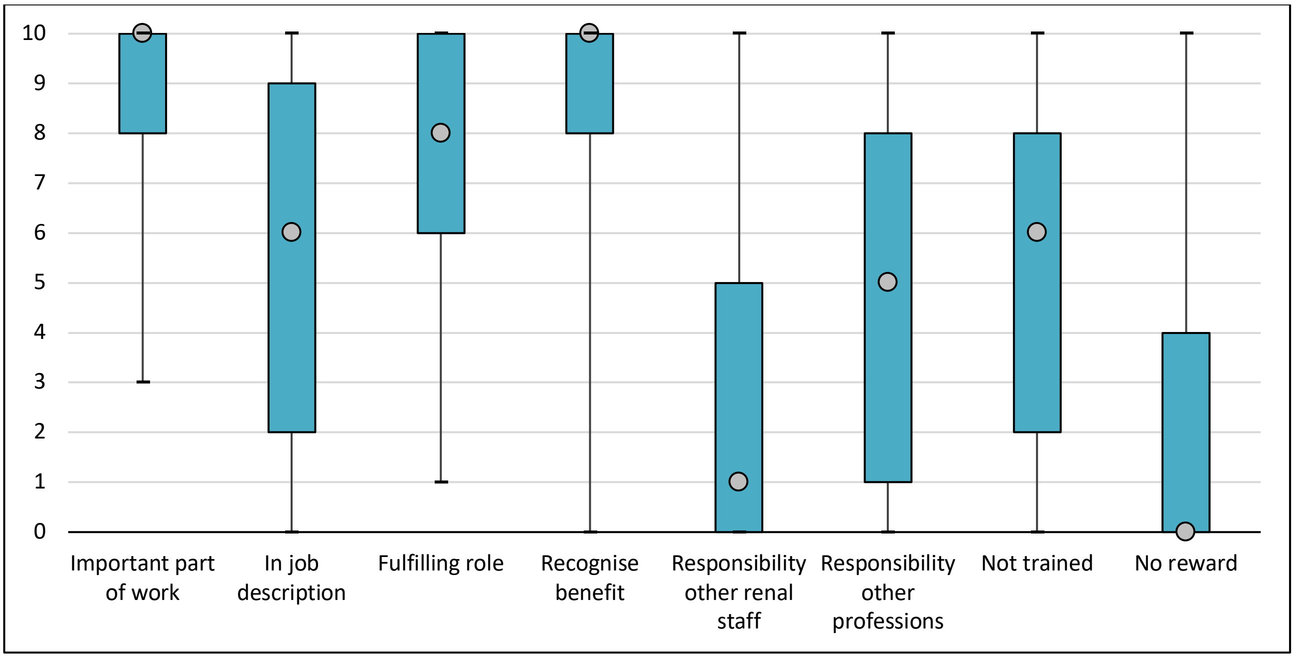
Responses were assessed first on the basis of study site, with analysis focusing on medians and IQR for scores in relation to each of the statements (Table 4.3, Figure 4.5). For three of the four positively worded statements, agreement with the statement was high. Nearly two thirds of respondents (58.3%; n=63) considered identifying and responding to the needs of renal patients to be an important part of their work. Responses to the statement did not differ significantly between study sites when medians were compared (p=0.765). Similarly, staff in both study sites tended to strongly agree that identifying and responding to distress in renal patients was fulfilling – 60.2% of staff scored this statement as an 8, 9 or 10 out of 10 (n=65) - and that there was a recognisable benefit to patients in doing this – 78.7% of staff scoring the statement 8, 9 or 10 out of 10 (n=85). There was no significant difference in median responses between study sites for either of these statements (p=0.604; p=0.610).

Table 4.3: Responses to statements regarding staff role in identifying and responding to distress

Statement	**Site 1 median (IQR)**	**Site 2 median (IQR)**	**All respondents**	**Comparison of medians**
It's an important part of my work	10 (8 to 10)	10 (8 to 10)	10 (8 to 10)	p=0.765
It's in my job description	6.5 (2 to 9)	5 (3 to 10)	6 (2 to 9)	p=0.951
I find it a fulfilling role	8 (5.5 to 10)	8 (6 to 10)	8 (6 to 10)	p=0.604
I recognise the benefit to patients	9 (8 to 10)	10 (8 to 10)	10 (8 to 10)	p=0.610
It's the responsibility of other renal staff	1 (0 to 5)	2 (0 to 7)	1 (0 to 5)	p=0.266
It's the responsibility of other professions	4 (1 to 7)	5 (2 to 8)	5 (1 to 8)	p=0.091
I'm not trained for this role	6 (2 to 9)	5 (2 to 8)	6 (2 to 8)	p=0.604
Little point taking responsibility without reward/promotion	0 (0 to 5)	0 (0 to 2)	0 (0 to 4)	p=0.139

Despite the majority of staff stating that identifying and responding to patient distress was important, beneficial and fulfilling, responses to the statement 'it's in my job description' were more polarised, with a median score of 6.5 out of 10 for site 1, and 5 out of 10 for site 2 and an overall median for all respondents combined of 6 (IQR 2 to 9).

Figure 4.5: Median scores for staff 'role' statements



0 = strongly disagree; 10 = strongly agree

Amongst the four negatively worded statements, there were again some variations in staff responses. Over half of the sample (55.6%; n=60) strongly disagreed with the statement that 'there is little point in taking responsibility without reward/promotion'. Similarly, renal unit staff agreed strongly that identifying and responding to the needs of distressed patients was not the responsibility of staff other than themselves in the renal unit. Responses were similar across Trusts for both statements (p=0.139; p=0.266). Despite perceiving that they had a personal responsibility towards distressed patients within the renal unit, when asked to consider the potential responsibility of staff in other professions (outside of the renal unit), opinion was more mixed. The median score for this statement was 5, with a large inter-quartile range of 1 to 8. This suggests that whilst renal staff are prepared to take responsibility for renal patients that may have support needs within the renal unit, they also believe that staff in other professions such as GPs and counsellors can play a useful role. The response profile to this statement did not differ between study sites (p=0.091). For the final statement, about whether or not staff perceived that they were trained in supporting distressed patients, the median score was 6 out of 10 (IQR 2 to 8). This suggests that there may be a training gap for renal unit staff – although they saw patient support as part of their responsibility, and they recognised the benefit for patients of them taking this role, around 30% of staff (n=32) believed that they were not adequately trained to undertake patient support. Median scores for this statement did not differ by study site (p=0.604).

4.3.2 Staff response to 'role' statements, according to training status

Table 4.4 shows median scores and IQR for each of the staff 'role' statements, according to whether or not staff respondents reported having any training in how to deal with distressed patients. Medians for each sub-group are shown graphically in Figure 4.6.

Table 4.4: Staff responses to 'role' statements, according to training status

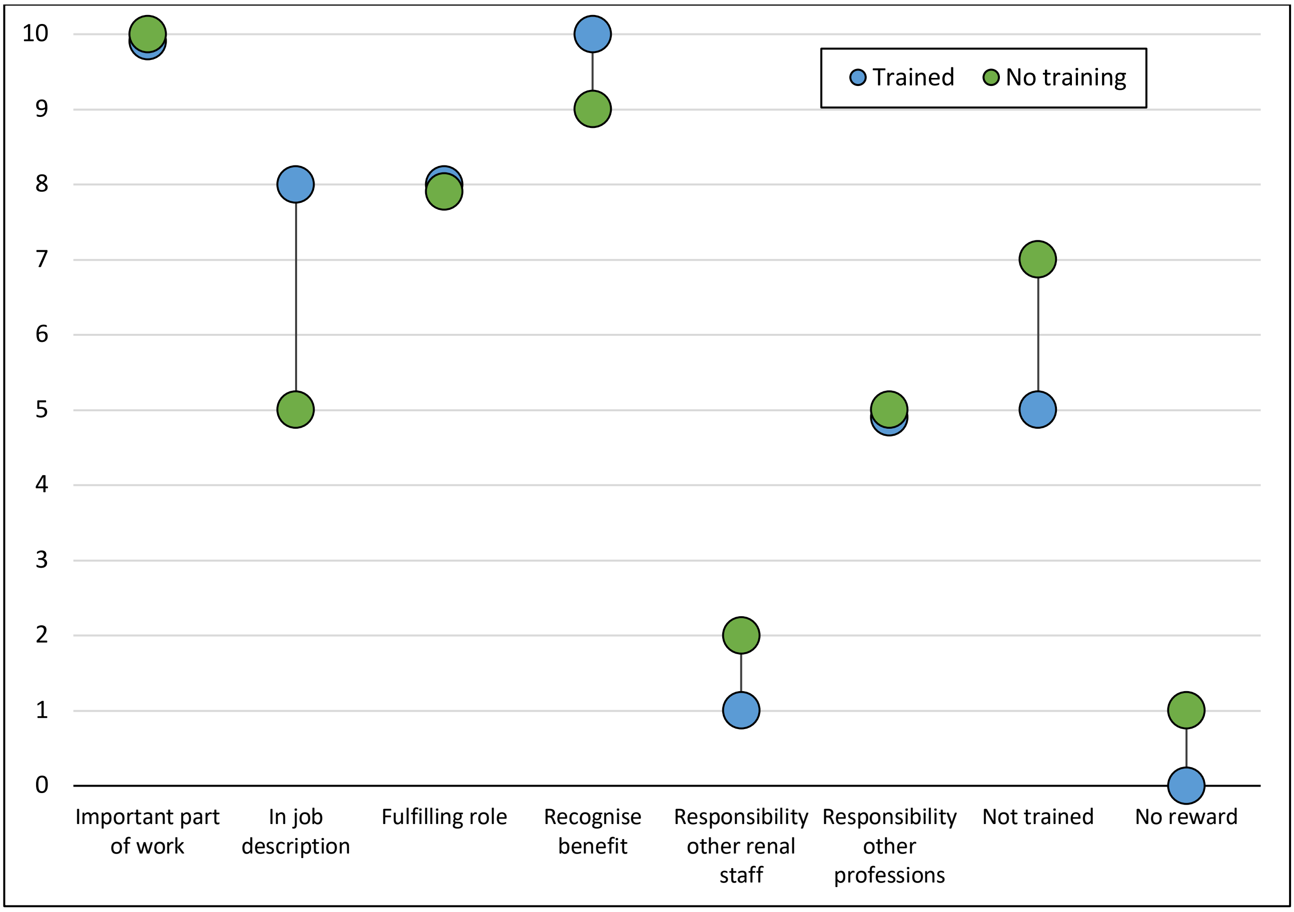
Statement	Training (IQR)	No training (IQR)	Comparison of medians
It's an important part of my work	10 (8.8 to 10)	10 (8 to 10)	-
It's in my job description	8 (4 to 10)	5 (2 to 8)	**p=0.008**
I find it a fulfilling role	8 (7 to 10)	8 (5 to 9)	p=0.088
I recognise the benefit to patients	10 (8 to 10)	9 (7 to 10)	-
It's the responsibility of other renal staff	1 (0 to 5)	2 (0 to 5)	p=0.108
It's the responsibility of other professions	5 (1 to 8)	5 (3 to 8)	p=0.997
I'm not trained for this role	5 (1 to 6)	7 (2 to 10)	**p=0.002**
Little point taking responsibility without reward/promotion	0 (0 to 1)	1 (0 to 5)	p=0.069

0 = strongly disagree 10 = strongly agree

For the majority of statements relating to staff perceptions of their role in identifying and responding to distress, there was little difference in median scores on the basis of staff training status. All staff, irrespective of their level of training in identifying and handling distress, felt that doing so was fulfilling, an important part of their work, and something which had recognisable benefits for patients. Similarly, staff in both training groups perceived responding to patient distress to be something which – in the renal unit – was their own responsibility, and that receiving reward/promotion for doing so was not necessary.

There were significant differences in median responses for two statements. Unsurprisingly, staff who had not received training in how to identify and handle distress in renal patients were significantly more likely to agree with the statement 'I'm not trained for this role' than those who had received some training (median score 7; IQR: 2 to 10 vs. median 5; IQR: 1 to 6; p=0.002). Staff who had received training in supporting distressed patients were significantly more likely than those without training to agree that identifying and responding to patient distress was part of their job description (median 8; IQR: 4 to 10 vs. median 5; IQR: 2 to 8; p=0.008).

Figure 4.6: Median scores for staff 'role' statements, by training status



0 = strongly disagree; 10 = strongly agree

4.3.3 Composite 'role' score for all staff

A composite 'role' score was created for each staff survey respondent, in which each individual's score for the eight statements relating to role perception were added together. This allowed sub-group analysis to determine whether there were any differences in composite role scores on the basis of gender, role, study site, length of time in current role, time since qualifying and training status. Negatively worded questions (i.e. where 'strongly disagreeing' denoted a positive perception of staff role) were rescored in the analysis so that a higher score rather than a lower score was associated with positive role perceptions.

Table 4.5 shows medians and IQR for composite role scores and compares them by sub-group (Mann Whitney U test for variables with two sub-groups e.g. gender, training status; Kruskal Wallis test for variables with more than two sub-groups e.g. role, time since qualifying). In Table 4.5, the higher the composite role score, the more positively a staff member perceived identifying and responding to distress in renal patients as being a central part of their role.

The only variable for which there was a significant difference in composite role score between sub-groups related to whether or not a staff member had received training in supporting distressed patients. Staff who had received training were significantly more likely to have a positive perception of their role than participants who stated that they had not received training (training median 63; IQR: 52 to 70 vs. no training median 52; IQR: 45 to 62; p=0.001).

Table 4.5: Composite ‘role’ score for staff and sub-group comparison

Variable	Sub-groups	Median composite ‘role’ score (IQR)	Comparison between groups
Gender	Male Female	51 (45 to 63) 58 (48 to 68)	p=0.099
Role	Nurse Healthcare Assistant Doctor Allied Health Professional Renal manager Administration	56 (45 to 69) 61 (49.5 to 73.8) 51 (45.5 to 61.5) 52.5 (47 to 68) 58.5 (49.8 to 65) 58.5 (55.8 to 62.5)	p=0.698
Study site	Site 1 Site 2	58.5 (45.5 to 66) 55.5 (47.5 to 68.5)	p=0.976
Time in current role	< 6 months 7 to 12 months 12 months to 2 years 2 to 3 years 3 to 5 years 5 to 10 years 10 to 20 years 20 to 30 years	52.5 (48.8 to 59.8) 61.5 (52.5 to 64.8) 45 (32 to 70) 58 (53 to 65.5) 53.5 (49.8 to 61.5) 59 (47 to 70) 57 (45.5 to 66.8) 61.5 (47 to 69.5)	p=0.935
Time since qualifying	12 months to 2 years 2 to 3 years 3 to 5 years 5 to 10 years 10 to 20 years 20 to 30 years 30+ years	58 (48.5 to 73) 47.5 (32.3to 51.5) 55 (52 to 64) 60 (48 to 68.5) 57 (45 to 66) 54 (47 to 66.5) 70 (61.5 to 76.5)	p=0.101
ANY training	Yes No	63 (52 to 70) 52 (45 to 62)	**p=0.001**

4.4 STAFF PERCEPTIONS OF THEIR CAPACITY TO IDENTIFY AND RESPOND TO DISTRESS

The second employment-related dimension of support for distressed patients focused on staff members’ capacity to identify and respond to distress. As with staff role, survey respondents were asked to indicate the extent to which they agreed with a series of statements (n=9) exploring various aspects of capacity. Analysis again focused on a comparison of medians and IQR on the basis of study site and training status. Three of the nine capacity statements were positively worded, in which agreement with the statement indicated a positive perception of capacity to identify and respond to patient distress, and six statements were negatively worded, in which agreement indicated a less positive perception of capacity.

4.4.1 Staff response to ‘capacity’ statements, overall and by study site

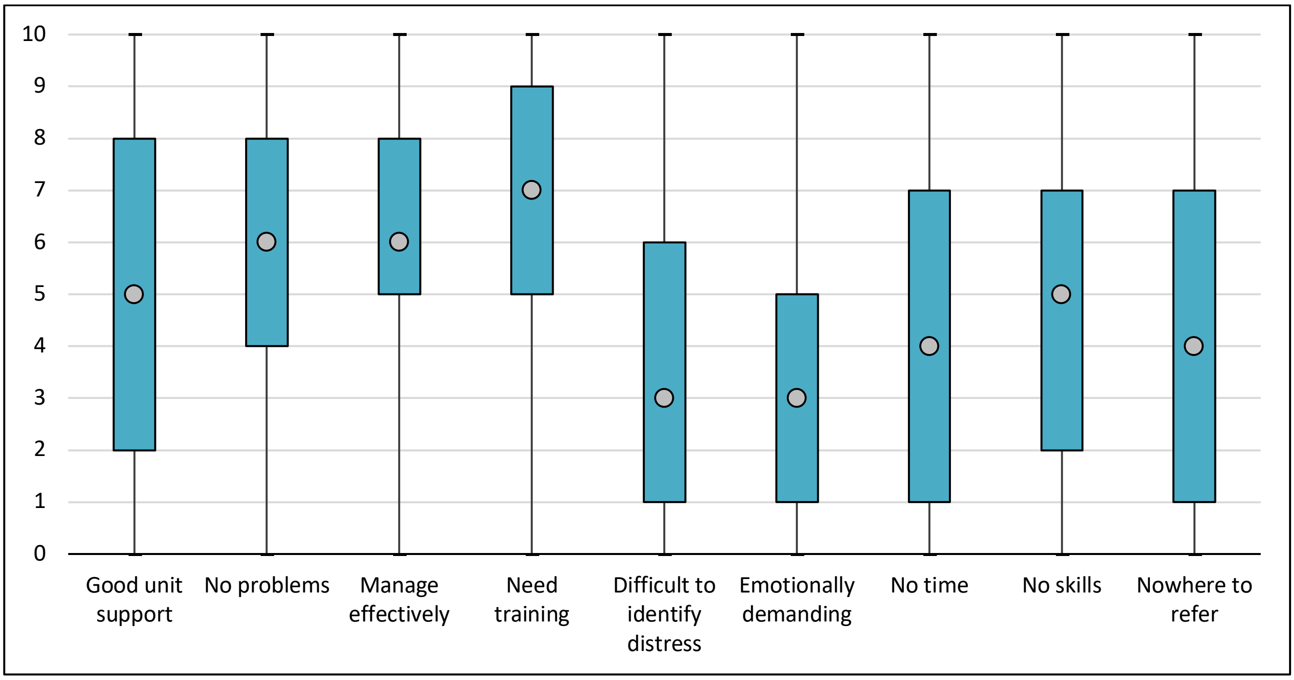
Overall, there was a greater degree of variation in responses to the capacity statements than there had been to the role-related statements (Table 4.6, Figure 4.7), and there were fewer responses at either extreme of the Likert scale (i.e. strong disagreement or strong agreement). There were also significant differences in median scores on the basis of study site for three separate statements.

Table 4.6: Responses to statements regarding staff capacity to identify and respond to distress

Statement	Site 1 median (IQR)	Site 2 median (IQR)	All respondents	Comparison of medians
I'm given good support by my renal unit to help me to identify and respond to patient distress	5 (1 to 7)	6.5 (5 to 8)	5 (2 to 8)	**p=0.016**
I have no problems that prevent me doing this well	6 (4 to 8)	5 (4 to 8)	6 (4 to 8)	p=0.387
I manage this effectively	6 (4 to 7)	7 (5 to 8)	6 (5 to 8)	**p=0.016**
I need more training to help me	8 (6 to 10)	7 (5 to 8)	7 (5 to 9)	p=0.054
I find it difficult to know when a patient is distressed	3 (1 to 6)	3 (1 to 5)	3 (1 to 6)	p=0.718
It is difficult because it is too emotionally demanding for me	3 (1 to 5)	2 (0 to 6)	3 (1 to 5)	p=0.549
I don't have the time	4 (1 to 6)	4 (1 to 7)	4 (1 to 7)	p=0.674
I don't have the skills	5 (2 to 8)	5 (1 to 7)	5 (2 to 7)	p=0.530
There's nowhere to refer distressed patients for support	6 (3 to 8)	1 (0 to 4)	4 (1 to 7)	**p<0.0001**

The first statement explored staff capacity in relation to the support provided to staff by their renal unit. Responses were wide-ranging across the sample, with an overall median score of 5 out of 10. Almost 20% of respondents (n=21) scored the statement as a 0 or 1, disagreeing that they receive adequate renal unit support. This suggests that there may be organisational issues that could be addressed to enhance support for renal staff within a given unit. There was also a significant difference in median scores for the statement between study sites: staff in site 2 were significantly more likely than those in site 1 to agree that they received adequate renal unit support (site 2 median 6.5; IQR: 5 to 8 vs. site 1 median 5; IQR: 1 to 7; p=0.016). Indeed, although absolute numbers were small, the proportion of staff at site 1 scoring the statement as 0, 1 or 2 was twice as high as that of staff at site 2 (35% vs. 15.8%).

Figure 4.7: Median scores for staff 'capacity' statements



0 = strongly disagree; 10 = strongly agree

In response to the statement ‘I have no problems or difficulties that prevent me from doing this [identifying and responding to patient distress] well’, there was again a wide spread of responses, but an overall trend towards agreement with the statement (median score of 6 out of 10). A comparison of medians showed no statistically significant difference between study sites (p=0.387). Staff also tended to agree that they identify and respond to renal patient distress effectively, with a median score of 6 across the sample. There was a significant difference in median scores between study sites, with respondents from site 2 reporting higher levels of agreement with the statement than those from site 1 (site 2 median 7; IQR: 5 to 8 vs. site 1 median 6; IQR 4 to 7; p=0.016). Although the difference relates to relatively small absolute numbers of individual staff in the two sites, 38.7% of respondents from site 2 scored the statement as an 8, 9 or 10 (strong agreement), compared to only 17.4% of staff from site 1.

The statement with the highest level of agreement in terms of median score related to training needs: with a median score of 7 out of 10. This suggests an unmet training need amongst staff responding to the survey. Indeed, 21.3% of the sample (n=23) scored the statement as a 10 in terms of strong agreement. Although it did not reach statistical significance, there was a trend towards staff at site 1 perceiving their need for training as higher than those at site 2 (site 1 median 8; IQR 6 to 10 vs. site 2 median 7; IQR 5 to 8; p=0.054).

The two statements with the lowest level of agreement were those relating to staff members’ ability to identify distress, and the degree to which doing so was considered emotionally demanding. For both statements, the median score was 3 out of 10, suggesting that staff believe that they know when a patient is distressed, and that identifying distress is not considered too emotionally demanding. Responses to both of these statements were similar for staff at both study sites (p=0.718, p=0.549).

The final three capacity statements related to: a) staff perceptions about the time available to provide support to distressed patients; b) their perceived skills to be able to do this, and c) the extent to which they felt there were adequate referral options for distressed patients. The majority of staff tended to disagree with the statement that there was not enough time to support distressed patients – the median score for all staff together was 4 out of 10, with nearly 40% of respondents (n=41) scoring a 0, 1 or 2, indicating strong disagreement with the statement. There was no difference in median scores between the two study sites (p=0.674). In relation to perceived skills to support distressed patients, the median score was 5 overall (IQR 2 to 7). The spread of responses around the mid-point of the scale may again suggest a training/skills gap: although 30% of staff scored a 0, 1 or 2 in disagreeing with the statement (n=33), nearly 25% of staff (n=24) scored an 8, 9 or 10, indicating strong agreement that they needed more skills to support patients. Finally, there was a significant difference in responses to the statement ‘there is nowhere to refer patients for support’ on the basis of study site: at site 1 (where there is no renal psychologist), there was strong agreement with the statement (median 6; IQR: 3 to 8), whereas at site 2 (where there is a renal psychologist), there was strong disagreement with the statement (median 1; IQR: 0 to 4). This suggests that renal psychologists can play a valuable role in giving renal unit staff referral options for patient support (p<0.0002).

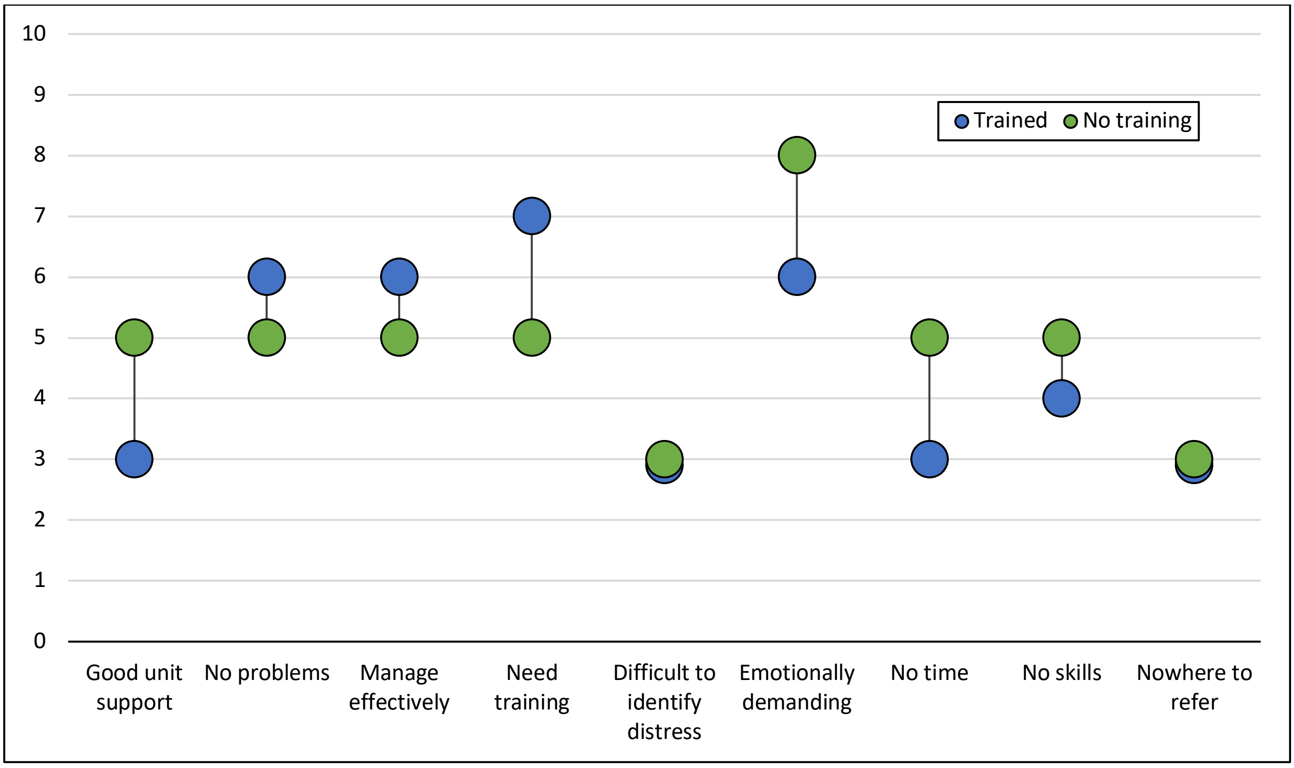
4.4.2 Staff response to ‘capacity’ statements, by training status

Each capacity statement was analysed to compare staff responses on the basis of training status (Table 4.7, Figure 4.8). For the majority of capacity statements, there was no significant association between training status and staff perception of their capacity to identify and respond to distress in renal patients. Perhaps surprisingly, staff who reported having some training in supporting distressed patients were significantly more likely to agree that they need more training than those who reported no existing training (training median 7; IQR 6 to 8 vs. no training median 5; IQR 2 to 7; p<0.001). Staff without training were significantly more likely to perceive supporting distressed patients as being too emotionally demanding than those with training (no training median 8; IQR 7 to 10 vs. training median 6; IQR 3.5 to 8; p=0.010). This suggests that one of the key benefits of staff training is to equip staff better to deal with the emotional burden of providing support to patients who are distressed.

Table 4.7: Staff responses to 'capacity' statements, according to training status

Statement	Any training (IQR)	No training (IQR)	Comparison of medians
I'm given good support by my renal unit to help me to do this	3 (1.5 to 6.5)	5 (2 to 8)	p=0.180
I have no problems that prevent me doing this well	6 (5 to 8.5)	5 (4 to 8)	p=0.700
I manage this effectively	6 (3 to 8)	5 (2 to 7)	p=0.059
I need more training to help me	7 (6 to 8)	5 (4 to 7)	**p<0.001**
I find it difficult to know when a patient is distressed	3 (0.75 to 5)	3 (1.5 to 6)	p=0.781
It is difficult because it is too emotionally demanding for me	6 (3.5 to 8)	8 (7 to 10)	**p=0.010**
I don't have the time	3.5 (2 to 6.25)	5 (1.25 to 7)	p=0.111
I don't have the skills	4 (0.75 to 6.25)	5 (1 to 8)	p=0.435
There's nowhere to refer distressed patients for support	3 (0.5 to 5.5)	3 (0.5 to 5)	p=0.961

Figure 4.8: Median scores for staff 'capacity' statements, by training status



0 = strongly disagree; 10 = strongly agree

Aside from the two statements with significant differences between staff in terms of training status, there were other differences in median scores for several statements that did not reach statistical significance: staff with no training were more likely to agree that they were given good support by their renal unit to help distressed patients. They were also more likely than staff with training to report that they lacked the time and/or skills to deal with distressed patients. In contrast, staff with training were slightly more likely to agree that they could manage distressed patients effectively and had no problems in doing this. This suggests that training in how best to support distressed patients can give staff more confidence to carry out this role effectively.

4.4.3 Composite 'capacity' score for all staff

As with the survey statements related to staff role, a composite total which aggregated scores for each of the capacity statements was calculated for each staff survey respondent, in order to explore whether there were any differences in capacity score on the basis of gender, role, trust, time in role, time since qualifying and training. Once again, all negatively worded Likert statements were rescored so that for all statements relating to staff capacity, a higher score denoted a more positive perception of staff capacity in being able to identify and respond to distressed renal patients (Table 4.8).

Table 4.8: Composite 'capacity' score for staff and sub-group comparison

Variable	Sub-groups	Median composite 'role' score (IQR)	Comparison between groups
Gender	Male Female	48 (38 to 62) 49.5 (40.3 to 59.8)	p=0.401
Role	Nurse Healthcare Assistant Doctor Allied Health Professional Renal manager Administration	50 (40 to 60) 57.5 (45.5 to 71) 41.5 (36.3 to 60.8) 49 (38 to 67) 46.5 (42.3 to 56.8) 54 (45.5 to 62)	p=0.654
Study site	Site 1 Site 2	47.5 (36.3 to 54.8) 55 (43 to 62.5)	**p=0.007**
Time in current role	7 to 12 months 12 months to 2 years 2 to 3 years 3 to 5 years 5 to 10 years 10 to 20 years 20 to 30 years	62 (37.5 to 66.8) 43 (38 to 49) 59 (48 to 60) 51 (37.3 to 68) 44.5 (38 to 54.5) 48 (38.5 to 58.5) 58.5 (39.8 to 67)	p=0.544
Time since qualifying	12 months to 2 years 2 to 3 years 3 to 5 years 5 to 10 years 10 to 20 years 20 to 30 years 30+ years	46 (41.5 to 57.3) 54.5 (27.3 to 63.8) 48 (39 to 66) 44 (31.5 to 54.5) 48 (37.3 to 56.5) 48 (40 to 61.8) 67 (56.5 to 80.5)	p=0.139
ANY training	Yes No	54 (43 to 67) 47.5 (36 to 56.3)	**p=0.003**

There was no significant difference between sub-groups on the basis of composite capacity score for the majority of variables. Two variables showed statistically significant differences. First, staff from site 2 perceived themselves to have a significantly higher capacity to identify and respond to renal patients' distress compared to staff from site 1 (site 2 median 55; IQR: 43 to 62.5 vs. site 1 median 47.5; IQR: 36.3 to 54.8; p=0.007). Second, staff members who stated that they had received training in supporting distressed patients had a significantly higher composite capacity score than participants who stated that they had not received any training (training median 54; IQR: 43 to 67 vs. no training median 47.5; IQR: 36 to 56.3; p=0.003).

4.5 STAFF VIEWS ABOUT POTENTIAL SUPPORTIVE INTERVENTIONS

The final group of statements on the staff survey related to potential changes to working practices or service delivery that may help staff to better identify and respond to renal patients with distress. A series of eleven different interventions was outlined, with staff asked to indicate the extent to which they felt each of these interventions would be beneficial on a Likert scale from 0 (not very helpful) to 10 (very helpful).

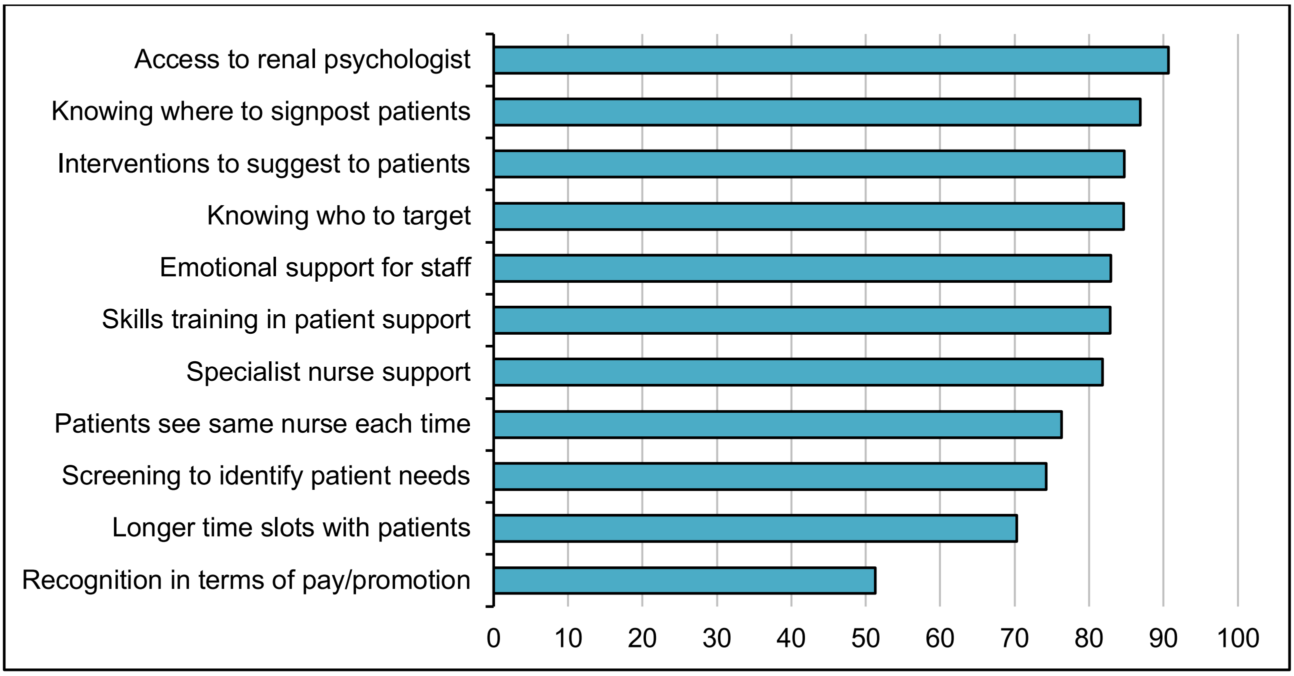
Interventions were ranked from most to least helpful on the basis of the percentage of the ceiling score achieved for that intervention. For example, if 100 staff responded to the statement about the perceived helpfulness of having longer time slots with patients, and all 100 considered this intervention to be extremely helpful, the maximum total score from summing the Likert scale responses for that intervention would be 1000 (100x10=1000). In summing the actual Likert scale responses for that intervention (e.g. 50 staff scored it as a 1; 20 scored it as a 2 etc.) and expressing this total as a percentage of the potential ceiling score, this gives an indication of the interventions that were considered more or less helpful by staff giving a score for each intervention (Table 3.18).

Table 4.9: Staff ranking of potential supportive interventions

Statement	Ceiling score	Actual score	% of ceiling score	Rank
Access to a renal psychologist	900	816/900	90.7	1
Knowing where to signpost patients for help	860	747/860	86.9	2
Interventions to suggest to patients	890	753/890	84.7	3
Knowing who to target	890	752/890	84.6	4
Emotional support for staff	890	737/890	82.9	5
Skills training about patient support	890	736/890	82.8	6
Specialist nurse support	880	719/880	81.8	7
Patients see the same nurse at each clinic	900	686/900	76.3	8
Screening tool to identify patients with needs	900	667/900	74.2	9
Longer time slots with patients	890	625/890	70.3	10
Recognition in terms of pay/promotion	870	446/870	51.3	11

Taking all responses together, the highest rated intervention was access to a renal psychologist, which scored 90.7% of its ceiling score (Figure 4.9). Close behind (86.9%) was knowing where to signpost patients for help, having interventions to suggest to patients (84.7%) and knowing who to target (84.6%). The least well-received interventions were introduction of a screening tool to identify patients who may be distressed (74.2%), staff having longer time slots with patients (70.3%) and – a long way behind all other interventions in terms of perceived helpfulness – recognition in terms of pay/promotion (51.3%).

Figure 4.9: Staff ranking of potential supportive interventions



4.5.1 Staff perceptions of supportive interventions by selected sub-group

The final analyses in this section compare intervention rankings: a) between nurses and doctors, and b) on the basis of staff training status. Table 4.10 shows the respective ranks of potential interventions for nurses who responded to the survey compared with doctors.

Table 4.10: Nurse vs. doctor rankings of possible interventions

Intervention	Nurses		Doctors	
	% of ceiling score	Rank	% of ceiling score	Rank
Renal psychologist	92.5	1	89.2	1
Patient signposting	90.2	2	78.0	2
Interventions to suggest	89.3	3	70.0	6
Skills training	88.3	4	64.2	10
Emotional support for staff	88.2	5	68.3	8
Knowing who to target	87.8	6	77.5	3
Specialist nurse support	84.7	7	69.2	7
Patients see same nurse	75.9	8	72.5	5
Screening tool to identify distress	75.6	9	65.8	9
Longer time slots	69.0	10	72.5	4
Pay/promotion	52.8	11	45.8	11

All interventions achieved a higher ceiling score for nurses than they did for doctors (with the exception of 'longer time slots with patients' which was ranked 10th out of 11 interventions by nurses and 4th by doctors). The top two potentially most helpful interventions were the same for nurses and doctors, with access to a renal psychologist and knowing where to signpost patients scoring most highly. Use of a screening tool to identify distress in patients was ranked 9th by both nurses and doctors, and recognition in terms of pay or promotion was ranked as the least helpful intervention.

There were some differences in the ranks given to specific interventions by nurses in comparison to doctors:

- Nurses ranked 'Interventions to suggest to patients' third, compared with doctors who ranked it 6th
- Nurses ranked 'Skills training about patient support' 4th, whereas doctors ranked it 10th
- Nurses ranked 'Emotional support for staff' 5th, compared to 8th for doctors
- Doctors ranked 'Knowing who to target' as their third most helpful intervention (nurse rank = 6th)
- Doctors ranked 'patients see the same nurse at each clinic' as 5th out of 11, compared to 8th out of 11 for nurses

Table 4.11 repeats the nurse vs. doctor analysis, with the group of respondents split according to their training status.

Table 4.11: Staff ranking of possible interventions by training status

Intervention	Training		No training	
	% of ceiling score	Rank	% of ceiling score	Rank
Renal psychologist	92.7	1	89.0	1
Patient signposting	86.8	2	86.9	2
Interventions to suggest	86.3	3	85.4	4
Emotional support for staff	86.1	4	80.2	7
Knowing who to target	84.8	5	84.5	5
Skills training for staff	83.2	6	85.6	3
Specialist nurse support	82.5	7	81.3	6
Patients see same nurse	77.3	8	75.5	9
Longer time slots	77.2	9	64.3	10
Screening tool to identify distress	72.6	10	75.6	8
Pay/promotion	47.3	11	54.9	11

For all staff, regardless of training status, the two highest ranked and the lowest ranked interventions were the same: staff in both training groups reported that access to a renal psychologist would be the most helpful intervention, which achieved 92.7% of its ceiling score for staff with training, and 89.0% of the ceiling score for staff without training in supporting distressed patients. Knowing where to signpost patients for help was the second ranked intervention, and having pay or promotion was the last favourable option.

For the remaining interventions, there was typically little difference in rankings by sub-group, with a difference of only one ranking place between the trained vs. untrained group. The only substantive differences were in relation to skills training, which was ranked as the third most helpful intervention amongst staff without specific training in handling distressed patients, but only 6th by those who already had some training. This suggests again that there is a training gap amongst renal unit staff in identifying and responding to patients with distress, and that in many cases, staff would value being given the opportunity to improve their skills through additional training. There was also a difference of several ranking places for the intervention related to the provision of emotional support for staff. For staff members with training in managing distressed patients, the provision of emotional support was ranked 4th out of 11 possible interventions, but only 7th by staff without training.

5. SUMMARY: QUANTITATIVE FINDINGS

This chapter summarises the findings from the renal patient and staff surveys and provides an overview of the implications of the quantitative element of the study for the identification and management of mild to moderate distress in patients with ESRD.

5.1 PATIENT SURVEY

5.1.1 Prevalence of mild to moderate distress

A total of 346/1040 survey respondents reported levels of emotional and psychological difficulty that met the criteria for mild to moderate distress (33.3%). Distress was evident across the ESRD pathway, with mild to moderate distress reported by around 35% of pre-RRT and dialysis patients, and 29% of transplant patients. The finding that the prevalence of distress was almost as high in transplant patients as in those undergoing dialysis or yet to start treatment for renal failure suggests that although the burden of physical problems may be reduced significantly for transplant patients, the need for ongoing psychological adjustment does not end after successful transplantation. Indeed, transplant patients may experience many of the same stresses as patients at other stages of the ESRD pathway, plus fear of graft failure and significant distress if a transplant fails.[15]

There was some variation in the prevalence of mild to moderate distress by dialysis type, with patients receiving HD reporting distress rates of 37.6%, compared to 41.9% for patients on home haemodialysis and 27.5% for patients undergoing peritoneal dialysis. The number of patients on modalities other than HD were too small to detect statistically significant differences, but lower rates of distress reported by patients undergoing peritoneal dialysis in comparison to haemodialysis have been found elsewhere.[62]

Distress prevalence was strongly associated with sociodemographic characteristics and was significantly higher in younger patients (44.8% in patients aged below 50; 32.9% in patients aged between 50 and 69, and 28.7% in those aged 70 and above), in BME compared to white patients (45.7% vs. 31.4%), and in females compared to males (38.1% vs. 30.2%). These trends have also been found in studies of anxiety and depression in renal patients.[63-65] There are numerous psychological theories of health and illness which may have a role in explaining patients' variable responses to ESRD diagnosis and treatment.[66-69] These theories typically emphasise that experience of distress (and ability to cope with it) is most likely to be determined by an individual's personal degree of resilience rather than being associated with specific clinical characteristics. So, the observed association between sociodemographic characteristics and the incidence of distress in the patient survey responses may point to the influence of individual coping resources on distress. In particular, the finding that distress prevalence reduced with increasing age may reflect a better adjustment to the psychological burden of ESRD by older patients.[70]

5.1.2 Problems experienced

Numerous studies have found that patients with chronic conditions are most likely to report physical and emotional problems,[71,72] and that distress levels are directly correlated with the number of problems reported.[73-75] This suggests that the overall quantity/burden of distressing factors and the specific problems reported are both important when evaluating distress and its consequences for patients.[8,76] In the patient survey, there was a positive and statistically significant relationship whereby patients with higher self-reported levels of distress reported a greater number of problems. Amongst the group of patients categorised as having mild to moderate distress, 98% reported experiencing at least one of the 36 problems from the problem list in the previous week, with problems in the physical and emotional domains the most likely to be cited. Worry (74.3%), fatigue (71.7%), dry/itchy skin (65%), problems with sleep (61.3%) and loss of interest in usual activities (53.8%) were the most frequently reported problems when incidence was ranked from most to least. Rates of problem reporting were particularly pronounced for patients currently receiving dialysis treatment. Patients who had been on dialysis for less than two years had the highest rate of problem reporting (36.3 mean percentage of problems reported). Transplant patients reported the lowest proportion of possible problems on all domains except for family problems, where their rate of reporting was the highest. Nevertheless, the top ten most frequently reported problems were largely the same across ESRD stage, suggesting that issues like pain, worry, sleep problems and fatigue are frequently experienced by patients at all stages of the ESRD pathway, regardless of whether a patient is pre-treatment, undergoing dialysis or post-transplant.

In terms of sociodemographic characteristics, the most substantial differences in problem reporting were associated with patient age group. Patients aged 70 and over had significantly lower rates of problem reporting in all domains (except for physical problems) when compared to patients in the two younger age groups. The inverse association between the incidence of physical stressors and age in particular has also been noted by others.[77] Female patients were significantly more likely than male patients to report physical problems. Although there were trends towards higher rates of problem reporting for BME patients on the emotional, practical and family domains, observed differences by ethnic group were not statistically significant.

5.1.3 Experience of distressing events

When asked about whether specific events had caused distress in the previous week, nearly 40% of patients in the mild to moderate distress group reported distress from such events. The events most likely to have caused distress related to the impact of dietary restrictions and crises in home or work life. As might be expected, the events causing distress differed substantially according to patient characteristics. Pre-RRT patients were most likely to have experienced distress related to their diagnosis with ESRD, being given a poor prognosis and in relation to choosing their mode of dialysis treatment. Patients who had been on dialysis for less than two years were significantly more likely than those in others ESRD groups to have been distressed by issues associated with changing dialysis type and deciding to stop dialysis. These findings suggest that there may be specific transitional points in the ESRD pathway where patients in particular groups may be more affected, either by the consequences of their illness or the choices that they may need to make with regard to treatment options.

In terms of the association between distressing events and sociodemographic characteristics, patients aged under 50 were significantly more likely than patients in other age groups to experience distress related to employment issues or failing transplants. Males were significantly more likely than females to have experienced distress caused by their ESRD diagnosis. Rates of event reporting were particularly high for BME patients compared to white patients, with BME patients expressing particular concern over events related to their disease prognosis, adjusting to dialysis, the possibility of a failing transplant and the decision to stop dialysis. As these patient groups are also those in whom the prevalence of mild to moderate distress was highest, targeting support towards these patients may be effective.

A limitation of the survey design is that we were unable to determine whether distress was caused by an event itself occurring recently, or whether an event that could have occurred months or even years previously was still causing distress in the previous week. We were also unable to assess the proportion of patients who had experienced specific events and not been distressed by them. The determinants of distress are clearly complex. For some patients, the occurrence of a specific event may have triggered distress in and of itself. For others, a patient's pre-existing distress may have made them less able to cope when a specific event occurred (i.e. impaired resilience).

5.1.4 Adjustment and coping

Adjustment and coping as measured using positive and negative affect scores (PANAS) showed positive affect scores (i.e. feelings of alertness and enthusiasm) to be lowest in pre-RRT patients and highest in transplant patients. Median negative affect scores (subjective distress and discomfort) were significantly higher for younger patients, female patients, and for BME patients. This suggests an impaired ability to cope in these groups, which reinforces the findings from the other validated measures that younger patients, females and BME patients are the most likely to experience distress and report a higher number of problems that contribute to their feelings of distress. Patient responses to a series of statements about the extent to which they felt able to cope with their condition showed a similar picture, with many patients reporting mixed feelings about their ability to cope. In general, patients felt that they were able to keep bad feelings under control and think positively about their condition. However, there was strong agreement with statements that concerned fear over worsening of their condition and/or distress, and nervousness about the future. The complex interplay between illness-related stressors and coping mechanisms is evident in the renal literature, particularly for dialysis patients.[4] Indeed, patients undergoing dialysis treatment were significantly less likely than pre-RRT or transplant patients to express satisfaction with how they were coping or to be able to think positively. Patients aged under 50 were significantly more likely than older patients to express difficulties coping with their condition and report a reduced ability to keep bad feelings under control. Similarly, patients from BME groups were significantly more likely to express concern that their distress would worsen over time.

Time since diagnosis was used as a proxy for assessing change over time for PANAS scores. PANAS scores showed a general trend across the entire cohort of survey respondents for positive affect to increase over time, and for negative affect to decrease. This suggests that in general, patients become more able to cope with the effects of their condition over time. However, this trend was not evident in the mild to moderate distress patient group, where positive and negative affect scores were consistent regardless of length of time since diagnosis with ESRD. The existing literature on correlations between depressive symptoms and time since initiation of treatment for renal patients shows mixed findings. Some studies have found no correlation between symptoms and time since treatment began,[5,14] whereas others have found a tendency for depression status to worsen over time.[70] Patients' experience of distress may vary over relatively short timescales, and be affected by specific life events rather than necessarily being tied to their illness and treatment (although the latter may make the former more difficult to cope with). Using a cross-sectional rather than a longitudinal design is a limitation of this study, and assessing changes to patient adjustment, coping and resilience over time by following a patient cohort longitudinally is an important area for future research.

5.1.5 Perceived need for support

It is important to recognise that patients with mild to moderate distress may not necessarily want to receive support, so scores on the 'need' emotion thermometer were used to assess potentially unmet support needs. For the entire cohort of patients, the perceived need for support increased significantly as distress increased. Only 0.2% of patients in the none to low distress group reported a need for support, compared with 40.8% of patients in the mild to moderate distress group and 64.7% of those categorised as having severe distress. Perceived support needs were lowest for transplant patients and those yet to start RRT, whereas 66% of patients on dialysis for less than two years and 56% of those on dialysis for two or more years reported that they required support. Support needs were also significantly higher in BME compared to white patients.

5.1.6 Patient views about renal services

In general, patients reported satisfaction with the support received from renal services. However, there were a number of differences between sub-groups which corresponded closely to the sub-groups of patients in whom rates of distress and perceived support needs were highest. Patients who had been on dialysis for two or more years were significantly more likely than those in other groups to say that they felt they were 'treated as a set of symptoms' by staff, and that staff 'did not have time to listen'. Similarly, patients from BME groups were significantly more likely than white patients to express concerns that they were treated as a set of symptoms, and that they 'didn't know who to talk to'. In contrast, patients in the oldest age group were more likely to feel comforted by the way they were treated by renal staff and to feel that they were able to discuss worries with them. Patients in the youngest age group (aged below 50) were most likely to express dissatisfaction with their care, feeling that staff did not have time to listen to them, and that they were treated as a set of symptoms.

5.1.7 Patient views on potential supportive interventions

When asked to rate the potential helpfulness of a series of interventions in providing support, patients with mild to moderate distress were most likely to favour those that involved face-to-face interventions focused on talking with healthcare professionals (nurses, doctors or renal psychologists) about distress, or one-to-one training in how best to handle negative feelings and emotions. 'Time to discuss emotional feelings during consultations with a doctor' reached 72.6% of its ceiling score in patient ratings, and 'time to discuss emotional feelings during nurse-run clinics' was closely behind, achieving 71.1% of its ceiling score. The lowest rated interventions were those that focused on physical activity programmes (47.8% of ceiling score), art/drawing groups (26% of ceiling score) and online options, with both an online patient support group and an online training course in managing feelings and moods reaching only 39.7 and 36.1% of their ceiling scores respectively. This suggests that above all, patients would value support in which they are able to talk face-to-face and on an individual basis about their feelings with the appropriate professionals rather than receiving support indirectly or via group-based methods.

There were some differences in the acceptability of supportive interventions on the basis of patient sub-group, although the top four and bottom four ranked interventions were typically the same for all patients regardless of their stage on the ESRD pathway. Instead, the acceptability of particular interventions may be linked more to personal preference and factors such as age and gender. For example, younger patients (aged below 50) were more receptive towards online support options than older patients. Female patients scored nearly all interventions more highly than males, suggesting that female patients may be more prepared to take up offers of additional support if these were made available. The finding that women are more likely to seek out and use supportive interventions and services than men has also been found in other studies.[65]

There is of course a limitation with asking patients in a survey whether or not they would like to receive a particular intervention, as the acceptability of such interventions is based on a hypothetical situation where patients rate interventions that they have not experienced in reality. A number of interventions that patients rated fairly low in comparison to those based on one-to-one discussions have a good evidence base for effectiveness, such as tailored exercise programmes;[78,79] peer support,[80,81] and issue sheets to prompt discussion about emotional concerns during consultations.[49] The poor ratings given to these interventions may stem in part from a lack of knowledge about what participation in these interventions would entail and how they may be beneficial.

5.1.8 Patient survey: limitations

There were a number of limitations associated with the patient survey. At 27.9%, the survey response rate was low, although the absolute number of surveys returned was large enough to allow sub-group analysis. Younger patients, those from BME groups and patients who had been more recently diagnosed with ESRD were under-represented in the sample. The low response rate meant that the study lacked power to assess differences in the prevalence and experience of mild to moderate distress in detail. For example, patient age was categorised into three broad groups, and the influence of ethnicity could only be assessed by grouping all BME patients together and comparing them with patients of white ethnicity, rather than assessing BME groups (e.g. Asian, Afro-Caribbean) separately. Given our findings that age and ethnicity in particular are strongly associated with mild to moderate distress, relying on broad patient groupings is a limitation of our approach. Similarly, participants in each ESRD pathway stage were treated as a homogeneous cohort when in reality there may have been differences between them that could have impacted on their experience of distress such as issues with medication or ESRD-related complications like fistula failure, infection or transplant failure.

We were also unable to say whether distress is more or less common in survey respondents compared to non-respondents. However, our findings with regard to the patient groups most likely to experience mild to moderate distress were similar to existing evidence on anxiety and depression in renal disease. Also, because younger and BME patients were under-represented in our sample, the finding that patients in these groups reported significantly higher rates of mild to moderate distress than older, white patients suggests that we may have under-estimated rather than over-estimated overall distress prevalence. Patients referred to psychiatric services (as noted in their hospital record) were excluded from survey mailings, but we cannot know whether our sample included patients who had independently sought counselling or support via their general practitioner.

The use of the distress and emotion thermometers may be questioned, as what these measures gain in ease of administration, they may lose in sensitivity. The evidence base also suggests that self-report scales may over-estimate the incidence of issues such as distress, anxiety and depression in comparison to interview-based estimates.[11] However, there was good internal consistency between the different validated measures used in the patient survey – patients with higher levels of distress on the DT/ET also reported a greater number of problems and had lower positive affect/higher negative affect on the PANAS measure, and in the absence of any validated measures such as the HADS or BDI specific to lower-level distress, we believe that the DT/ET was the most appropriate tool. Future research into the development and validation of a more comprehensive tool to measure distress, with validated cut-offs for thresholds between distress groupings may be useful.

The study was also cross-sectional rather than longitudinal, and consequently allows limited understanding of the relationship between time since ESRD diagnosis and ability to cope with the resulting stressors. Although we attempted to use time since diagnosis as a proxy for trends in distress prevalence over time, future work using a cohort study design would aid understanding of the way that individuals adapt to ESRD diagnosis and its ongoing management over time.

5.2 STAFF SURVEY

5.2.1 Staff perceptions of support for distressed patients

Renal unit staff overwhelmingly considered support for distressed patients to be beneficial. However, there was only a moderate level of staff satisfaction with the support that their renal unit provides to patients, with a median score of 6 out of 10. This suggests that there is substantial potential for renal units to improve the organisation and delivery of support that is available to distressed patients.

5.2.2 Staff perceptions of their role in identifying and responding to patient distress

Renal staff generally reported that identifying and responding to distress was an important part of their work, that doing so was fulfilling and brought recognisable benefits to patients. Staff responses to the survey ‘role’ statements showed a strong feeling that they did not seek reward or promotion for supporting distressed patients, nor did they feel that dealing with distressed patients was the responsibility of other renal staff. However, despite perceiving that they had a personal responsibility towards distressed patients within the renal unit, when asked to consider the potential responsibility of staff in other professions outside of the renal unit (e.g. GPs, counsellors), opinion was more mixed. This suggests that whilst renal staff are prepared to take responsibility for renal patients that may have support needs within the renal unit, they nevertheless believe that staff in other professions can and should play a role in supporting patients. There was also a clear training gap evident in the staff responses, with a median score of 6 for the statement ‘I am not trained for this role’. This was reinforced by staff responses to questions about their training status: with 56.5% of respondents reporting that they had not received any training in dealing with distressed patients, regardless of whether training was given as part of their initial professional qualification, during their current role or within the past three years.

There were no differences between study sites in median scores given by staff to any of the ‘role’ statements in the survey, suggesting that staff perceptions of their role in identifying and responding to patient distress were similar between sites.

5.2.3 The influence of staff training status on role perception

For the majority of the role statements, comparing staff on the basis of training attainment did not show substantial differences in responses – all staff, irrespective of their level of training in identifying and responding to patient distress considered that doing so was fulfilling, important and was of benefit to patients. Similarly, staff in both groups perceived that responding to patient distress was not something for which they sought promotion or financial reward, and that it was part of their responsibility within the renal unit. Nevertheless, staff with training were significantly more likely than those without training to feel that they were adequately trained. Staff who had received training were also significantly more likely than those without training to feel that identifying and responding to patient distress was part of their job description.

5.2.4 Composite role score for all staff

When scores given by staff respondents for each of the role statements were aggregated and compared across sub-groups on the basis of gender, role, time since qualifying etc., the only variable for which there was a statistically significant difference in ‘role’ totals related to staff training status. Here, staff who had received training were significantly more likely to have a positive perception of their role than participants who stated that they had not received training (p=0.001). This suggests that training staff in how to handle patient distress is a fundamental part of shaping positive staff views about their role in identifying and responding to patient distress.

5.2.5 Staff perceptions of their capacity to identify and respond to patient distress

Although staff responses regarding their role in identifying and responding to patient distress were relatively consistent, the extent to which staff felt that they had the capacity to do so was more mixed, with issues evident at both the organisational (renal unit) and individual staff levels. There was some evidence that improvements could be made to the support offered to staff at the renal unit level, with median scores for satisfaction with renal unit support of 5 out of 10. On an individual level, staff tended to agree that they were able to manage distressed patients effectively without any significant problems, and that identifying patient distress was not particularly difficult or emotionally demanding. These responses may indicate a degree of social desirability bias i.e. staff responding to the survey were keen to emphasise positive qualities in terms of the way that they perform their professional role. Potential over-reporting of positive elements of staff capacity contrasted with staff responses regarding skills and training - despite the apparent ease with which the majority of staff reported being able to identify and manage patient distress, there were clear skills and training gaps identified by a number of respondents. For example, the median score for the statement 'I need more training to help me' was 7 out of 10, and the statement 'I don't have the skills' was scored 5 out of 10. This again suggests an unmet training need amongst staff responding to the survey.

Staff tended to disagree that there was not enough time to support distressed patients, but also highlighted a gap in options for onward referral of distressed patients, with median scores of 4 out of 10 for the statement 'there's nowhere to refer distressed patients for support'.

The influence of local context

Responses to three of the nine capacity statements differed by study site. Staff at site 2 were significantly more likely than those at site 1 to agree that they are given good support by the renal unit to help them identify and respond to patient distress ($p=0.016$). Staff at site 2 were also more likely to agree that they are able to manage distressed patients effectively ($p=0.016$) and to disagree with the statement that 'there is nowhere to refer distressed patients for support' ($p<0.0001$). The response to the latter statement is likely to be influenced by staff at site 2 having access to a renal psychologist – a role which is not available at site 1. This suggests that renal psychologists have a potentially valuable role in allowing staff to refer distressed patients for professional support, and that the addition of renal psychologist expertise to renal units is an important means by which distressed patients can be offered support over and above that provided by frontline staff.

The fact that there were no significant differences between sites for staff responses to the role statements but several differences for the capacity statements may indicate that despite staff members' consistent views of their role in supporting distressed patients, there are local factors operating at the level of the renal unit that impair or enhance staff ability to manage distress effectively.

5.2.6 The influence of staff training status on perceptions of capacity

For the majority of 'capacity' statements, there was no significant association between training status and staff perceptions of their capacity to identify and respond to distress in renal patients. Staff who reported having some training in supporting distressed patients were significantly more likely to agree that they needed more training than those who reported no existing training ($p<0.001$). Staff without training were significantly more likely than those with training to perceive supporting distressed patients as being emotionally demanding ($p=0.010$), which suggests that training has a positive role in equipping staff to deal with the emotional burden of supporting patients who may be distressed and in giving staff confidence to support patients effectively.

5.2.7 Composite capacity score for all staff

As with the composite role score, there was a difference between staff respondents on the basis of training status when sub-groups were compared. Staff with training had significantly higher capacity scores than those without training, suggesting that training can be associated with positive attitudes towards staff members' capacity to support distressed patients (p=0.003). There was also a difference in composite capacity score between study sites, with staff in site 2 having a significantly higher capacity score than those in site 1 (p=0.007). This is likely to be largely due to positive scores given by staff in site 2 with regard to having a renal psychologist to whom they could refer distressed patients.

5.2.8 Staff perceptions about potential supportive interventions

When all staff responses were taken together, most interventions were ranked highly. The three highest ranked interventions related to having access to a renal psychologist (90.7% of ceiling score), knowing where to signpost patients for help (86.9% of ceiling score), and having interventions to suggest to patients (84.7% of ceiling score). The least well received interventions were introduction of a screening tool to identify patients who may be distressed (74.2%), staff having longer time slots with patients (70.3%) and recognition in terms of pay/promotion (51.3%). This ranking of interventions reinforces the staff responses to the role and capacity statements i.e. staff feel in general that they are able to identify patient distress, but that their ability to respond is impaired by a lack of onward referral options for patient support.

When intervention rankings were compared between nurses and doctors, access to a renal psychologist and knowing where to signpost patients for support were the top two interventions reported by both groups. The position of the several of the other interventions in the ranking list differed – nurses were more likely to emphasise the potential utility of skills training and emotional support than doctors. Doctors also rated 'patients seeing the same nurse in each clinic' as 5th out of 11, compared to 8th out of 11 for nurses. This suggests that although staff may feel in general that identifying and responding to patient distress is their responsibility rather than the responsibility of other staff within the renal unit, there may nevertheless be a difference between doctors and nurses in terms of their view of their respective responsibilities in managing patient distress or in their perception of the way that this can be improved.

There were few differences in intervention rankings on the basis of training status; the top two interventions were again the same. The only substantive differences were in relation to skills training, which was ranked as the third most helpful intervention amongst staff without training, but only 6th out of 11 by those who already had some training in supporting distressed patients. Again, this may indicate a training gap for renal unit staff, and that staff would value being given the opportunity to improve their skills via additional training.

5.2.9 Limitations of staff survey

The staff survey had a number of limitations. The response rate was relatively low, although the proportion of staff responding to the survey from each relevant job role at each study site was similar and data were directly comparable. Nevertheless, the small number of responses meant that the possibility of sub-group analysis was limited and was restricted to considerations of training status and study site only. There were also very few responses from HCAs. Given that HCAs have a substantial role in day-to-day contact with renal patients, the lack of responses meant that we were unable to explore the dimensions of role and capacity in this staff group.

The major limitation in the design of the staff survey was that it conflated identifying distress with responding to distress. It is reasonable to expect that there may be different barriers and enablers to the identification of distress than there may be in responding to distress, but the survey did not allow us to separate these issues clearly in the analysis. Nevertheless, semi-structured interviews undertaken with a number of staff survey respondents (Chapter 7) allowed these issues to be explored separately and in depth. Finally, although the inclusion of multiple study sites is likely to have minimised any bias that may have arisen from variations in the organisation and delivery of renal services, the staff survey was only undertaken at two of the four study sites where the patient survey was undertaken. This limited our ability to understand some of the mediating factors associated with the local context of individual renal units that may have improved or inhibited staff members' ability to identify and respond to patient distress, although these issues were explored in the qualitative element of the study.

6. RESULTS: PATIENT INTERVIEWS

6.1 RECRUITMENT AND SAMPLING

After completing 12 interviews at site 1 and 21 at site 2, 13 additional interviews were conducted with patients at site 3 (n=7) and site 4 (n=6) (n=46 total) in order to increase the diversity of the study sample. All interviews were undertaken between March 2016 and May 2017 (Table 6.1). Interviews lasted between 25 and 55 minutes. Three patients were interviewed in their own home; 43 were interviewed over the telephone.

Table 6.1: Timing of patient interviews by site

Site	First interview	Last interview	Total at site
1	April 2016	August 2016	12
2	March 2016	August 2016	21
3	December 2016	May 2017	7
4	March 2017	May 2017	6

6.1.1 Characteristics of patient interview sample

Table 6.2 outlines the characteristics of patients interviewed, according to key sampling criteria.

Table 6.2: Characteristics of patients interviewed

		Site 1	Site 2	Site 3	Site 4	Total
	Eligible	37	37	63	66	**203**
	Interviewed	12	21	7	6	46
ESRD pathway stage	Pre-RRT	3	3	2	0	**8**
	Dialysis <2 years	3	2	0	4	**9**
	Dialysis 2+ years	1	8	5	1	**15**
	Transplant	5	8	0	1	**14**
Gender	Male	6	12	5	5	**28**
	Female	5	9	2	2	**18**
Age group	Under 50	2	7	0	1	**10**
	50-69	4	9	5	4	**22**
	70+	5	5	2	2	**14**
Ethnicity	White	7	17	4	5	**33**
	BME	4	4	3	2	**13**
Dialysis type	HD	4	9	2	4	**19**
	HHD	0	1	3	0	**4**
	PD	0	0	0	1	**1**
Type of interview	Telephone	11	18	7	7	**43**
	Face-to-face	1	2	0	0	**3**

6.2 PATIENTS HAVE COMPLEX, MULTI-FACETED SUPPORT NEEDS

Many questions in the topic guide for patient interviews focused on the practical and emotional support that was offered to patients by their renal unit. Participants were asked about what support they wanted, what support they received, who offered them support, and for any recommendations to improve support. Participants often struggled to explain any formal process of support and stated that nurses and renal consultants on the renal unit offered informal, *ad hoc* support during HD sessions or during consultations, but that time pressures often made this difficult. This led to some participants not seeking support at the renal unit to avoid further pressuring staff. A few participants discussed sessions with psychologists or counsellors who had offered support, but these were often limited to a small number of sessions and did not seem to be routinely offered to participants who were distressed.

6.2.1 Self-support

Some of the participants described ways in which they would support themselves throughout difficult periods. At a basic level, this tended to involve patients talking to themselves in a motivational way. When asked if she needed any emotional support, one woman said:

> *"…yes, but not very often. I sort of say to myself, look, get yourself out of this, you know? Pick yourself up. But I've always been rather independent."* (70 year old female, pre-RRT)

Self-motivation and self-reliance were common themes amongst people who bottled up their emotions and preferred to maintain their independence by trying to control who knew about their negative emotions. As part of this process of hiding one's emotions, participants described purposefully altering their behaviour to seem more jovial or carefree. Here, the same woman as above when asked if staff on the renal unit recognise times when she is feeling down, replied:

> *"Not really, no, because I'm usually bubbly when I go there."* (70 year old female, pre-RRT)

Despite describing the staff on the renal unit as "approachable" and emphasising that she felt that "they do listen to you", this woman maintained a 'bubbly' exterior to hide her negative feelings. This seemed to be a common emotional tactic that participants employed to hide their true feelings so as not to concern staff or their family.

6.2.2 Staff recognition of distress

All participants were asked if staff recognised distress and their experiences varied greatly. It was common for participants to discuss their distress with close family members, particularly spouses, but some felt that talking to healthcare professionals was preferable because staff were more likely to be able to help with the problems identified. This was problematic, however, as staff were often perceived as being too busy to talk to participants about specific problems. This caused frustration among some who had tried to talk to staff about their feelings but felt ignored. One participant, when asked if staff on the renal unit recognised his distress, replied:

> *"No, from hospital they don't - they don't care about it. They just ask you if you need anything like, but nothing else… they are too busy, they have no time. No time to see all the patients that's having dialysis."* (43 year old male on HHD)

When this participant did try to talk to staff about his distressing feelings, he was referred to a psychologist by the nurse and told to make an appointment to discuss his distress. This was not what the participant wanted, however. He was feeling distressed when he talked to the nurse and wanted to talk about his problems immediately, not after making an appointment:

> *"I tried to speak to somebody, she sent me to a doctor, to see a doctor you know. I make an appointment. But nothing happened, I did not have an appointment… I didn't see him because I need an appointment. It's not that important now. (*43 year old male on HHD)

Later, he talked about what he wanted in terms of support:

> *"I want to speak to somebody just outside my wife. I think I would rather chat with somebody else… I need to speak with somebody you know to have another opinion or another... That's it I would guess. Just have a chat."* (43 year old male on HHD)

This participant did not want to be referred to another healthcare professional, he wanted someone on the renal unit to recognise his distress and have the time to talk about it. Further, he seemed frustrated that staff had the time to check immediate medical or dialysis issues, but did not have the time to talk about mentally distressing problems. His distress was recognised by staff on the renal unit, but instead of being able to deal with the distress immediately, he was referred on to other staff and there seemed to be no option to follow up on his distress within the renal unit.

Another participant acknowledged that staff do recognise distress, but that it can be slow. When asked about recognition of distress, she described seeing a consultant and, when the consultant asked how she was, she "just burst into tears". This simple question seemed to completely overwhelm the patient, as well as the consultant. Eventually, two nurses came in to talk to the patient and console her:

> *"I was sobbing. And this poor* [consultant] *was just sat there and he didn't really know what to do. I had two nurses come in and they were there with the tissues, you know. One nurse like brought herself down…and was eye level with me. And she was holding my hand, you know… it was just,* [I was saying] *I can't do this anymore, there's nothing I can do, you know."* (46 year old female, pre-RRT)

After this, the nurses and consultant referred the participant to a psychologist. The strength of feeling here seems upsetting and it is surprising that the woman's distress had not been picked up beforehand. She had evidently reached a literal breaking point when asked a simple (albeit emotionally charged) question by her consultant. Although staff have recognised the participant's distress here, it seems likely that there were points prior to this where her distress could have been identified and a referral made, as well as immediate conversations. In addition, given how many patients reported they felt distress, it seemed slightly unusual that the consultant was so taken aback. Perhaps the intensity with which this participant reacted was what shocked the consultant, particularly if it was strong enough to make two nurses immediately enter the room.

When this participant did see a renal psychologist, she found some of the sessions useful but did not continue with the full set of sessions. When asked if she had any unpleasant feelings related to ESRD and its treatment, she immediately replied:

> *"Oh God, yes, absolutely yes… I got the depression through losing mum anyway but the physical restraints I now have got worse. So I am down. I do get depressed."* (46 year old female, pre-RRT)

She explained the difficulty of having ESRD and talked about some of the physical symptoms that had taken a significant toll on her mental wellbeing. Working with the psychologist, she had been able to develop a coping strategy that began to help her understand and accept the limitations caused by ESRD. Before seeing the psychologist, she had been trying to do the same things that she had always done, but was finding this impossible. She described trying to run down the street but realising that the after-effect of that short burst of exercise was horrendous. She described slowly realising the things she could not do anymore, and that this realisation, like the disease itself, slowly worsened over time and turned into depression:

> *"…it doesn't happen from like you're find one day then you're poorly the next. It happens slowly over a gradual period of time and you don't realise how down and low and fed up you are until someone points it out to you, and then it just hits you like a brick."* (43 year old female, pre-RRT)

She went on to describe part of the third session with the renal psychologist:

> *"And it wasn't until she said to me, 'you need to accept that you can't do it.' Which just like, oh, I came home, and I just cried my eyes out. Because it was just that realisation that you can't, but there was no-one else I could talk to. I don't know anyone else that's going through what I'm going through."* (43 year old female, pre-RRT)

After this appointment, the patient did not return to the psychologist. In the remainder of the interview, this was explained as being due to the breakthrough realisation which made it sufficient for her to cope with her problems adequately afterwards.

6.2.3 Counselling

Some participants doubted that talking to a counsellor or psychologist about their problems would be helpful. One patient described himself as a practical, "hands-on person", and did not think that talking about his problems would help:

> *"…I can tell you anything, can't I, but you can't actually help me, if you get what I mean. I can tell you everything but when I come back to my own home, my problems are still here in the four walls, you know what I mean. So I could come on that but all it's doing really is unloading… You can't actually help me because it's in my head. So I've got to deal with that…"* (59 year old male on HD)

It seemed that this participant was looking for help and had been offered and considered counselling or a form of talking therapy but dismissed it as ineffectual. He described himself as more practically orientated and saw this as being at odds with what might be termed a talking therapy. Earlier on in his interview, he was asked how staff on the renal unit noticed when he was down. He said:

> *"Because I was quiet. Normally, I'm quite upbeat and quite sociable… Quite chatty and tell jokes… But then obviously when I'm a bit down, I'm really quiet and they say, are you alright? You're really quiet."* (59-year-old male on HD)

Unlike other participants, this patient did not adopt a façade of joviality to try and mask his distress, instead renal staff noticed that he had become quieter than usual. During his quiet periods, it seemed likely that this participant was thinking potentially distressing thoughts that could be explored with a talking therapy. He was, of course, right that talking therapies would not solve his problems, but they may have been able to offer alternative coping strategies and to normalise the distress that he was feeling. Interestingly, he suggested that instead of being offered counselling, he would appreciate being able to do something practical while dialysing. His suggestion was to form a knitting circle around the time for dialysis (either before, during, or after). This would potentially be an excellent opportunity to introduce some form of talking therapy (albeit a 'lite' version).

6.2.4 Renal unit atmosphere

Most participants who received HD were extremely pleased with the service they received from the renal unit and individual staff. However, participants did report that staff were often rushing around the renal unit and were too busy to talk about anything other than the practicalities of dialysing. As mentioned above, participants found that staff were unable or unwilling to talk about emotional distress in any detail. This was usually attributed to either a lack of time or a lack of training. It seems that the atmosphere on the renal unit made patients and staff alike feel that it was inappropriate or abnormal to discuss emotional problems. One participant, when asked if staff on the renal unit recognised her distress, said:

> *"I don't think so, I've never told them that, you know. You don't want to be a bother to them. As I say, they do answer everything and they're really good. But no, I've never told them that I get these down times. So, no."* (57 year old female on HD)

This participant had already stated during the interview that she routinely asked questions directly related to her dialysis and that staff were quick to answer these queries. Here, in relation to her emotional distress and "down times", she believed that talking about this would only be a "bother" to the staff.

It seems that a part of the problem on the unit is the light-hearted atmosphere routinely created by the unit staff: joviality seemed to be both positive and negative from the perspective of the patients. Staff should be commended (and often were by the participants) for creating an environment of relaxed informality and a sense of camaraderie among the participants which was reported to soften the impact of dialysis and reduced the potential dread participants felt in relation to HD. However, it was also noted to create an atmosphere in which people felt unable to discuss their emotional problems, in part because the renal unit was a jovial, jokey place where negative emotions may bring down the overall positivity. Several participants mentioned that the atmosphere on the renal unit was relaxed and that staff do ask how everyone is, but in a conversational-manner that usually elicits a variant on, "I'm fine, thanks for asking, and you?". One participant, when asked if he would have liked to have been offered support, said:

> *"The choice would have been nice. I'm probably alright at the moment but I think you know there have been a few times in the past 12 months or so where I maybe could have done with just having a chat with somebody."* (53 year old male on HD)

Even in reporting his need for further emotional support, this participant was hesitant. The assertion that he was currently "all right" seemed slightly defensive and perhaps reflected this participant's acknowledgement that talking about feelings on the renal unit was unusual.

Another participant offered an interesting take on this same issue. He was very positive about staff and the renal unit in general, stating that they were always there to support him and that they were very good at offering support. When asked who he would go to first if he was feeling upset, however, he stated that he would either keep those feelings to himself or go to a close friend:

> *"I think…keep it to meself. I've got a very close friend at work that I share problems with… the nurses and everything at the hospital, they're busy, aren't they? …they've got more serious people to be looking after than me. I don't regard myself as a priority."* (51 year old male, pre-RRT)

This participant seemed to think of himself as a low priority, that because his concerns were more about emotional problems than medical emergencies, he should not bother the renal unit staff. This is understandable from both a patient and staff perspective; medical emergencies will of course take immediate priority, but there should be a receptive atmosphere on the renal unit that allows an appropriate response to any problems.

6.2.5 Healthcare professionals and support

Participants tended to be complimentary about individual healthcare professionals (HCPs). Occasionally, some participants had a bad experience with HCPs but tended to offer a qualifier as to why that may have happened. There were isolated cases of participants whose entire experience of HCPs was negative. This tended to be in complex medical cases or where participants were unable to get the treatment they wanted. However, the relationship between participants and HCPs was – for many – most problematic in relation to participants' support needs. Participants were often unsure what support was available, appropriate, or needed. Some participants felt that staff, particularly nurses and consultants on the renal unit, could not offer appropriate support because they did not have personal experience of ESRD and its treatment. One person said:

> *"They do their best but they haven't been there, they haven't done it, they don't tell us what signs to look for or what process is going to happen. They don't tell you what you're going to go through, what you're going to feel or anything like that. So you know just a couple of people getting together."* (63 year old female with a transplant)

The distressing experience of ESRD and its treatment seemed to create a barrier between some participants and staff. There was a palpable sense of exasperation for this participant – she had not been given the information she wanted in the way that she preferred it, and seemed to feel that she was unprepared for the impact of her treatment. She went on to say:

> *"Well it's OK staff telling me, but they haven't been through it. They don't know exactly what it's like."* (63 year old female with a transplant)

This second statement conflicts with her first: in the second statement, she suggested that staff did talk her through some of the impact, but she felt that they were not capable of conveying all the feelings that a transplant may induce. Staff do talk to participants about the impact of ESRD and its treatment, and do try to prepare participants for every eventuality, but seem to be giving too little information. With some participants, there is a lack of trust. This woman continued:

> *"I can cope with something when somebody's straight, I can cope with it, but not knowing I can't."* (63 year old female with a transplant)

This is perhaps where the lack of trust originates. This woman had a difficult time throughout her transplant and continued to struggle. She had felt completely unprepared for some of the problems and distressing feelings she experienced, and felt that she never received straight, unfiltered information. She therefore concluded that staff were at least partially unaware of the potential for distressing feelings. It is plausible that the way in which information was presented to her focused on the positive impacts of having a transplant and somewhat glossed over the negative. This links with how some participants experienced the general atmosphere on the renal units; it is generally a positive place, but the positivity means that the negative side of ESRD and its treatment is not discussed. This may be to the detriment of many patients.

All participants, if time was mentioned, said that HCPs did not have enough, were too busy, and were not able to give the participants the time needed to explain everything:

> *"…they're too busy. They're not awful people, they're lovely people and they really kind and very caring. They're too busy. Way too busy. They've got too many people to look after. Their job is to keep us safe while we're on ward on the machine and that's all they have capacity to do."* (44 year-old female on HD)

This quotation perhaps encapsulates the dilemma facing both participants and staff. Participants, particularly when on the renal ward, can see that staff are busy and appreciate that they are "lovely" people, but, underlying this, participants expressed a wish to have more information and to have more time to discuss things with renal staff. The participants recognised that renal staff are highly trained and competent in most areas but felt unable to discuss emotional problems, either because they felt that staff were not aware of these problems or that there was no appropriate time to discuss them.

6.2.6 Family support

Most participants either lived with or spoke to their family on the telephone regularly. A few participants stated that they had no family to draw on and this tended to be a source of distress. Families generally offered participants emotional as well as practical support:

> *"My son, every hospital appointment I have for my eyes he drive me, for my kidney problem, he takes me, brings me home, I couldn't ask for more. So, I've all the support I can expect from the family."* (73 year old male on HD)

Despite the positive impact most families had on participants, a regular tension in family networks was about the capability of the person with ESRD. Some participants felt that their families, although supportive, often did not understand the impact that ESRD had on their lives. Some felt under pressure to hide the negative impacts of the illness and its treatment. It was difficult to determine if this pressure came from the family or from the participant; some men expressed the wish to continue being the 'provider' in the family, despite their illness, and were uncomfortable with their family knowing how much ESRD had impacted on them. This conflict, between a supportive family network and pressure to carry on in the same way as before ESRD, put pressure on participants:

> *"…my family's been fantastic… while I was in hospital they were here, they were doing what they needed to do looking after my father, making sure my son was OK. They did all*

> *the right things, but as soon as I came out of hospital, bearing in mind that I was still unable to walk, they then left to go back to their normal lives. So I was still then left to deal with day to day stuff a bit too quickly. So yes they are helpful but they're not helpful as well and I wouldn't talk to them about everything."* (44 year-old female on HD)

6.3 THE EMOTIONAL LOAD OF ESRD AND ITS TREATMENT

Participants tended to have a difficult relationship with dialysis treatment and the way in which they described their emotions was often distressing. In many of the interviews, the interviewer had to stop several times because the participant was either crying or needed some time to recompose themselves. Despite this, no participants expressed a wish to stop the interview despite being informed by the researcher that they could end the interview whenever they wished.

6.3.1 Life-saving treatment

The majority appreciated that dialysis was a lifesaving treatment but resented the limiting effects it had on their life. Participants mentioned that the side effects of the medication for ESRD were often unpleasant, and that after dialysis they would feel exhausted for the rest of the day. For participants on HD, this meant that a seven-day week became a four-day week, with at least three days written-off for dialysis. For some, the three sessions of dialysis per week were never far from their thoughts because of the amount of planning necessary to ensure they did not miss their appointments. A number of participants highlighted the extreme difficulty that being on dialysis presents when planning any time away from their dialysis centre and noted the restrictions on their life:

> *"Everything has to be planned around that particular day. If I want to go down to my daughter's place for the weekend, I've got to be back by six o'clock on Monday morning… So you're restricted, your life is ruled by the three appointments per week. Even if I've got another appointment anywhere, it can't be done on a Monday, Wednesday, or Friday. So that sort of throws half the week out." (*76 year old male on HD)

This participant echoed the sentiments of others, feeling frustrated, upset, and trapped by ESRD and its treatment. He noted feeling grateful for the treatment and was aware that without it his life expectancy would be extremely short, but he described being depressed by the restrictions that have been placed on his life:

> *"…so at the beginning I got very depressed, extreme depression. The fact that my whole life was being regulated by this… But I find that I just pray for Friday afternoon when it's finished. That's - I find that's just wishing your life away." (*76 year old male on HD)

This participant had a slightly paradoxical relationship with HD; the life-saving treatment that he receives has severely restricted his life as he counts down the days until he has two days free from dialysis.
Perhaps echoing this paradox, some participants described dialysis as being like a job, particularly when factoring in the often-complicated medication regimen and associated fluid and dietary restrictions. One participant summed up this paradox when asked to describe their feelings about the treatment:

> *"I shouldn't really be here and very appreciative of that… I think people struggle to know what to say. I don't like people feeling sorry for me, but I also like people to appreciate that life is a bit harder when you...it's like having a part-time job doing the routine, monitoring all*

> *the medication, organising the stock, all the hospital appointments."* (53 year old female on PD)

This participant clearly recognised that without the treatment they would not be here, and later mentioned how astounded they were by the capability and capacity of the NHS to "keep people alive". Combined with this recognition, however, was a frustration at the complexity of the various processes and of other people's reactions. A few participants expressed this latter frustration i.e. that other people were often unaware of the serious and debilitating nature of ESRD. This participant compared people's awareness of ESRD to their awareness of cancer:

> *"…no one can really relate to me. Because it's quite- it's not unique obviously but it is in the general sense of the word. But you know, even cancer a lot of people around you have had cancer or know somebody close to them that have. So it's* [ESRD] *not relatable to anyone, so that can feel a little bit isolating sometimes."* (53 year old female on PD)

This sentiment was echoed by another participant:

> *"…most* [dialysis patients] *are so resilient and just get on with it and make very little of it and it's very difficult to get other people to understand what it's like being a kidney patient so I think you've* [got to do] *something like promoting it like cancer is promoted. I know that's an awful way of saying it but that's what I actually feel."* (74 year old female with a transplant)

Participants seemed frustrated that their struggles were not routinely recognised. Perhaps, in part, the positive atmosphere on the renal unit contributed to this by tacitly ignoring the negative aspects of ESRD and its treatment.

Some patients were frustrated with their treatment and had thought about a point when they would refuse further dialysis. One patient on HD described a balance between being able to do his gardening and dialysing. If the side effects of ESRD and dialysis interfered with his ability to do his gardening too much, he stated that he would reconsider his options.

> *"…it's very important to me because if I can't do* [gardening], *I'm going to pack up altogether. And I'm not being melodramatic. I'll just call it a day... And it's got to balance. If it goes out of balance, I don't know how I'm going to react."* (83 year old male on HD)

Although the statement above is very matter-of-fact, the participant remains unsure how he will react. He implied that he would consider conservative management if he was unable to do his gardening and accept the seriously reduced life expectancy that accompanies that decision. This conflict, between receiving life-saving treatment and living a life that participants wanted to live, seemed extremely difficult for many patients to respond to.

6.3.2 Emotional burden

For many participants, ESRD and its treatment placed an immense psychological, emotional, and physical burden on their lives. Some patients managed to continue working and were able to balance the need for dialysis with family life and work, but these participants were rarely encountered in the qualitative work. Most participants did not seem prepared, particularly for the psychological and emotional toll that ESRD created.

Physically, most participants seemed aware of the difficulties they would face, and this was rarely discussed other than when they were having difficulty dialysing or struggling with medication side effects.

The psychological problems, however, were frequently discussed, yet very few participants who seemed aware of the potential for distress induced by ESRD and its treatment could talk effectively about a successful coping strategy. Participants discussed multiple issues in relation to the distress associated with ESRD. Many of these issues stemmed from participants' fundamental difficulty in accepting that they were chronically ill. What seemed particularly difficult for participants was the near-constant flux of the illness; the multiple stages of ESRD, as well as the multiple treatments, which meant that participants were rarely stable (either medically or psychologically). When they were stable, participants were capable of coping with smaller problems without difficulty. When they were experiencing multiple difficulties coming from different places, they often struggled to cope.

One participant was constantly surprised by her own ability, both positively and negatively. Over the previous few months, she had experienced several bouts of severe illness, both related to ESRD and incidental, which left her unable to move in a hospital bed. Following that, she recovered and was relatively well again, and certainly able to look after her son and do usual household tasks. She then suffered a relapse and was back in hospital, unable to move. When asked how all of this made her feel, she replied:

> *"Lost. I feel very lost at the moment… It makes me feel really demotivated actually."* (44 year-old female on HD)

Even though she had been discharged from hospital and was back to relatively good health, this participant still felt lost. She was almost separated from her body by the ESRD and felt unable to predict what would happen next, thus was unable to plan for the future.

Some patients struggled to obtain enough information to be able to understand what was going on in their treatment or what would happen next. This caused anxiety and concern that could be (sometimes) alleviated when staff answered questions the patients had:

> *"…thinking to myself well, you know, I'm going to die sort of thing. You've got an illness that you don't know much about, if you like. There's not a lot said. You're told you've got the illness but there's not a lot of explaining being done. I did ask quite a few questions actually and I did get some answers."* (69 year old female on HD)

This participant seemed content with the responses to her questions but went through a distressing period when she thought she may be about to die. Participants seemed to find the emotional toll of ESRD and its treatment surprising and struggled to find ways to cope with it and find enough information to allay their worries.

6.3.3 Bottling up emotions

Many patients mentioned that they didn't like talking about their emotions so tended to bottle up their emotions and not tell anyone, akin to the stereotypical view of the British 'stiff upper lip'. Participants often expressed a perception that staff were unable to recognise emotional problems or patients' support needs. Patients tended to say that they were sure that some people would appreciate emotional support, but because they were the type who did not like expressing emotion, they personally may not find it useful.

Participants also tended to report that they would not open up to a counsellor, although they recognised that this may be an appropriate intervention for others.

Patients often hid their feelings, saying that they ‘put on a brave face’, but obvious evidence of distress was often not far from the surface. One patient reported that they did not report their feelings to staff when on the renal unit and that they were preparing their belongings in case they deteriorated quickly – they did not say that they were worried about dying but that was certainly on their mind.

6.3.4 Coping strategies

Given that the questions posed during the interview were predominantly about the difficulties participants faced and what support they received, the lack of discussion about coping strategies was surprising. It was difficult to identify many coping strategies that participants adopted to deal with the distress of ESRD and its treatment. There seemed to be two main coping strategies: patients would accept their condition and the various limitations or ignore the problems and assume they were temporary and would improve. Patients who seemed to accept their condition reported being able to cope with minor problems or distress easier than patients who tried to ignore the issues.

However, these two coping strategies were not constant. Very few patients were able to accept everything or ignore everything. Instead, most patients seemed to display a mix of both strategies. This blending of the two strategies is perhaps emblematic of the *ad hoc* way that patients were dealing with ESRD and its treatment. No patients explicitly discussed their coping strategies and very few gave examples of where they were able to draw on a specific strategy that would reliably inform their own coping. A small number did state that counselling from either a psychologist or other member of staff had helped them to cope with the distress and emotional concerns they had, but most believed that coping with the illness was something they should do on their own.

6.4 ESRD AND PERSONAL HISTORY

All participants gave at least a partial medical history that included details about how they had come to be receiving dialysis treatment or had received a transplant (often both). All participants were asked the same question by the interviewer, with little variation; “Perhaps you could tell me a little bit about yourself and your illness?” Participants interpreted this slightly differently. Some only talked about their history of chronic or acute kidney disease, while others included details about their family lives, hobbies, and other biographical elements. Participants who were stable and had a transplant seemed to talk about their lives outside of ESRD more often. Participants who had polycystic kidney disease, had a complex medical history, or were experiencing intense distress about their ESRD were less likely to talk about their lives outside of the illness. This perhaps reflects the all-encompassing nature of chronic illness. When everything was going well, such as when a transplant was successful and there were relatively few ongoing problems or when dialysis treatment was running smoothly, people were able to see beyond the illness and talk about their wider lives. When their illness presented difficult problems or interrupted their lives, people became preoccupied and, in this case, interpreted the first question as being only about ESRD.

6.5 WHAT NEEDS TO CHANGE

Participants suggested a wide range of potential service improvements, but most suggestions fundamentally centred on increasing communication between all staff and patients. Increasing staffing levels and therefore increasing contact time between staff and patients was suggested to help improve communication.

Participants' perceived the medical treatment received for their condition as exemplary, with virtually no scope for improvement. However, many participants felt that their emotional and psychological distress was not being addressed, and that this was a key area where change was necessary. A number of participants stated that they had been offered counselling, usually while they were on the ward, which they had refused at the time. When asked if they would accept counselling now, some had changed their mind. Some stated that although they personally would still not accept counselling, others would probably accept and so it should be offered more widely. However, in many cases, participants seemed proud that they could bottle up their emotions and attempt to deal with them on their own and often reported that although renal staff did ask patients how they were, it was usually in a conversational rather than professional or counselling tone. At the very least, regular counselling would help to normalise the overwhelming distress reported by many participants.

Some participants, particularly those not on HD, wanted more contact with other patients in a more social environment. Participants reported feelings of isolation even when with family members or friends. These participants felt that more contact with people who were dealing with similar problems may help to alleviate their isolation and would also be a chance to socialise more.

Some participants felt that their fear of the unknown was particularly distressing and that the renal units could do more to inform them about the potential that they may experience distress during the course of their illness and its treatment. One participant had researched statistics related to mortality and the treatment he was undergoing, after failing to receive adequate information from his clinician. Communication with patients is a difficult topic and certainly problematic for clinicians to get right, but there seemed to be a reluctance on the part of staff to have potentially difficult conversations with participants about their treatment viability or their prognosis, particularly with relation to any psychological and emotional distress.

6.6 SUMMARY OF PATIENT FINDINGS

Most participants suffered from emotional and psychological distress due to the impact of ESRD and its treatment. Participants described many problems and potential sources of distress, but the hardest single factor to deal with seemed to be coping with the often unanticipated impact that ESRD and its treatment had on a participant's life. The unknown elements of ESRD, treatment, and the impact on quality of life were factors in many participants' reported distress and were issues that participants felt the renal units and staff struggled to alleviate. This was in part due to their focus on medical rather than emotional issues. Participants were more likely to be prepared for the physical impact of ESRD than its emotional and psychological burdens, and participants found the impact of ESRD and its treatment on their life surprising. Participants would describe treatment days on HD as essentially unavailable for anything other than treatment due to a combination of fatigue following dialysis, diet and fluid restrictions, and the potential for transport issues (even if none occurred).

Many of the problems described by participants – such as the fatigue that dialysis causes – are unresolvable. However, participants can be pre-warned about the tiring impact of dialysis and the myriad other problems that treatment can cause. While pre-dialysis education does prepare participants for some of the issues they discussed, it does not make them adequately aware of the potential for emotional distress. Furthermore, when participants become aware of the psychological difficulties through personal experience, they then assume that staff are unaware of these issues because they did not tell the participants about them. Properly armed with the knowledge about the potential for psychological distress, patients would be more emotionally prepared for the potentially negative consequences of treatment.

These are not easy conversations to have with patients, even within the context of pre-dialysis education, and there is evidence that the atmosphere on the renal units is not conducive to having these negative conversations. Almost all participants reported that staff on the renal unit were cheerful, tended to focus on the positives (although there was the potential for this to be biased toward the dialysis modality that they were most familiar with), and shy away from discussing emotional problems. There are many benefits to adopting this positive atmosphere on the unit, for both participants and staff, but it is perhaps damaging in the long-term for patients to gain knowledge about the potential for emotional problems through their own experience.

7. RESULTS: STAFF INTERVIEWS

7.1 RECRUITMENT AND SAMPLING

Thirty-one interviews were conducted, between April and December 2016 at site 1 (n=16) and between April and November 2016 at site 2 (n=15). Seven staff were interviewed at their renal unit, and 24 were interviewed by telephone, with all interviews lasting between 30 and 75 minutes. The roles of those who were interviewed are set out in Table 7.1.

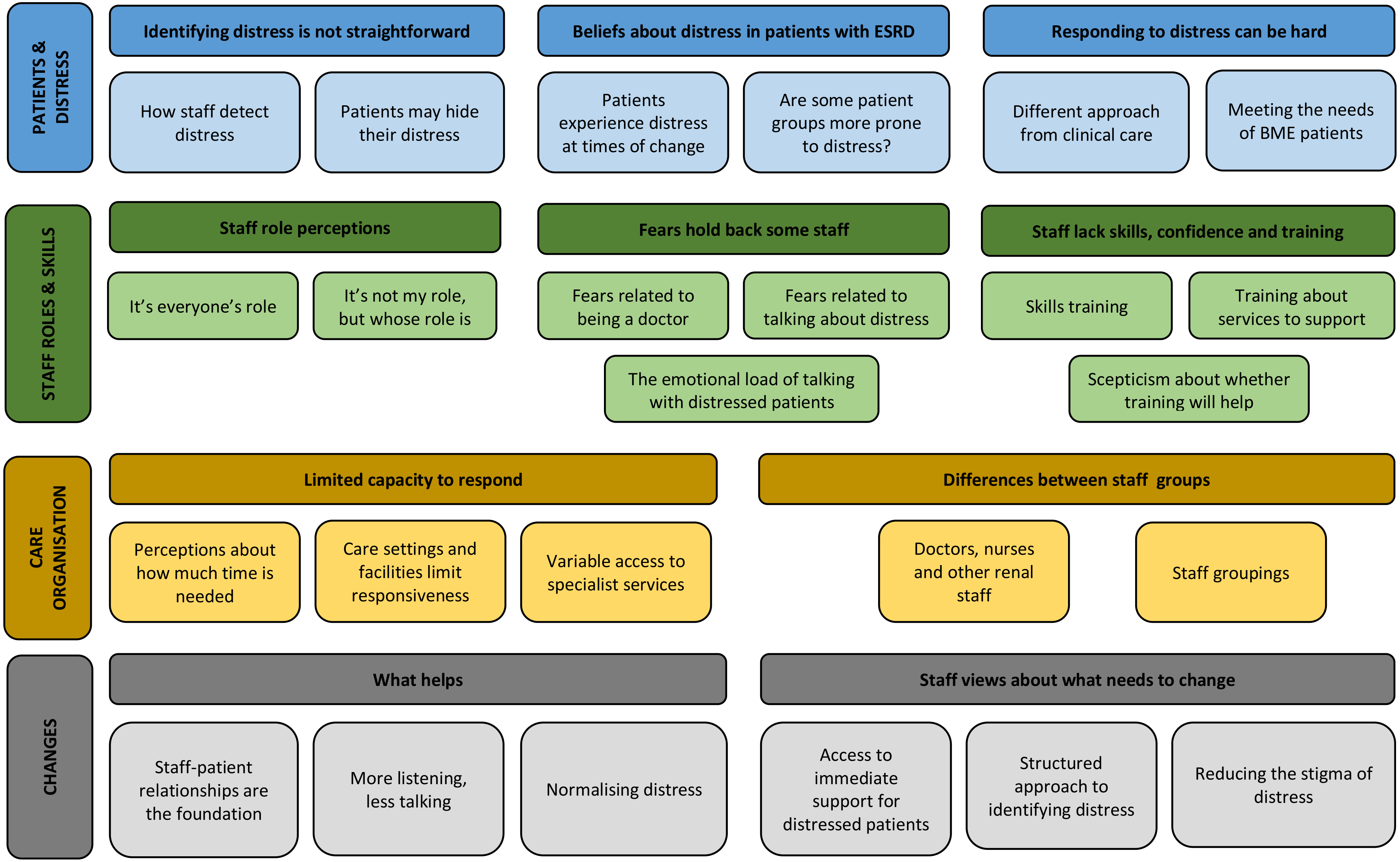
Table 7.1: Roles of renal unit staff interviewed

Staff roles	**Site 1**	**Site 2**	**Total**
Renal consultant lead	1	1	2
Renal consultant	3	2	5
Consultant total	**4**	**3**	**7**
Dialysis unit nurse manager	0	1	1
Dialysis nurse	5	4	9
Dialysis unit nurse total	**5**	**5**	**10**
Acute ward nurse	0	1	1
Specialist nurse (PD, HHD, Pre-dialysis)	3	3	6
Renal research nurse	1	0	1
Renal nurse total	**4**	**4**	**8**
Dietician	2	1	3
Social worker	0	1	1
Occupational therapist	0	1	1
Welfare rights officer	1	0	1
Other renal staff total	**3**	**3**	**6**
TOTAL	**16**	**15**	**31**

Given the relatively small numbers of staff in some roles, staff roles have been amalgamated into four groups to protect anonymity: consultants; dialysis unit nurses; renal nurses; and other renal staff.

This chapter starts with a short introductory section which provides a factual overview of staff views about distress, the main causes of distress and how renal units currently respond to patient distress. This shows that although most staff see identifying and responding to patient distress as important, the ways in which it is currently identified and managed are variable and *ad hoc* within each site. The thematic analysis therefore focuses on an in-depth exploration of the multiple barriers to the provision of high quality emotional and psychological support to patients and what has been found to help. The section concludes with a discussion about what staff think needs to change. Figure 7.1 summarises the themes and sub-themes identified in the analysis.

Figure 7.1: Summary of themes and sub-themes, staff qualitative analysis



7.2 OVERVIEW OF STAFF VIEWS ABOUT DISTRESS AND HOW CARE IS CURRENTLY ORGANISED

7.2.1 Why distress is important

Most staff considered the prevalence of distress to be high, and an inevitable consequence of ESRD. They wanted help to be provided to distressed patients, and for this to be integral to routine patient care. However, they knew from experience that patients who are not supported well could disengage from the service and potentially have worse medical and psychological outcomes. In contrast, patients who are well supported emotionally, are more likely to engage with staff and with their own care, which can have long-term health benefits.

7.2.2 Why patients become distressed

Staff had a good understanding of the reasons that patients become distressed. Some causes were seen as intrinsic to ESRD and its treatment, whilst others were more extrinsic. The intrinsic factors related to feeling unwell on an ongoing basis, the rigours of treatment, and uncertainties about the success of treatment. Uncertainty about prognosis and worries about death were also highlighted as underlying causes of distress. Extrinsic factors related to the impact of treatment and ESRD on patients' daily life, including work, relationships, sexuality, family life, social life and finances.

7.2.3 How renal units identify and respond to distress

Neither of the renal units had well established or routine ways of identifying patients' distress, and this *ad hoc* approach was seen by staff as one of the reasons why patients may not receive appropriate emotional support. Patients were not asked routinely about how they felt and it was largely up to individual staff to do what they felt was appropriate, if anything. However, this lack of consistency was thought to lead to delays in identifying some patients' distress or in them missing out on support altogether. Both sites had some specialist services they could refer patients to: site 1 had a renal psychology service, welfare rights officer and peer support; site 2 did not have a psychology service but did have a peer support scheme, an occupational therapist and a social worker.

7.3 BARRIERS: IDENTIFYING DISTRESS IS NOT STRAIGHTFORWARD

7.3.1 How staff detect distress

Although staff were aware that distress was prevalent amongst their patients, they reported finding it hard to identify. Some thought that psychological and emotional problems can masquerade as physical problems, whilst some emotional problems could in fact have a physical cause, which could lead to confusion about the most appropriate action to take. This partly explained why some of the doctors would first look for a physical cause of distress before considering psychological causes.

Whilst some staff talked about using their intuition, clinical experience or a "sixth sense" to alert them to distress, others relied on observing body language or behaviour. If they noticed that patients were unusually upset, moody or angry, or were suddenly not complying with treatment, this would trigger a conversation with patients about how they are feeling:

> *"It's looking out for the signs, it could be anything; somebody quieter than normal. It could even be somebody more chattier than normal, noticing something different… very difficult to put your finger on it* [recognising distress].*" (*A4, Other renal staff)

Although these appeared to be useful ways of identifying distress, some staff erroneously assumed that the absence of obvious outward signs meant that patients were not distressed. They did not see it as their role to probe or actively look for distress, assuming that distressed patients would raise concerns or initiate a conversation about their feelings:

> *"I would like to think that if they* [the patients] *were feeling like that* [distressed] *they would say. But, you know, patients tend to go away happy, if that makes sense… We've all been nurses a long time in renal, you know, all worked here for many years so I'd like to think you would know if something was wrong."* (A2, Dialysis unit nurse)

For this member of staff, the assumption was that if a patient seemed happy on the surface, there was nothing wrong, and this view was shared by many staff for whom the default position was not to ask patients about how they were feeling:

> *"I suppose because we don't really ask them. I don't know. We don't really sort of broach it with them."* (B2, Dialysis unit nurse)

However, the assumption that patients will, and are, responsible for self-identifying as distressed, contrasted with the experiences of other staff who had found that patients may not volunteer information about how they feel and are waiting to be asked by staff:

> *"Sometimes people are just looking for somebody to ask them the question and they will tell you 'actually I feel pretty lousy' or 'actually things have been awful with my fistula this month and my sick pay has stopped and I can't pay the bills and I just feel dreadful and I really don't know how I'm going to get out of this one'."* (B11, Renal nurse)

This led to an exploration of why patients may hide their distress from staff.

7.3.2 Patients may hide their distress

One doctor summed up some of the reasons why patients may not show their distress to staff:

> *"So there'll be some that definitely want their privacy, there'll be some people that won't think us effective, there are others that are embarrassed and there are others that don't think it's the right place to mention* [distress]*, and the others that don't know how to articulate it."* (A17, Consultant)

In addition, staff thought that admitting to being distressed can be taboo, because patients don't want to be labelled as not coping, or that they may equate distress with mental health problems:

> *"And just the admission that you need support, it's just for all of us isn't it, we all like to be self-sufficient….they will access support from our benefits advisor when they have financial difficulties, quite regularly, because the disease has caused that, rather than <u>them</u> being the problem… they'll shout when they're short of money, but not when they're crumbling psychologically."* (A5, Renal nurse)

Whilst these are understandable reasons for hiding distress, staff also thought that the strength of their clinical relationships with patients could inadvertently work against distress being identified. They were aware that patients increasingly perceive staff to be extremely busy. Patients may then conclude that staff did not have the time to talk to them about how they felt, and that they may want to avoid adding to the pressures on a member of staff they know well and may like. Staff also thought that some patients may feel that they are 'letting down' staff if they admit to feeling low or not coping emotionally, and this desire to please staff and be a 'good patient' was thought to apply particularly to patients' interaction with the doctors:

> *"I think there's a tendency, it depends a little bit on the doctor, but I think patients are seeing medical staff less frequently and they may put on a bit of a show for a doctor."* (B10, Consultant)

One member of staff also thought that patients can assume that clinical staff have agendas or goals which exclude wider aspects of wellbeing, and this can stop patients from opening up about how they feel:

> *"I think a lot of the time patients view health professionals as not really understanding their situation….they have their sort of set jobs that they're doing, and their set goals that they're trying to achieve. I think that that can make it difficult for them* [patients] *to talk openly … rather than it being to do with them and their sort of mental wellbeing or whatever, it's going to be more focused towards the aim of that health professional."* (A9, Other renal staff)

Staff therefore identified multiple reasons why patients may hide their distress. This means that the job of identifying distress is much more challenging for staff than it might at first seem, and is definitely more complex than just looking out for obvious signs of distress or waiting for patients to say they are distressed.

7.4 BARRIERS: BELIEFS ABOUT DISTRESS IN PATIENTS WITH ESRD

Staff expressed a number of strong beliefs about distress in patients with ESRD, including which patients are most likely to experience distress, when they are most likely to be distressed, and the role that ethnicity plays.

7.4.1 Patients experience distress at times of change

Many staff believed that patients were most likely to be distressed when they experienced significant changes in either their treatment or their lives. Three points on the pathway were identified as most likely to trigger distress: a) being diagnosed with end stage renal disease, b) the pre-dialysis stage, and c) the point of treatment initiation, with some staff believing that support needs reduce or stabilise after that:

> *"OK, it's either very early on, where it's almost a shock situation when somebody's first been diagnosed with failure, pre-dialysis almost. And I think once they start dialysing as well, because that's a very, it's very unfamiliar… almost a settling-in phase."* (B2, Dialysis unit nurse)

Other staff highlighted that emotional support is often needed when there has been little time for pre-dialysis preparation or when patients move onto conservative care:

> *"I guess the obvious times are the adaptation phase where you first start, and it's particularly intense in those patients who haven't had good pre-dialysis preparation. Because it can come as a terrible shock to them. So in the early phase to build those*

> *relationships and then at the end, so at the beginning and the end really, which I just mentioned about the end of life where it's clear that length of life is now limited."* (B7, Consultant)

The recurring theme of patients needing support at times of change was also reflected in comments from staff that patients experience distress if their treatment becomes difficult, for example because of infections or problems with fistulas, or when treatment needs to change:

> *"… they've been on peritoneal dialysis and they're moving to haemodialysis, then that's a big change and they might need to be support[ed] there. Because it can be quite a confusing time, it's a big change and a very difficult thing to do. So I think at each of the points where things change, where perhaps it would be good for people to be offered, sort of, a more formal opportunity to talk through what their issues are and any concerns they have."* (A9, Other renal staff)

Staff highlighted that although points of change in patients' treatment might be *more* likely to lead to distress, ironically, the need to deal clinically with these changes can often lead to there being much *less* time available than usual for providing support:

> *"And it's not because we don't want to, we know in the back of the mind, the more challenging the patient medically is, proportionately the emotional side of things also will be quite high. But the time which we have will be largely focused on the medical side of things and then they miss out on the emotional side of it".* (A7, Consultant)

In addition to this extra emotional load, staff recognised that switching treatments in either of the participating renal units involved a change in the staff who care for patients, which can mean that patients suddenly feel less supported. They are suddenly required to relate to new staff who don't know them and who may be less likely to notice their distress.

Although some staff clearly found it useful to think about change as a trigger for distress which could help renal units to target their support, they also acknowledged that some patients may try to 'get through' the change, deferring their distress, which only surfaces much later on. This means that renal units would need to take a flexible approach so that support can also be provided whenever patients need it:

> *"It depends on the individual….You know it just depends on when it hits them really. And that's the point at which they need it* [support]*…but the point at which you need it is the unknown, but you need to know that it's available for you when you need it."* (A5, Renal nurse)

7.4.2 Are some patient groups more prone to distress than others?

There were varying views about whether there are some groups of patients who are more likely to be distressed than others. There was some discussion of potentially unhelpful stereotypes: about men, who were perceived as reluctant to talk about emotions; about younger patients who were perceived as likely to need more support; and about older people who were perceived as being more stoical and less likely to want support. However, staff were quick to point out that patients did not always conform to these stereotypes:

> *"We have younger patients who tend to struggle a bit because they're young and they've got the rest of their lives ahead of them. And then we've got older patients, say in their 80's and they've never had a day's illness in their life and it's always 'why me, why now, all my life I've been good or I've had a good diet and I've exercised'?"* (A6, Dialysis unit nurse)

In contrast, other staff emphasised individual differences and the importance of understanding each person's distress reactions and circumstances. For example, some patients may have limited support at home and are therefore more likely look to the staff for support:

> *"Some of the people who come in won't have family support at home. So I think if we can provide a talking point for them when they come in, I think they're more likely to come in and have the dialysis."* (B12, Renal nurse)

There were also beliefs expressed about BME patients who were simultaneously viewed as likely to experience more distress than patients in other ethnic groups, but also less likely to need to support. Some staff assumed family and community networks were helpful, so that patients were less likely to need emotional support:

> *"Usually, the Asian community they sort of look after their own groups because I think they're very community based …..and everybody supports each other."* (B15, Dialysis unit nurse)

For others, family support was seen as double-edged, and could potentially contribute to patients' distress:

> *"Certain cultures have a lot of family support around them all the time, but they may or may not talk to their family members about what's going on in their head."* (B7, Consultant)

> *"Once they become a kidney failure patient and start dialysis, then a lot of their autonomy is taken away by the family and a lot of decision making process will then automatically shift to the family rather than the patient….from the outside it looks like they've got more family support, but actually that's not really helping them. Yes it does help them in physical looking after them, but I think the emotional side of things, they are more vulnerable than the Caucasians I think."* (A7, Consultant)

Several staff had also observed that Asian men were unlikely to talk about their feelings, whilst Asian women were seen as overtly expressing a lot of emotional need, although sometimes this was demonstrated in different ways from other ethnic groups:

> *"I'm just using the stereotype of an Asian lady that she will have the complaint of pain all over, but maybe that's the way she can emote."* (B5, Consultant)

7.5 BARRIERS: RESPONDING TO PATIENTS' DISTRESS CAN BE DIFFICULT

Many staff reported that they had found it challenging to respond to and manage patients' distress. They felt they lacked the skills and confidence to talk with patients about feelings, had concerns or fears about what might happen when patients opened up to them, and thought there were insufficient specialist resources to which patients could be referred. These barriers are explored in detail in Sections 7.8 to 7.10. This section first looks at the tensions between providing clinical care and emotional care, and then considers the additional challenges that staff have experienced in meeting the needs of patients from BME groups.

7.5.1 Distress needs a different approach from usual clinical care

For some staff, often the doctors, there was a tension between patients valuing the opportunity to talk and the doctor's predominant perception that they need to resolve patients' problems:

> *"Medical problems, this is a problem, this is a solution…you can sort it. But when it comes to the emotional side of things or depressive side of things, then it's* [a] *challenge."* (A7, Consultant)

These staff found it hard to value listening to patients talk about their feelings unless they could make the patients feel immediately better:

> *"I think my interactions with patients tend to be pretty focused on the hard things that I think I can help them with and I guess part of it is that I don't think I can help them as much with their emotional needs."* (A8, Consultant)
>
> *I know that you can only give what you have, and I know that a lot of people* [staff] *can't cope with distress. They can't cope with, I don't know, not being able to help. So some of them might not want to go too far into problems.* (B1, Dialysis unit nurse)

Some staff also talked about particularly challenging patients whom the renal unit had struggled to support, for example:

> *"I have one lady who, she's slippery, she will come up with a number of concerns or symptoms or acutely describe the distress. But then when you try to tackle it as such, you're so overwhelmed by the enormity of the distress, that it's very difficult to get to the bottom of it…. The distress comes with such pessimism and negativity that you really come to a point that you can't actually come up with a plan that's going to be credible in the eyes of the other person because of their pessimism."* (A17, Consultant)

7.5.2 Meeting the needs of BME patients

A number of different views were expressed about how ethnicity can affect how well renal units are able to provide support to patients. All of the comments were about South Asian patients (the largest BME group in both sites). An extremely wide range of views was expressed, ranging from Asian patients being least likely to experience distress or need support because of perceived strong family and community support, to this being a group which experiences higher than usual levels of distress, requiring more support. The comments made by staff primarily related to language, culture and religion.

A number of staff talked about finding South Asian patients a relatively challenging group when it comes to both identifying and responding to distress. For some, the main issue was the language barrier for patients whose first spoken language was not English. Interpreters were seen as difficult to access, particularly in the dialysis units located away from main hospital sites. Speaking through an interpreter was also often found to be difficult:

> *"It's difficult to be able to communicate with the patient if they don't speak the same language with you, and even if they do speak that language, there's so many dialects. I think interpreters don't necessarily – the interpreter puts their own spin on it."* (B5, Consultant)

Speaking via an interpreter was also thought to make it difficult to build up the necessary rapport with patients, whilst speaking to someone in their own language can help them to open up:

> *"We do use interpreters but you don't get the same connection with the patient if you use an interpreter compared to speaking to them yourself."* (B10, Consultant)

> *"And you talk to* [them] *in their own language but sometimes they feel like it, yeah she knows my language so sometimes they open it up, and then they will start telling you like, sometimes they like tell you what is causing the distress."* (A15, Dialysis unit nurse)

In the absence of interpreters, staff had found they have to rely on relatives to interpret:

> *"I mean, from a language point of view with the Asian patients it's more difficult, it is difficult. But here I'm lucky in that I've got a lot of good relatives who come and will speak English, so they will do the translation there and then."* (B8, Other renal staff)

Some staff were cautious about doing this, because they were aware that Asian patients may not want their families to know how they are feeling, because they may feel they are letting their family down:

> *"…the way they approach sort of depression within the family is very different isn't it, they're not really allowed to feel low."* (B8, Other renal staff)

> *"And also the prejudice, they don't want to be labelled as depressed, because they think that if they feel that they're depressed they are putting down the family, and they want to keep those things to themselves."* (A7, Consultant)

There were also beliefs and uncertainty expressed about the interplay between religion, culture and ethnicity how this can affect the likelihood of patients talking about their distress:

> *"I'd say they're more likely to open up and say they're feeling distressed or the family members will tell you. You know, like from a lot of the Muslim cultures the family I think are quite forthcoming … I think they're more expressive…but I can't be absolutely sure because once again I think because they've got their family there supporting them, they don't seem to be as distressed."* (B3, Dialysis unit nurse)

> *"I find that some cultures are more willing to talk about things and they perhaps have had support from their religion or from going to the temple or mosque or a church. I think sometimes people have, that are perhaps more spiritual, sometimes find it easier to talk about things."* (A9, Other renal staff)

7.6 BARRIERS: STAFF ROLE PERCEPTIONS

7.6.1 It's everyone's role

When asked about whose role it is to identify and respond to distress in patients, many staff considered it to be everyone's role in the renal unit:

> *"We all have that role. We all have that responsibility to do that. Whether it's a domestic, whether it's a HCA, whether its band six, band five, doctor, we all have that responsibility."* (B15, Dialysis unit nurse)
>
> *"Oh we all do. I don't think it should be, I've never thought it should be one person. I think we all do."* (A17, Consultant)

Some staff were quick to point out that this includes non-clinical staff, who may know patients well and are in a good position to notice any changes in patients. Non-clinical staff may also be perceived as being more approachable than clinical staff:

> *"Just somebody they can have a chat with I suppose and say if they're OK. And somebody that's not in uniform and they might tell them a bit more than what they would you, you know."* (B11, Other renal staff)

7.6.2 It's not my role, but whose role is it?

Despite most staff initially responding that it's everyone's role to respond to patients' distress, a number of staff then talked about that being the case in theory, but not in practice. Some staff seemed to view dealing with distress as optional, depending on whether individuals had a particular interest or inclination to include it in their role:

> *"Yeah, I think it's down to different colleagues as well who think differently. Some people would see it like 'well, it's not my job'. You get that sort of attitude. And then other people like myself you know I'm as soft as anything…. some people will be more interested in that side of things than other people."* (A6, Dialysis unit nurse)

A number of staff quickly deferred to other members of staff, saying that patients would feel more comfortable and possibly talk more openly to a different member of staff or other staff groups. For a number of consultants, nurses were thought to be better placed to undertake this role than doctors:

> *"Even though I don't think I'm intimidating,* [the patients] *might be intimidated by coming to see a consultant. Some people might not tell me things that they'd be quite prepared to tell the cleaner or a nurse or a physio."* (B4, Consultant)
>
> *"I don't see myself as providing* [emotional support]. *It's not that I don't see it as my role, but I also don't necessarily see myself doing it day to day… I don't think I can help them as much with their emotional needs…. perhaps they* [nurses] *are better at identifying this level of, or this kind of distress or stress or difficulty that we're talking about."* (A8, Consultant)

Nurses tend to have more frequent contact with patients compared with doctors, and therefore it was thought more appropriate that they deal with patient distress. However, this approach of feeling that another staff group is better equipped to deal with emotional issues was often mirrored by the nurses and other renal staff. They in turn felt that the consultants should talk about emotional issues as this is such a serious topic, even though they knew that some consultants would probably not deal with these issues well:

> *"I would have to defer to a consultant and hope that they would deal with it in a manner appropriate. So either via referring on or to a different specialty."* (A4, Other renal staff)

Again, some nurses, particularly dialysis unit nurses, thought that nurses in other parts of the renal unit were better placed to deal with patients' distress:

> *"I've always seen it as being more their* [nurses] *role than my role and I think I have a bias as well to thinking that they're probably better at it than I am."* (B4, Dialysis unit nurse)

Overall, although most staff thought that providing emotional support to patients was a part of everyone's role, there was recognition that this did not happen in practice. Differences in role perception were found to be important, and related to perceptions of who was best placed to deal with distress in terms of skills, seniority and opportunity. A significant minority of staff felt it was not their role to deal with patients' distress, whilst the staff groups they thought would be better placed to deal with it thought similarly. It seems likely that the result is that some patients' distress is not dealt with. The next few sections explore some of the underlying reasons for staff not identifying or responding to patient distress as part of their role.

7.7 BARRIERS: FEARS HOLD BACK SOME STAFF

A range of fears and concerns were expressed by staff. Some of these related to their role, particularly for doctors, and other fears centred on what could go wrong and the impact on themselves as individuals.

7.7.1 Fears related to the role of being a doctor

For most of the doctors, there was a tension between dealing with medical issues and dealing with emotional issues. Some felt they had to take a 'medical investigation first' route, in order to rule out any physical causes of distress:

> *"So, you know, and a lot of clinicians will try desperately to look in the blood test. How can I explain the fact that this patient's not feeling right? So the worst case scenario is that all the bloods are fine and it's actually 'your bloods are all fine, I'm not quite sure why you're feeling like that'."* (A5, Consultant)

Doctors also expressed feelings of helplessness: they felt there was little they could do to help distressed patients, and this contrasted with their usual approach towards dealing with medical issues:

> *"I mean why open up a can of worms that you can't actually address. If the patient says to you 'I'm really depressed, I'm not really depressed, but I really feel down', can you do anything about it? You can talk to them but its empty words really, isn't it? You can't give them a pill to turn off their kidney failure. On the other hand if you've got somebody with anaemia you can deal with it…I can give them an endoscopy, I can stop their aspirin.*

> *There's so many things that I can do and I'm comfortable doing those things."* (B5, Consultant)

Several doctors were also concerned about getting too involved and feared not being objective, which could impact on their role as a doctor, because objectivity and detachment were seen as essential for their role:

> *"…if I don't have a degree of emotional detachment, I can't do what I need to do for them… Plus the fact that you see an awful lot of problems in medicine and it is very difficult to manage the emotional pressure of that if you get too involved. So there's a personal issue as well in terms of stepping back a little bit so that you don't get too sort of personally upset by things."* (A8, Consultant)

7.7.2 Fears related to talking about distress

A number of staff said that although they could identify distress, they were unlikely to deal with it because they just did not feel comfortable in talking about feelings in general, or with patients:

> *"I feel a bit uncomfortable with too much emotion, I'll be frank."* (B4, Consultant)

Some staff were fearful that patients might not open up to them, which could cause awkwardness in the future:

> *"And again, sometimes I know that* [patients] *have symptoms suggestive of depression, but I don't want to ask them because in the first instance, because of the fear of what doesn't come forward and then there is a blockage there."* (A7, Consultant)
>
> *"I do not know some patients well and the fear of whether they might come forward, open up to me…"* (B1, Dialysis unit nurse)

Staff also feared saying the wrong thing or making matters worse for patients:

> *"At the end of the day you could say something really wrong couldn't you, you know. You're only going off your nursing that you've done nursing, how do you know you're saying the right thing? You don't do you."* (B13, Dialysis unit nurse)

There were also fears that problems might be uncovered which would be hard to deal with:

> *"I guess on some level it might actually uncover a problem that, it might create a problem or identify a problem for me. I mean there might be a selfish reason for it in that I'm just wanting you know, to move through the consultation quickly without uncovering something that might be a problem. I don't know, I don't know how to describe it. And I guess on some level it would be sort of like, why go there if you don't have to."* (A8, Consultant)

7.7.3 The emotional load of talking with distressed patients

A number of staff were fearful of the emotional impact on themselves of dealing with patients' distress:

> *“I don’t know, I guess it makes me emotional as well. I mean I don’t want to give you the impression that I’m completely cold and completely shut down, but I must say I don’t particularly feel comfortable with it.”* (A8, Consultant)

> *“It’s not easy to provide comfort when somebody is very distressed. Not everybody can manage that very well. We all struggle at times, I do. And often if you know that person, you can feel distressed [too], but it’s managing that.”* (B9, Other renal staff)

In a similar vein, some staff thought that it was only possible to deal with patients’ emotional problems when everything else around that member of staff was going well. If there were any problems at home, staff potentially did not have the emotional capacity to cope with the additional toll of patients’ problems:

> *“…if you are not strong emotionally yourself, or if you are going through stuff at home, you find that by the time you’ve come to the unit you have nothing to give… So* [the nurses] *have to deal with their [own] emotional situation before they can help others.” (A1, Dialysis unit nurse)*

Finally it is important to note that some staff had difficulty talking about how they dealt with emotional problems. The speech patterns used were often stilted, with lengthy pauses and abrupt changes of sentence structure. Staff seemed conflicted and this came out in the slightly unclear way they talked about dealing with emotional distress. For some, this conflict often seemed to be resolved by actively avoiding any discussion of distress with patients, or assuming that other staff would deal with emotional problems:

> *“So those* [emotional problems] *are the things that sometimes it’s better to avoid. And then if it’s there, we know, then we can ask for the nurses to speak to the family or get a psychologist to see* [them]. *And the problem then shifts if we get the psychologist to deal with it.”* (A7, Consultant)

Again, staff had a dilemma. They were able to identify distress, but then were not confident to help. By ignoring distress or referring the patient to someone else, the problem essentially goes away but this reinforces these individuals’ lack of confidence and experience of helping patients with their distress.

7.8 BARRIERS: STAFF LACK SKILLS, CONFIDENCE AND TRAINING

Some of the staff fears cited in the previous section related to a lack of understanding of distress and having limited skills to deal with it, which resulted in staff lacking confidence:

> *“I think it’s got to be training again really* [priority for what needs to change]. *For both sides really, identifying [distress] and when I need to support the patients. Yeh, because without that - without that background knowledge I feel like, you know, useless.”* (A6, Dialysis unit nurse)

It was notable that none of the staff felt they had been adequately trained to deal with patients’ distress. Most had received no training whatsoever, whilst a few had found that some of their learning from previous mental health or palliative care training was relevant and that the skills gained were transferable.

7.8.1 Skills training

Training was seen as useful because it was perceived as being able to help staff develop new skills for dealing with challenging patient scenarios. The most common suggestion was the provision of training in how to approach patients, how to get them talking and what not to do:

> *"You know, to perhaps sort of how to word questions, and how to respond to patients. Making sure that they are aware of all the services that are offered, you know, where they can signpost people to if they don't want to talk. I think that that would probably help."* (A9, Other renal staff)
>
> *"How to approach people, if there's key words, or picking up on signs. Or if there's you know if there's no-no's you shouldn't do. Or you perhaps shouldn't approach them in this state, or don't offer that or whatever really you know."* (A13, Renal nurse)
>
> *"And you know I don't feel that I'm particularly good at managing it either. I always feel like I don't know what to say, you know when people get that upset."* (A8 Consultant)

Some staff felt that training should include methods focusing on ways to develop/show empathy with patients and how different styles of consultation can help or hinder this:

> *"Staff training. So, you know, be it HCA, nurse and porters, you know, I think staff training there in relation to empathy."* (B12, Renal nurse)
>
> *"The younger doctors, the trainee doctors, they inevitably tend to focus on the things that they learn about, the biomedical things they learn about, the checklist of numbers rather than starting from the premise of 'how are you, let's have a chat, what do you want to talk about', which to them would seem to be too woolly, too ill-focused. So I do think that style of consultation needs support and education."* (B7, Consultant)

Some of the more experienced staff also wanted training that would enhance their existing skills and complement what they had learned from experience:

> *"And so it's not necessarily a lack [of training], it's just that we could do things a lot better, if we looked at skill sets. It would maybe move it to a different level."* (B10, Consultant)
>
> *"Although I feel I do as good a job as I possibly can, I personally would like further training, because I might be missing something which, you know, I don't know and I wouldn't look for that… And what I've learned is what I've picked up over the years really."* (B16, Dialysis unit nurse)

7.8.2 Training about services to support patients

A number of staff felt they needed a much better understanding of the services available to support patients, particularly in terms of what psychologists can do for patients and when to refer/not refer:

> *"Just what could be achieved? You know I think we get quite imbibed in the physical and we know what dialysis does and we know what transplant does, but quite what does the*

> *psychologist do? You know we'll send the patient there and hope they come back better and in a better mood perhaps. But I don't think people are quite aware of what they can achieve."* (A5, Renal nurse)

> *"Yes, if I knew what the renal psychologist, more in depth, what that role was, then you know some people I might refer to the renal psychologist and there's no need. I could have dealt with all myself or as a team, we could have sorted it all out between us."* (A6, Dialysis unit nurse)

Staff linked the lack of training in one of the sites to the lack of a renal psychologist. They were aware that in other renal units, psychologists may provide training in the use of specific psychological techniques that staff could use with patients:

> *"I mean, there's a lot of good techniques out there but we don't have access to them. We don't have a clinical psychologist attached to the unit, which you know."* (B8, Other renal staff)

7.8.3 Scepticism about whether training will help

Although many staff wanted to see education and training provided, others were sceptical about whether it would help. There was a debate about whether some individuals are just better at dealing with patients' distress because of their individual experience and their own personal characteristics, and therefore whether education and training can really make a difference:

> *"Well I'd like to see more education but, you know, I don't know if you can teach this kind of thing. I think with that it's either experience or education, I don't know. I think it comes with experience and what you've learned from others, whereas other people learn it through education so I don't know. So it's a combination of both, education and experience."* (B15, Dialysis unit nurse)

> *"Sometimes you have to have life experiences to be able to relate to someone. And I know you can't teach life experiences but you can teach counselling and listening. So if people can have the basics of actively listening then that might help."* (A14, Dialysis unit nurse)

Table 7.2 summarises the main training issues which were identified through the staff interviews.

Table 7.2: Main training issues identified by staff

Identification of distress	Which patients are most likely to experience distress and when
	How to spot distress; direct and indirect signs
	Why patients may hide their distress
Dealing with distress	Understanding our own fears as staff and what holds us back
	What patients want
	Dos and don’ts; what can go wrong
	Practising different patient scenarios
	Knowledge of what services are available to refer to
	Psychological techniques and how they help
	What psychologists do and when to refer to them
Communication skills	Active listening and empathy
	Basic counselling skills
	How to get patients to open up
	Closing down a conversation about distress
	Different consultation styles and how they help/hinder

7.9 BARRIERS: LIMITED CAPACITY TO RESPOND TO PATIENTS’ DISTRESS

7.9.1 Perceptions about how much time is needed

Lack of time to respond to patient distress was commonly mentioned as a problem. There seemed to be different dimensions to the problem of limited time. Some staff observed that as renal units have got busier in recent years, staff have less time to talk with patients, particularly nurses on the wards and in dialysis units:

> *“And I don't think the nursing staff have the time like they used to just sit and talk.”* (B8, Other renal staff)

> *“I think probably the immediate thing that comes to me, is time for patients. And I don't think its rocket science, I don't think that staff need to deliver something, they just need to have time to talk to patients, maybe just to listen, maybe not intervening in a conventional sense. And I think that’s a component, that’s something that is of value, that’s diminishing or under huge pressure really.”* (B10, Consultant)

In outpatient clinics and in the dialysis units, staff tend to prioritise clinical care, so that the emotional aspects of care are left to last, which results in them being neglected if time is short:

> *“I want to focus on the medical side first and then deal with that. And sometimes I might not have enough time* [for the emotional side]*.”* (B1, Dialysis unit nurse)

An added dimension to this is the need for staff to focus on achieving the medical outcomes and key performance measures which are routinely monitored by the hospital Trust. Dealing with issues related to distress was considered challenging to relate to these outcomes:

> *"I guess to a certain extent there's the time factor. There are certain things that I have to achieve in a consultation and it's very hard to measure the emotional support. There's a lot of talk about patient experience but that doesn't always fit with the hard outcomes that we need to achieve."* (A8, Renal consultant)

For some staff, there were concerns about the unpredictable nature of asking patients about their feelings, and that any problems raised may take a lot of time to address:

> *"If you ask the question 'how are you?' you must be prepared to sit and listen to the full answer. That's important. For example, from that answer it will tell you what to do next. And it's not the sort of thing you can do when you're doing something else."* (A10, Other renal staff)

Some staff were also are wary of raising the issue of distress with the more challenging patients, whose high level of need means they take up a lot of time:

> *"But I think there are some patients that find it so difficult to cope with their illness that they need quite a lot of, or they need a lot of input, they need a lot of opportunity to talk about all their concerns and anxieties, and I don't think we've got collectively enough time within conventional staffing to do that."* (B10, Consultant)

Some of the doctors were very focused on time as a major barrier:

> *"And how to do it* [talk about emotional problems] *in a short time? If we have the principles to solve that in 10/15 minutes, that's fine. We have that sort of time. But if the discussion - if we have to spend half an hour or a bit longer than that, then that's difficult."* (A7, Consultant)

If, as this consultant suggests, they felt confident that talking about emotional problems would only take 15 minutes, then staff might feel more comfortable having those discussions. Without the knowledge of how to deal with emotional problems in a time-limited way, some staff appear to be reluctant to start conversations with patients about their emotional wellbeing.

Finally, although many staff talked about the need for more time to talk with patients, some felt that this was primarily about re-organising time rather than needing extra time. They thought it was always possible to find extra time if a patient needed it:

> *"We've got time. Quite often – you can make time. There's no reason why nobody cannot make 20 minutes…. I don't think time is an issue, but sometimes I think it's actually, it's not supporting them, it's actually getting to the point where you've actually discerned that they need support."* (B5, Consultant)

This consultant makes a useful distinction between identifying what the emotional problem is, which can potentially be done in a time-limited consultation, and actually providing the support which a patient needs, which may take longer and would therefore need to be done by others or at another time. Providing doctors and dialysis unit nurses with the appropriate skills to open up and then close down conversations with distressed patients in a time-efficient way, may help with this.

7.9.2 Care settings and facilities limit responsiveness

Staff thought that the likelihood of addressing patients' distress was affected by different patient care settings. Dialysis unit staff were highlighted as the group of staff least likely to see patients' emotional well-being as part of their role, due to their focus on the technical aspects of dialysis:

> *"But I just find like some nurses, caring and good as they are, they just see it as, do the dialysis and then get, you know, carry on to the next group, and it's all more like a production line rather than actually, you know, a caring role."* (B3, Dialysis unit nurse)

> *"Well some* [dialysis] *units are so under pressure, they are just processing, it's a dialysis factory, you know, they're processing treatments…we've got people queuing up for the treatment, let's get them through sort of thing. And I think it's the emotional support and the passion that can get lost very quickly when that's the case."* (B7, Consultant)

The lack of private spaces in some dialysis units was also highlighted as a significant practical barrier to dealing with distressed patients' emotional issues:

> *"And again the dialysis units, and I think there are challenges, I don't want to talk about the emotional side of things in the dialysis unit because it's very open and you can't speak to them without the next person hearing… So we don't want to talk about that in the unit. And then these patients come to the hospital three times a week and if I have to bring them another day to the hospital to discuss the issues, that's a challenge."* (A7, Consultant)

*S*everal doctors also noted the importance of continuity of care and that doctor rotas can affect this negatively, making it less likely that distress will be dealt with well:

> *"So it's easy for me if a patient in my dialysis unit, if I have looked after the patient for pre-dialysis….I know them prior to starting them on dialysis and that helps me. It's a personal bond between the patient and the doctor, it helps me a lot in addressing the emotional side of things. But it doesn't happen all the time because the way the units are, we are allocated different dialysis units….if I do not know them from before, then it takes a huge time to get that rapport, build that rapport and confidence….I mean, sometimes it could be three or four visits before you know the patient well, so that three or four visits is almost a year gone. So that's a long time."* (A7, Consultant)

In contrast, staff who visit patients at home had found that patients were more likely to open up in their home environment compared with the hospital:

> *"And once I'm in their house people often open up to all sorts… When* [in] *their own home, they're inviting you in and they can tell you what they want you to hear. And it's calmer, it's quieter, and it's private. There are only the people there that they want to be there and you can have frank conversations then, without the worry of anybody else listening in."* (B8, Other renal staff)

7.9.3 Variable access to specialist services

Staff commented at length about the importance of having specialist support services they could refer patients to. Having access to a renal psychologist was seen as the most important specialist service, yet waiting times were seen as problematic, because patients' needs were not being met in a timely fashion:

> *"But yes, we do have a very good psychologist, psychology team, who work with the patients. But they are stretched, and it is, it is difficult to get them seen quickly. We can do it, but usually it's about a six week wait. And then by that time that six weeks arise, sometimes the patient is over the crisis, if you like, and then doesn't attend the appointment."* (A12, Renal nurse)

Although waiting times were an issue, staff had found that some patient groups such as older people were reluctant to access the service, because they thought they should be able to manage, whilst other patients thought there was some stigma attached to going to see a psychologist. Staff in site 1 were not always fully informed about what the psychology service did, and thought they needed more information about how the psychologists work, in order to make best use of the them. In site 2, where there was no renal psychology service, staff thought that patients probably had not missed out, as they used other resources flexibly, such as the social worker and occupational therapist, to plug the gap. However staff thought that they may be missing out by not having access to advice and training from a psychologist:

> *"…there's a lot of good techniques out there but we don't have access to them. We don't have a clinical psychologist attached to the unit…there's [not] a great awareness of the wide-ranging, as I say, techniques that could be used to actually help the patients. I think we need to do so much more on that side."* (B8, Other renal staff)
>
> *"But I think a psychologist would be able to equip the staff better to deal with low levels – because you couldn't get a psychologist dealing with everybody with low levels of emotional distress, but I think what we really lack is for the staff."* (B5, Consultant)

Site 2 had also attempted to access community mental health services for some patients, but had found this to be a frustrating experience, where patients were bounced back and forth between hospital and general practice:

> *"If somebody says 'I just feel down', I mean apart from suggesting this is normal and perhaps would you like to speak to somebody else who went through this, or go and see your GP which is, you know, the easy way out. And the GP says 'well you've got kidney failure so go back to your clinic doctor'."* (B5, Consultant)

Frustrations were also expressed about limited access to social services which might potentially help patients with the wider impacts of their kidney disease:

> *"The other big area that patients have major issues in that I think there is it's very difficult to access social services… It is the social consequences of having kidney failure, the impact it has on their employment, their earning ability, their home life, their family life, the extended impact that it has on their kids…."* (A8, Consultant)

7.10 DIFFERENCES BETWEEN STAFF GROUPS

7.10.1 Doctors, nurses and other renal staff

There were distinct differences between most consultants and the rest of the staff (nurses, dialysis unit nurses and other renal staff) in their attitudes to patient distress and their experience and confidence in dealing with it. Although not all of the nurses had an active interest in providing emotional support to patients, they were all keen to have training that would provide them with the appropriate skills to support patients. Most thought that supporting distressed patients should be part of their role, and this is reflected in Section 7.8, where the majority of quotations about the need for skill development and training are from nurses and other renal staff.

In contrast, although most of the doctors thought patient distress was important, they tended not to see it as integral to their role and acknowledged that they may not have the requisite skills. They did not see themselves as being good at providing emotional support, particularly in contrast to medical care, and often thought time pressures mitigated against them asking patients about their emotional and psychological health. This was reflected in a lack of enthusiasm for training, with some consultants saying that even if they were trained, they would be unlikely to use the training as they would continue to prioritise medical care over emotional support. However, some consultants who reported being active in providing emotional support for patients saw it as an important part of their role, and expressed some frustration about the lack of interest from their consultant colleagues.

7.10.2 Staff groupings

Although there were some marked differences between staff according to their role, there were also exceptions to this, and it may not be particularly helpful to think about broad occupational staff groups. An alternative is to consider how staff vary in their attitudes, beliefs and experience, irrespective of role, as this can help with designing interventions to improve how renal units manage distress. The analysis identified three broad groupings of staff.

1) **Enthusiasts**: These staff thought that identifying and responding to patient distress was an intrinsic and significant part of their role, they felt comfortable with it and had developed skills and confidence through experience. They were proactive about identifying and managing patients' distress and thought of themselves as 'going the extra mile' for patients. They tended to be critical of colleagues who appeared to take this issue less seriously.

2) **Equivocators**: These staff thought that managing distress should be part of their role in theory, but in practice they had mixed feelings about whether they dealt with it well and felt they were lacking in confidence and skills. They were not particularly proactive. Although they appeared to be comfortable with identifying distress, they preferred others to deal with those who had been identified as distressed.

3) **Avoiders**: These staff thought that dealing with patient distress was an important part of care, but definitely did not see it as part of their role. They felt uncomfortable talking about feelings, thought they did not have the right skills or disposition to do so, and actively avoided the subject with patients. They prioritised physical health and medical care over emotional well-being and tended to see other staff groups or individuals as much better placed to deal with patient distress than themselves.

The Enthusiasts were a relatively small group, made up mostly of highly experienced nurses and other renal staff, along with a small number of consultants. The Equivocators were the largest group of staff and was made up almost entirely of nurses and other renal staff. The Avoiders was also a relatively small group, made up mostly of consultants and a small number of nurses.

7.11 WHAT HELPS

Staff shared some of their positive experiences of how renal units can encourage patients to talk about distress and what can be done to support them. Three strong themes emerged from an analysis of this data: that open, positive and trusting staff-patient relationships are the foundation for dealing with distress; that staff need to do more listening and less talking; and that staff and renal units need to let patients know that distress is a normal part of having ESRD.

7.11.1 Staff-patient relationships are the foundation

Strong staff-patient relationships, which are well established over time, were thought to be fundamental to renal units and individual staff being able to deal well with distress. If staff are primarily using changes in patient behaviour or demeanour to identify distress (Section 7.3.1), staff need to know patients well, as described eloquently by this dialysis unit nurse:

> *"I think when you get to know them, because you see them 3 times a week, every day* [sic] *of the year, you just pick up on little things. And we had a patient come in this morning and he was unusually quiet, so I've put him on dialysis, he didn't really want the same sort of conversation that he normally has with me. It was just kind of yes, no answers and I said to him later on I said 'you're really quiet today, are you alright?' …And I think if we didn't know him as well as we do, then it would be quite easy to just dismiss him as being a miserable so and so."* (A6, Dialysis unit nurse)

When staff do not know patients well, the signs of distress can be missed or patients may be less inclined to be open about how they are feeling. Staff found that open and trusting relationships with patients were usually a precursor to patients talking about how they were feeling. Some staff described this as having an established rapport, which takes time to develop:

> *"If you've got a rapport with somebody you'll suss them out. Sometimes it's really hard to get that rapport, and sometimes it's hard to get that rapport because they are distressed and they just will not engage with you…"* (B5, Consultant)

This point was reinforced by staff having observed that patients may not open up when staff first notice that something is wrong, but over time, as trusting relationships develop with patients, they are more likely to talk about how they feel:

> *"Yeah, I think it's the personal bonding, it's the confidence between the patient and the doctor will help us to deal with the emotional side. I mean, it's just that the patients might not open up to you in the first instance at all. And, again, sometimes I know that they have symptoms suggestive of depression… So we sometimes, we know that but we will keep that in the background and try to build a relationship, and then ask them subsequently."* (A7, Consultant)

This has implications for how care is organised, so that staff-patient continuity of care is not compromised (Section 7.9).

7.11.2 More listening, less talking

The staff who were more experienced in working with distressed patients attached a great deal of value to simply listening to patients. They had found that often patients just want to air their thoughts and feelings rather than wanting staff to do anything about them. The act of talking and sharing their worries with a member of staff seems to help alleviate those worries:

> *"Sometimes it could be they just need an outlet. Sometimes it could be those few minutes where you just sit and say nothing, and you listen."* (A4, Other renal staff)

Thus, the role of staff could be seen as being about encouraging patients to talk, showing empathy and listening, rather than being always solution-focused or intervening:

> *"I think they need a listening ear, they need somebody to not agree with them, but to understand what their thoughts and feelings are at that time. Show some empathy into their situation, for whatever it is that's causing their distress."* (B9, Other renal staff)
>
> *"I don't think staff need to deliver something, they just need time to talk to patients, maybe just to listen, maybe not intervening in a conventional sense."* (B10, Consultant)

Key to this is that staff understand the impacts of ESRD, which may be why some patients prefer to talk with staff rather than family or friends:

> *"They need to off load and there may not be anybody at home or anybody that they feel would understand and listen. I think the staff are going to be the first point of contact in reality."* (B9, Other renal staff)

However, it is also worth noting that patients may vary in whether or not they want staff to just listen or be solution-focused:

> *"Some people want you to do something about it. So I think it depends what the patient's expectations are. I mean some people come and say to you I know you might not be able to do something about x, y and z, but the mere fact that they've actually managed to tell you what x, y and z is, you know. All they want is a bit of reassurance….I think nine out of ten times they don't want you to do anything."* (B5, Consultant)

Some staff had also found that for some patients, knowing that they could talk to staff was enough, even if they didn't take up the offer to talk:

> *"But I think sometimes just somebody* [staff] *offering, sort of, the chance to talk to somebody, even if you don't actually have that talk, just that it has been offered and somebody's taken the time to offer it. It does help patients to, you know, feel a little bit more comfortable".* (A9, Other renal staff)

7.11.3 Normalising distress

Some staff had found that it can be very useful to let patients know early on that experiencing distress is a normal part of having ESRD (although this did not happen routinely in either site). By normalising distress, patients may be more likely to share how they feel with staff and not suffer in silence, or feel there is a stigma attached to feeling distressed:

> *"I think it's just about keep saying to them, you know, the need for this level of support is normal in your situation…. It's perfectly normal to need this level of support with what you're going through."* (A5, Renal nurse)

Staff had also found that some patients need to be given permission to talk about distress, particularly with doctors, and this can be helped by having a patient-led agenda for consultations:

> *"….it's giving the agenda to the patient, and finding ways to put them at ease so that they believe you mean it, rather than you're just being polite, but actually you just want to get on with doctor-y things…. You do really want to know how they feel, and you're not frightened of what you might uncover."* (A7, Consultant)

7.12 STAFF VIEWS ABOUT WHAT NEEDS TO CHANGE

When staff talked about distress, they talked about a range of approaches that were being used that were often inconsistent. Staff in the same renal units presented a variety of different ideas about how to identify, talk about, and deal with distress. While there was inconsistency in terms of approach, most staff thought that improved communication between patients and staff, along with specific training for staff and increased access to psychological support services, would be positive, necessary steps for improvement. Better staff training was the most frequently mentioned change that would help staff support patients, whilst better access to psychological and social support was the most mentioned intervention to alleviate distress. Whilst some staff did mention increased contact time and increased staffing levels as being important, it was generally acknowledged that other, more specific changes, such as staff training in how to deal with patient distress, were more important. Time was important but knowing what to do with time was more important. The remaining sections explore a number of potential improvements in more detail.

7.12.1 Structured approach to identifying distress

Many staff thought that it would be beneficial to take a more structured approach to the identification of distress, although there was a variety of views about how to do this. Some staff were keen to see routine periodic screening introduced, either in outpatient appointments, or on a targeted basis, for example when a patient is first diagnosed or has started a new treatment modality. Suggestions about the behaviours or emotions it would be helpful to screen for, included observable behaviours such as crying or anger, and non-compliance with medication, diet and fluid restrictions. These screening items would not necessarily identify which patients are most distressed but would enable screening to be targeted at patients most likely to be distressed. One person pointed out that if the renal unit began to focus on identifying distress, any screening tools would also have to include psychosocial items related to the wider impacts of ESRD and not just observable behaviours.

Other staff were less keen on screening or regular reviews, and felt that the renal unit should follow up explanations that distress is a normal part of ESRD, with more overt questioning about how patients feel, as a part of routine care:

> *“Even if it’s a matter of questions that are asked monthly to somebody even or fortnightly, ‘hey how are you feeling’, or ‘how have things been, how are you compared to last month, has anything changed?”* (B11, Other renal staff)

As this member of staff noted, if it’s incorporated into routine care, then the chances of reviewing it regularly are increased, and this would compare well with the current ad hoc approaches in use:

> *“If it’s brought up* [in clinic] *then it’s reviewed.”* (B11, Other renal staff)

7.12.2 Access to immediate support for distressed patients

Many staff were very frustrated about the lack of specialist services to which patients could be referred, or the length of time it took for them to be seen. One solution to this which was suggested by a number of staff, could be access to more immediate support from a counsellor or trained support worker:

> *“We should probably accommodate concerns and be able to respond to them in a more timely way, meaning more immediate really…. People who are slightly upset, they want immediate advice.”* (A17, Consultant)

> *“It’s almost like you need a wellbeing worker or a wellbeing person that will just go in, and you know be able to monitor these patients, have the time to talk to them, but you know, when you're talking about hundreds of patients it can’t be one person because what about if that person’s on leave. So you need almost like a team of people.”* (B5, Consultant)

This type of service would be less formalised than going to see a psychologist and might therefore be more acceptable and less stigmatising for some patients:

> *“You know, more of a drop in service as well, they don’t have to make an appointment … and often with* [an] *emotional and mental state somebody needs it addressing then. They don’t want to wait for appointments in a few days or a week or whatever. Because whatever their crisis is at that time it could have passed, or been resolved, or accelerated into something more.”* (A13, Renal nurse)

However, staff were also aware that this kind of service might not be affordable, and thought a peer support scheme could be a useful alternative for some patients with lower levels of need:

> *“So for them to have access to peer support and other patients and relatives and to share their experiences and ideas as well, how one person’s coped with something, might be very beneficial to have that contact.”* (B2, Dialysis unit nurse)

> *“And that’s why I think the peer support is really important. Because we can explain from all our years of experience, and we can explain how the dialysis works, but we can’t really, we can’t really explain how it’s going to feel.”* (A12, Renal nurse)

Some staff also thought it would be useful to try to sit patients next to one another in dialysis units who get on well or who have experiences in common, as this might provide some support:

> *"And sometimes just the person that they're sitting next to, they might say 'oh, can I sit next to so and so in the unit because I was talking to them about something last week and I found it really helpful'. So it's about rearranging a unit so that the two patients that particularly support each other well can get on together and do it that way."* (A5, Renal nurse)

Finally, a number of staff thought that staff themselves need to have more support, as providing emotional support to patients can be personally demanding:

> *"I think the patients need some support but I do think the staff do too, because speaking from my own experience, there are times when it's quite, not wearing in a bad way, but you feel like you're taking on everybody's worries. And sometimes you can deal with them, great, sometimes you can't and that can wear you down quite a lot."* (A2, Dialysis unit nurse)

7.12.3 Reducing the stigma of distress

A number of staff thought that one of the most important changes would be to reduce the stigma of distress and the need for support. Staff knew that many patients felt that experiencing distress was not normal and perceived needing psychological support as a sign of weakness. Patients seeing staff talking about distress openly and regularly would help to normalise distress. Letting patients know that help is available would also be beneficial, particularly if patients know that psychological support is available as a routine part of care:

> *"I think sometimes that the benefit for that would be to mention it way before they show any signs of distress, and say 'look, what we offer is financial, dietetic, psychological, medical* [help]*' you know, and just have it as part of the package, and say 'when you need that, it's there for you'."* (A9, Renal nurse)

The contribution of open, patient-centred communication to reducing the stigma of distress and encouraging patients to talk about their feelings, was summed up well by this interviewee:

> *"Just improving and recognising the importance of our communication skills, making sure we listen sufficiently to our patients and just sometimes knowing when to probe a bit deeper and say 'so what do you mean by that' and 'how's the family' and 'is everybody –', I don't know, just improving our communication and making sure the patients feel that they're valued and listened to and that we really, really do care…."* (B2, Dialysis unit nurse)

7.12.4 Culture change

Earlier sections have noted that the culture of the dialysis units and the pressure to get patients dialysed and out of the unit, can mitigate against patients feeling able to talk about their distress. A number of staff felt that this culture needs to change, so that the mindset of staff is not machine-led, but human-led:

> *"You can change the culture* [in the dialysis units] *to emphasise and develop and support and encourage activities that deal with the patient as fellow human beings, rather than patients…. who have intrinsic worth as fellow human beings, so are suffering a problem, rather than being your 'subjects'. "* (B7, Consultant)

The same consultant noted another key aspect of culture change, namely that senior staff need to be setting the standard, so that expectations are clear about the importance attached to dealing with patient distress. Without this, improvements are likely to be piecemeal:

> *“Who sets, not the standard medical rulebook, but also sets the emotional and the cultural bar. People may go up to the bar that you set, but they will not tend to go above it unless they are unusual people. So if you set the bar low, everybody else will aim low and that applies to this issue as much as anything else.”* (B7, Consultant)

8. DISCUSSION AND RECOMMENDATIONS

This mixed methods study was designed to understand how the recognition and management of renal patients' emotional and psychological difficulties can be integrated effectively into the ESRD pathway.[51] The overarching aims of the study were to estimate the prevalence of mild to moderate distress in patients with ESRD; to understand how distress may differ for patients at different stages in the ESRD pathway; to explore the support that patients with ESRD need, want and expect, and to understand the factors that may help or hinder renal staff in identifying and responding to patients with ESRD who have mild to moderate distress. This chapter synthesises the findings from the quantitative and qualitative elements of the study, discusses their implications for healthcare providers and renal units, and outlines some potential areas for future research. The chapter is structured around the headline findings from the study (Table 8.1). Each of the headline findings is then elaborated on and discussed in more detail throughout the remainder of the chapter.

Table 8.1: Headline study findings

- Mild to moderate distress is common in patients with ESRD
- Distress impacts negatively on patients' quality of life and wellbeing
- Who will be distressed and when is unpredictable
- Patients want help from the renal unit to manage distress, and specific patient groups expressed a particular need for support
- Patients may be reluctant to disclose distress
- Staff may find patient distress difficult to recognise
- Staff may lack the capacity and capability to provide appropriate support
- A number of changes at the organisational (unit) and individual (staff) levels may have the potential to improve how patient distress is identified and managed

8.1 MILD TO MODERATE DISTRESS IS COMMON IN PATIENTS WITH ESRD

The prevalence of mild to moderate distress in patients who responded to the survey for this study was 33.3% (346/1040). Distress was evident across the pathway, from pre-RRT, through dialysis and in patients with a functioning transplant. It was also strongly associated with sociodemographic characteristics: the prevalence of distress was highest in patients aged below 50, female patients, and patients from BME backgrounds. Comparable national figures for the pre-RRT group are not available, but if the prevalence of mild to moderate distress found in this study was standardised to the current population in England undergoing dialysis treatment or with a functioning transplant, it would equate to 18970 patients with ESRD experiencing distress, of whom 7835 may want support.[1]

8.2 DISTRESS IMPACTS NEGATIVELY ON PATIENT QUALITY OF LIFE AND WELLBEING

In both the quantitative and qualitative data, patients described a number of impacts that distress has on their quality of life and their ability to live their life the way they want to. In addition to physical problems, emotional problems such as 'worry', 'loss of interest in usual activities', 'sadness' and 'depression' were commonly reported by respondents to the patient survey. Interview participants frequently described the burden that ESRD placed upon them, using language that expressed negative emotions such as 'trauma', ‘desperation’, ‘demotivated, ‘fed up’ and ‘helpless’. Some patients described a sense of losing their individuality and identity since being diagnosed with ESRD, and noted the difficulties they had experienced in coming to terms with the fact that they were no longer able to do many of the things that they used to do – because of the physical and emotional burden of ESRD itself, the lifestyle impacts of diet and fluid restrictions, or (for patients on in-centre haemodialysis in particular), the limitations imposed by the need to plan and undergo dialysis, and to allow for post-dialysis recovery.

8.3 WHO WILL BE DISTRESSED AND WHEN IS UNPREDICTABLE

At the start of this study, it was hypothesised that it would be possible to predict which patients were most likely to suffer with mild to moderate distress, and that such patients could be defined according to their stage in the ESRD pathway and support tailored accordingly. However, this study has shown that the incidence and consequences of distress are determined by a complex interplay between sociodemographic, treatment-related and individual coping resources/resilience that transcend simple sociodemographic or clinical groupings of characteristics. There may be specific transitional points in the ESRD pathway that generate particularly strong stressors, such as first diagnosis with ESRD, initiation of dialysis treatment or changes in treatment modality,[82] but adjustment to ESRD has been described as a dynamic and constant process rather than having an end point.[3] Consequently, distress may affect any ESRD patient at any time.

This study has shown that some patients with ESRD are able to adjust and cope better than others with the stressors they face. Despite the frustrations of dealing with an uncertain future because of the physical, emotional, psychological and social changes associated with managing ESRD, most patients noted in the qualitative work that they attempted to maintain a positive attitude towards their illness and the restrictions that treatment imposed upon them. A number of cognitive and behavioural reasons were associated with some patients’ perceptions that they were able to cope better than others with distress. Some of these reasons were influenced or mediated by experiences in relation to the renal unit or renal staff, whereas others were closely related to personal circumstances and individual coping resources (Table 8.2). These findings reflect those elsewhere in the evidence base where it is argued that a person’s personality, psychological functioning, personal resources and cultural beliefs may affect their ability to respond effectively to the challenges associated with renal failure.[14]

Table 8.2: Renal unit and individual factors influencing patients’ ability to cope with ESRD

	Influenced by renal unit/staff	**Influenced by individual resources**
Cognitive reasons	Perceived close relationship with renal staff	Strong personal support network
	Perception of consistent renal unit support	Well-developed self-efficacy
	Feeling well-informed about ESRD and treatment	Positive illness perceptions
	Feeling in control of ESRD and treatment	Ability to recognise unhelpful thoughts
Behavioural reasons	Able to express feelings of distress to staff	Able to discuss emotions with family/friends
	Able to share experiences with other patients	Use of adaptive coping techniques
	Effective coping strategies developed with support from the renal unit	Able to sustain family and social relationships
	Gained confidence from increased knowledge and understanding about ESRD and treatment	Able to maintain hobbies, activities and interests

Nevertheless, in both the quantitative and qualitative data, many patients reported mixed feelings about their ability to cope, and patients frequently expressed fear over the possibility that their condition and distress would worsen over time, along with nervousness about the future. These fears were particularly evident in younger patients, who often had to cope with the competing demands of work, family and ESRD treatment, and in BME patients. There was evidence from the qualitative data that patients from BME backgrounds often had a poorer understanding of their illness, which could be influenced by language or cultural barriers that inhibited discussion about ESRD and distress with renal staff. There was also a greater perception of chronic illness being stigmatised within BME patients' communities, and despite typically having strong family networks, these patients often felt unable or reluctant to seek emotional support from them.

8.4 PATIENTS WANT HELP FROM THE RENAL UNIT TO MANAGE DISTRESS, SPECIFIC PATIENT GROUPS EXPRESSED A PARTICULAR NEED FOR SUPPORT

It is important to note that not all patients with ESRD are distressed; not all distressed patients want support, and not all distressed patients who want support necessarily want this to be provided by their renal unit. A number of interview participants believed that coping with distress was their own responsibility and that it was not necessary for the renal unit or staff to provide them with specific support. It must also be noted that experiencing some degree of distress should be considered a normal response to having a chronic disease. Nevertheless, both the quantitative and qualitative elements of this study identified several groups of patients with ESRD who were particularly likely to report a need for support. Younger patients, females, patients from BME groups and those who have recently begun dialysis treatment may face particular challenges, and patients in these groups had: a) the highest rates of distress reporting; b) the greatest degree of impairment in their ability to cope with their condition, and c) the highest self-reported levels of support need. Although patients generally reported satisfaction with the support they had received from renal services, patients who had been on dialysis for 2 or more years, BME patients, and those aged below 50 were most likely to express dissatisfaction with their care, and by extension, with the extent that they had received effective support for distress from renal units and staff.

8.5 PATIENTS MAY BE RELUCTANT TO DISCLOSE DISTRESS

Providing effective support for distressed patients requires that: a) renal staff are able to identify those patients who may need help, and b) that staff have the capacity and capability to help patients manage their distress. One of the strongest findings to emerge from this study was the difficulty of identifying and managing patient distress – due to both patient and staff-related factors - which pose challenges for both renal unit staff members and for the organisation of renal services.

The quantitative and qualitative data showed that many patients viewed their emotional concerns to be insoluble, or that they deliberately avoided disclosing information about distress so as not to burden healthcare staff who were often perceived as being under stress themselves, or too busy managing clinical tasks; consequently having limited time to discuss emotional issues. Some patients also felt that talking about emotions with staff on the renal unit was inappropriate due to a perception that staff may not understand their situation or may lack the relevant skills to handle any emotional issues raised. Other research has also found that for many patients with emotional difficulties, fear of the stigma of being perceived as suffering from a mental health issue is a significant barrier to sharing their feelings with healthcare staff and/or taking up the offer of supportive interventions.[83] Some groups of patients also have limited contact with renal staff, such as those on HHD/PD or transplant patients who may attend follow-up clinics relatively infrequently. For these patients, the opportunities to raise emotional issues are correspondingly reduced and may add to patients' reluctance to disclose distress to their healthcare professionals on the occasions that they interact with renal staff or attend the renal unit.

8.6 STAFF MAY FIND PATIENT DISTRESS DIFFICULT TO RECOGNISE

Staff survey respondents and interviewees recognised that providing emotional support to patients should be part of high quality care, can be associated with better health outcomes, and that addressing patient distress had intrinsic value. However, even when patients show signs of distress, healthcare professionals may be relatively poor at recognising the signs in their patients, especially when patients may normalise their feelings or go out of their way to 'bottle them up'.[84] Key barriers to renal staff being able to identify distress were related to: a) renal unit organisation, b) time, c) training/skills, and d) perceptions of responsibility.

Renal unit organisation
Identifying distress was largely dependent on an individual staff member's personal interest, skills, personality and individual approach to patients, rather than emotional support being considered an integral part of ESRD patient care. There was a sense that the majority of performance indicators perceived as having value were metrics related to clinical care, and this leads to emotional support not being prioritised. The organisation of care in outpatient clinics and dialysis units meant that staff did not always see the same patients, making the recognition of distress difficult as staff did not always know patients well. Patients often noted that the deliberately jovial and upbeat atmosphere created by staff within the renal unit inhibited discussions about distress as this atmosphere gave the impression that negative emotions should not be expressed.

Time
The perception that renal staff did not have enough time to identify and manage patient distress was more a factor reported by patients than by staff members themselves, although heavy workloads and the need to give priority to addressing clinical rather than emotional issues were noted by some staff as a barrier to discussing distress with patients.

Training and skills
Staff training and skills were found to be strongly linked to whether or not renal unit staff – particularly nurses – felt that they were able to identify patient distress. Renal staff who had received training in how to handle distressed patients were more likely to feel that dealing with distress was part of their role, and these staff members typically reported a significantly greater level of confidence in being able to handle patient distress effectively. Other staff members who had not developed key skills, either due to a lack of training or a lack of long-term experience in working with renal patients, often described feeling less able to recognise and interpret non-verbal signs of distress; not knowing how to ask patients about their emotions; not feeling able to 'contain' distress so that dealing with a distressed patient did not take up a disproportionate amount of time, and not knowing what to say and do when faced with a distressed patient. There is thus a substantial training and skills gap amongst renal staff at all levels of the clinical hierarchy that could be addressed by the introduction of staff training in identifying and handling patient distress.

Perceptions of role and responsibility
Although many staff considered identifying and responding to patient distress as being part of everyone's role in the renal unit (including non-clinical staff), there was a recognition that this was often not the case in practice. Differences in role perception were a key issue, related to staff perceptions about who was most appropriate to deal with distress in terms of having the skills, seniority and opportunity to do so. There was a perception for some staff that distressed patients should self-identify as distressed rather than distress being

something that staff should actively look for. Some staff felt that dealing with distressed patients was the responsibility of staff members with specialist skills, or that it was something that was optional, based on individual professionals' interests and personal inclination to include this in their role. A number of staff deferred to other staff members. For example, there was some evidence that consultants felt that nurses should take primary responsibility for dealing with distressed patients as they were thought to have the most appropriate skills for doing so. This view was not always shared by nurses, who felt in many cases that patients' emotional concerns could be most effectively dealt with during consultations with doctors.

Staff fell broadly into three groups. First, the 'enthusiasts' who thought that identifying and responding to patient distress was an intrinsic part of their role. These staff members were proactive in identifying distress and had developed the skills and confidence to do so through experience. Second, 'equivocators' considered managing patient distress to be part of their role in theory, but in practice felt that they were lacking in skills and confidence to do this effectively. Third, 'avoiders' who thought that dealing with patient distress was a key element of *care*, but who did not see this as part of their own *role*. These staff actively avoided the issue of distress with patients, prioritised clinical care over emotional wellbeing and tended to see other staff as better placed to manage patient distress than themselves.

8.7 STAFF MAY LACK THE CAPACITY AND CAPABILITY TO PROVIDE APPROPRIATE SUPPORT

Even if renal unit staff are able to identify distress in their patients, they may lack the capacity and capability to provide appropriate support. This may be because staff members feel that they lack the necessary training and skills to facilitate the provision of support, or because of the way that support services are organised and accessed.

Training and skills

As was the case with the identification of patient distress, study data from staff participants showed evidence of a perceived lack of training and skills relating to their capacity to *manage* patient distress once identified. Some staff felt that dealing with patient distress was more challenging than dealing with clinical issues, and that emotional issues were often too complex, taking a significant amount of time to discuss and resolve. There was also a perception that emotional issues required a specialist skill set to manage – some staff found it difficult to get to the root of the causes of patient distress, or to gauge the kind of response that should be offered. Staff who had not received any formal training in how to handle patient distress often showed concern that their lack of training may mean that any attempt to manage a distressed patient could make the distress worse rather than improving it. The lack of training and skills were often cited as a reason for avoiding the proactive identification of patient distress for fear that the 'floodgates would open', without the possibility of providing acceptable or appropriate support.

A number of renal staff also noted the difficulty of providing a resolution for patients. Clinical staff are typically trained to offer a solution to a given problem, and many felt an expectation from patients that distress should be managed in the same way. However, data from the patient interviews showed a different picture – many patients who disclose emotional issues to renal staff are not seeking a solution, but simply want to be listened to by an empathetic and sympathetic member of renal unit staff. Whilst some staff were aware of this, many were not. This suggests that patients and many staff may differ fundamentally in what they consider 'support' to entail, and that the avoidance of emotional issues by some staff due to the perception that they are unable to provide a solution may be based on a largely unfounded view about what patients expect from them.

Organisation of, and access to support services

The organisation of support services was seen by many staff as a barrier to the effective management of patient distress. Many staff participants noted a lack of information about support options that they could offer to patients. Further to this, onward referral of patients to services such as renal psychologists, counselling in primary care, or other services within the community was seen as difficult given the need to wait for such referrals to be processed and for appointments to become available. There was a recognition that waiting times to see a counsellor or psychologist were often too long given that many patients wanted immediate support at the time of need. As a result, patients typically reported reluctance to take up the offer of a referral to (for example) a renal psychologist due to lengthy appointment waiting times. Thus, an important issue related to the provision of emotional support concerns the immediacy of access to support options.

Another key factor influencing the acceptability of emotional support for patients was the perceived degree of formality of support. Whilst patients often noted that formal psychologist services had a place in helping to manage distress for some patients, there was a sense that there may be some stigma associated with referral to such services – formalising support also acts to formalise distress. As a consequence, patients who were asked by renal staff whether they would like to be referred to a renal psychologist often rejected the offer. In addition, as noted above, patients do not always expect a ‘solution’ to their distress, and in both the quantitative and qualitative work, patients were less likely to report formal options such as counselling with a renal psychologist as being their preferred means of support when compared with the option to discuss their emotional issues during face-to-face meetings with renal doctors or nurses. Thus, having a wider range of less formalised options for managing distress may be effective and acceptable to patients.

8.8 RECOMMENDATIONS FOR CHANGES AT ORGANISATIONAL (UNIT) AND INDIVIDUAL (STAFF) LEVELS

The findings described in sections 8.1 to 8.7 suggest that there are a number of ways that renal services could be modified in order to enhance emotional support for patients with ESRD. Renal units should avoid attempting to address the barriers to providing effective support in isolation, as this is unlikely to be the most effective way to improve care. Following this, there is unlikely to be a single intervention that will be effective for patients and staff: patient distress often has complex roots and influences, and staff experience multiple challenges in being able to identify distress and respond effectively. Thus, the complexity of the issues investigated in this study suggests that any modifications to service organisation and delivery would need to be complex and multi-faceted,[85] encompassing changes at both the organisational (unit) and individual (staff) levels. In particular, understanding how multiple barriers interact is essential. For example, simply providing training and skills development opportunities for staff may not lead to significant improvements *per se*, as unless some of the other barriers identified in this study are removed, staff may be unable to use their newly acquired skills effectively. The recommendations described in this section are typically inter-related but the individual components of a complex intervention could be based on the following recommendations:

8.8.1 Patient education should be offered throughout the ESRD pathway

Participants in this study frequently reported a desire for support to be available on an ongoing basis, and there is scope for improved education about the distress that patients may experience at different stages of the ESRD pathway. This has implications both for *when* in the pathway education is appropriate, and in terms of *what* information is conveyed through education. Evidence from this and other studies suggests that patients receive a substantial amount of pre-RRT education. This is partly due to the fact that – unlike some other chronic conditions with an unpredictable onset – patients with renal failure can usually be supported throughout their initial period of deterioration, allowing a relatively incremental adjustment to life on dialysis.[40]

Consequently, patient education typically stops after the successful initiation of dialysis treatment. There may be scope for continuing patient education throughout the ESRD pathway,[86] and for appropriate education also to be made available to patients who have received a transplant, as distress was still prevalent in this patient group.

8.8.2 Patient education should fully explain the potential for patients to experience distress

In addition to providing ongoing patient education, the content of education could also be modified. Effective education may entail the provision of practical, factual information about treatments and prognosis, as well as information that signposts patients to the full range of available support services. There is also scope for modifying patient education to become more effective in managing expectations amongst renal patients about the distress they may experience as their condition and treatment progresses. This approach has been found in other studies to be effective in reducing distress and improving general wellbeing.[87,88] Patients who participated in the qualitative work for this study frequently mentioned feeling that they had not been told enough about some of the negative consequences associated with managing a chronic condition like ESRD over time. For renal consultants and nurses, there is clearly a balance required between emphasising the positive and negative elements of managing ESRD. Although withholding information about some of the more negative elements of ESRD may be done with the best of intentions, this may be damaging to patients in the longer-term. This is particularly pertinent for dialysis patients, as research has found that staff are overly positive about what living on dialysis will be like.[86] Therefore, ensuring openness and full disclosure of the negative issues (such as distress) that may arise for patients should be an integral component of routine patient care, ongoing throughout all stages of the ESRD pathway.

The provision of support throughout the pathway should also recognise that the roots of distress may differ for different patients and could be tailored accordingly. For example, when asked about their experience of events that had caused distress, pre-RRT patients were most likely to have experienced distress related to their ESRD diagnosis, being given a poor prognosis, and in relation to the need to choose options for dialysis treatment. Patients on dialysis were most likely to have been distressed by issues associated with dietary restrictions, changing dialysis modality and the potential decision to stop dialysis. In transplant patients, distress was still prevalent, and was often unexpected, with patients reporting fear and uncertainty over the possibility that their transplant would fail. For some transplant patients, there was also a feeling of isolation or abandonment that receiving a transplant meant that they were no longer part of the renal unit.

8.8.3 Building patient resilience and coping should be central to the support offered

As well as providing patients with factual information and education about the potential for distress, findings suggest that in most cases, a key support goal should be to take a proactive approach towards equipping patients to cope with the distress they may experience.[83,89] Respondents to the patient survey rated highly the suggestion of interventions built around training in how to handle negative feelings and emotions. Building emotional resilience and coping mechanisms into pre-RRT education and into education offered to patients at other stages of the pathway could help patients to release stressful emotion, develop coping skills, build healthy emotional responses and establish balance in their life.[90] Although it is not possible to predict who will be distressed and when, there were certain groups of patients in whom resilience and coping may be particularly impaired: younger patients, females, patients from BME communities, and those who have recently begun dialysis.

Educational drop-in sessions on building resilience and coping could be offered periodically by renal psychologists, counsellors or by specialist nurses. An additional benefit of offering support on an ongoing basis in a less formalised manner could be the ‘normalisation’ of discussions about distress rather than patients feeling that the renal unit is not an appropriate place to raise emotional issues. It would also be useful for patients who do not attend the renal unit very frequently, such as patients on HHD, PD or with transplants. Even if patients do not frequently access the support being offered, it may be reassuring for them to know that it is always available if needed.

8.8.4 All renal staff should be given training in how to identify and manage patient distress

A lack of staff training in identifying and handling patient distress was commonly cited as a barrier to the provision of appropriate and effective support. Whilst healthcare professionals are aware of the clinical challenges associated with managing ESRD, they may be less aware of the psychological processes that patients can use in order to adjust to ESRD and its treatment.[2] It was clear from the staff data that those who had received training in how to identify and manage distress in their patients were more likely to feel that managing patient distress was their responsibility rather than that of other professionals. They also felt more confident in their ability to handle distress effectively.

A number of studies have found that educational or training interventions can help clinical staff to become more adept at recognising and addressing patients' emotional needs. The overall goal of training would be to facilitate both the *proactive* identification of patient distress, and the appropriate *reactive* skills once distress has been identified. Whilst it is important that training should be available to all renal unit staff (including non-professionals), the identification of the three main staff groups in Chapter 7 ('enthusiasts', 'equivocators' and 'avoiders'), suggests that there may be the most potential to make progress if training interventions were initially offered on a targeted basis. For example, it could be argued that training and skills development should be targeted towards the 'equivocators', who feel that managing distressed patients should be an intrinsic part of their role, but who feel that they lack the skills and confidence to do so effectively. The 'enthusiasts' are already skilled and confident in their ability to identify and manage patient distress, and it is likely that these staff would benefit from having more personal support and space to debrief their work with patients. In the same way, the 'avoiders' may not benefit greatly from training and skills development opportunities in the short-term, as they do not see the provision of emotional support to patients as being part of their role and there may be substantial groundwork required to convince these staff that they need to change. This may be more likely to happen if there is visible senior leadership behind any changes to training and skills development, and if the provision of emotional support is effectively formalised into the renal pathway at the renal unit level.

Patients in this study frequently reported that they wanted talking about distress to become part of routine care. Indeed, when asked to rate the potential helpfulness of a series of support interventions in the survey, patients with mild to moderate distress were most likely to favour those that involved face-to-face interaction focused on talking with healthcare professionals (nurses, doctors) about distress. This finding suggests that above all, patients value support in which they are able to talk on an individual basis about their feelings with appropriate professionals. Following this, training for renal staff could include education focusing on patient-centred communication strategies, such as the use of open-ended questions and empathetic statements.[91] Recognising that distress can manifest itself in a number of ways, training could also include information about the signs to look for that indicate a patient may be distressed (both verbal and non-verbal communication), how to identify distress quickly, case scenarios about handling difficult situations, and learning from the experience of other professionals such as counsellors and psychologists. A tailored approach to building these skills in renal unit staff may be helpful, depending on staff role. For example, given consultants' concerns that they do not routinely have time to respond to patient distress, it could be useful to prioritise training about how to time-limit distress-related conversations with patients so that clinical care is not compromised. For staff working in dialysis units, training which focuses on developing simple techniques for encouraging patients to open up about their distress would appear to be the priority.

8.8.5 Emotional support should be made available to renal staff

Although staff in this study tended to report that they did not find responding to patient distress as being too emotionally demanding, it is important to ensure that a greater emphasis on renal unit staff taking a proactive role in identifying and managing patient distress is not associated with a greater incidence of staff burnout (i.e. exhaustion caused by work demands) or 'compassion fatigue' (i.e. the personal costs over time of caring for patients who are suffering). A number of studies have found clear links between healthcare professionals' sense of personal wellbeing and their ability to provide good quality patient care.[92,93] Evidence from oncology settings suggests some benefit to staff from the provision of emotional support based on regular group meetings or peer support groups to enhance personal coping resources, or the use of mindfulness approaches.[94,95]

8.8.6 Immediately accessible support options should be made available to patients

Compassion fatigue and staff burnout are made more likely when staff lack the appropriate tools or options for managing patient distress. A clear finding from the qualitative work for this study was that the proactive identification of patient distress is often avoided by staff because they feel there is little that they are able to do immediately to alleviate the issues raised by patients. Staff training in identifying and handling patient distress 'in the moment' (as outlined above) through the use of empathy and sympathetic listening may be effective in the short-term for many patients, particularly as patients often reported that they did not necessarily want a solution to their problems but may simply want to unburden themselves of their emotional issues.

For patients who need further information or onward referral, it is important that a series of options are available and that renal units have appropriate pathways in place so that patients can be referred or signposted to additional support. This relies on staff members having clear, practical information about distress that they can pass on to patients. Key issues for patients related to: a) the formality of support options – patients may be more likely to reject the offer of referral to a renal psychologist for example, as this may carry a stigma that distress is not 'normal', and b) the immediacy of access to support – lengthy waits for counselling appointments are not consistent with the often transient nature of distress for patients with ESRD. Consequently, renal units could provide drop-in sessions and in-house emotional support services that can be immediately accessed at the time of need rather than requiring formal referral. For example, smaller renal units could have an embedded specialist nurse with counselling expertise who could take the role of providing more informal emotional support to patients at the time of need. This would be particularly useful for patients on in-centre haemodialysis who regularly visit the renal unit. For renal units spread across a number of sites (e.g. multiple satellite dialysis units), nurses with specialist training could visit each unit several times per week so that all dialysis patients at a given site are given the opportunity to talk about their distress. For transplant patients, or those on home-based dialysis modalities, having a named nurse as a patient's direct contact could be effective in allowing the disclosure of emotional concerns to become normalised and managed in a timely manner.

8.8.7 Formal screening for distress is unlikely to be effective

It has been argued that screening for distress, by introducing a tool such as the emotion thermometers into patient consultations or into routine use by renal nurses, could help to identify patients whose distress would otherwise remain undetected. In doing so, screening could enable the targeted provision of appropriate support services.[96] However, the findings from this study suggest that screening may have limited utility given the nature of patient distress and its complex manifestation. Indeed, if the other potential changes suggested by this study were implemented in renal units and they became environments in which talking about distress was considered normal, screening for distress would not be necessary as a tool for identification, as both patients and staff would be better equipped to discuss and manage distress.

8.8.8 Renal unit culture change

Research has found a consistently positive association between healthcare setting culture and patient outcomes.[97] The changes described in this section amount to a recommendation for a change to renal unit culture to ensure that distress is seen as a normal part of ESRD and is discussed routinely with patients, and that patients are encouraged to seek help and to develop appropriate coping skills. Culture change is thus necessary both to support the introduction of other recommendations that make the identification and management of patient distress more central to renal unit activities, and to create an environment for patients and staff where talking about distress is normalised and emotional support valued. Of course, the onus for improving the management of patient distress is not just on the organisation of renal services and the actions of staff – patients must be more prepared to disclose emotional issues if they are to receive effective support. Nevertheless, strong leadership is required to maximise the likelihood that the recommendations outlined in this section could be successfully introduced. A culture change in the renal unit, which gives greater recognition to the value of providing emotional support to patients would also benefit the ‘equivocator’ and ‘avoider’ staff groups by demonstrating the centrality of emotional support as a key element of providing effective care for renal patients.

8.9 FUTURE RESEARCH

Several potential areas for future research have emerged as a result of this study:

1. Most importantly, future research should focus on implementing the complex change recommended in this report at a single renal unit and assessing whether patients and staff perceive distress to be managed more effectively as a result.

2. A key limitation of our approach was its cross-sectional design, which only allowed a snapshot of patient and staff views at a single time point. Given the often transient nature of ESRD patient distress, research that takes a longitudinal approach and looks at how the prevalence and determinants of distress may change over time for patients in different groups would seem important.

3. There may be value in future work that attempts to understand differences in the incidence of distress for dialysis patients being treated via different modalities. In this study, mild to moderate distress was evident in around 42% of patients undergoing home haemodialysis, compared to 27.5% of patients treated via peritoneal dialysis. The potential differences between groups here would benefit from further exploration, as home therapies are increasingly recommended to patients as a favourable option for dialysis treatment.

8.10 CONCLUSIONS

Providing emotional and psychological support is mandated in national ESRD guidelines, and effective support is considered important for the optimal care of patients with ESRD. Evidence suggests that reducing emotional and psychological difficulties may enhance overall wellbeing and improve patients’ ability to engage with complex and demanding treatment regimes. Benefits may include reduced symptom burden, increased patient understanding of their illness and its potential consequences, improved treatment compliance and greater patient satisfaction with services.[76]

This large, multi-site study is, to our knowledge, the first to explore the prevalence of mild to moderate distress in patients with ESRD. Our findings show that mild to moderate distress is common – even after successful transplantation – and there are potentially substantial unmet support needs within the ESRD patient population, with younger patients, females, and patients from BME communities particularly affected. Effectively identifying and responding to patient distress requires changes to renal unit organisation and to the way that individual staff manage their patients. There is unlikely to be any single intervention that can support patients with distress – its incidence is largely unpredictable and its duration uncertain. Further research must determine which combination of renal unit, renal staff and patient-focused interventions may be the most effective in optimising the identification and management of mild to moderate distress in patients with ESRD.

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APPENDIX 1: PATIENT SURVEY DISTRESS BY SUB-GROUP

Figure A1.1: Distress groupings by study site

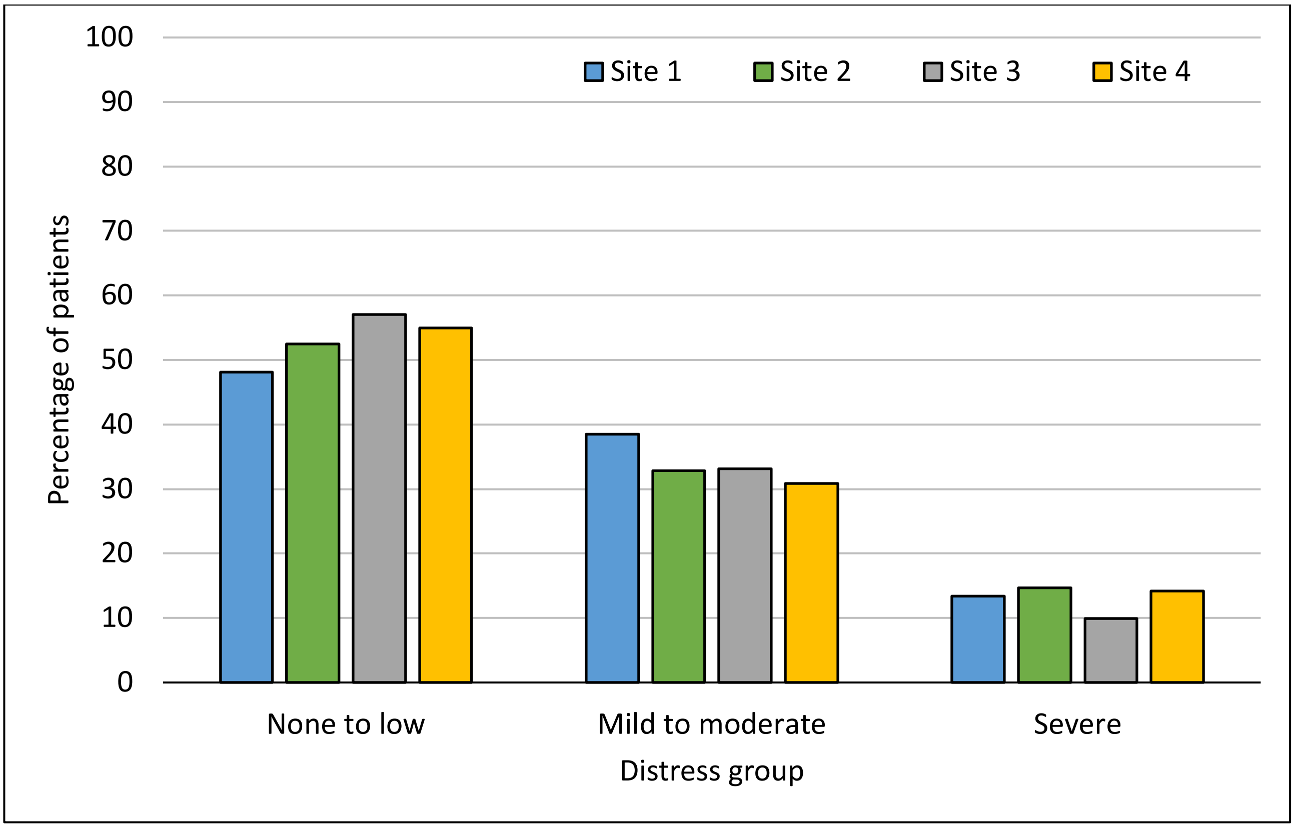


Figure A1.2: Distress groupings by ESRD pathway stage

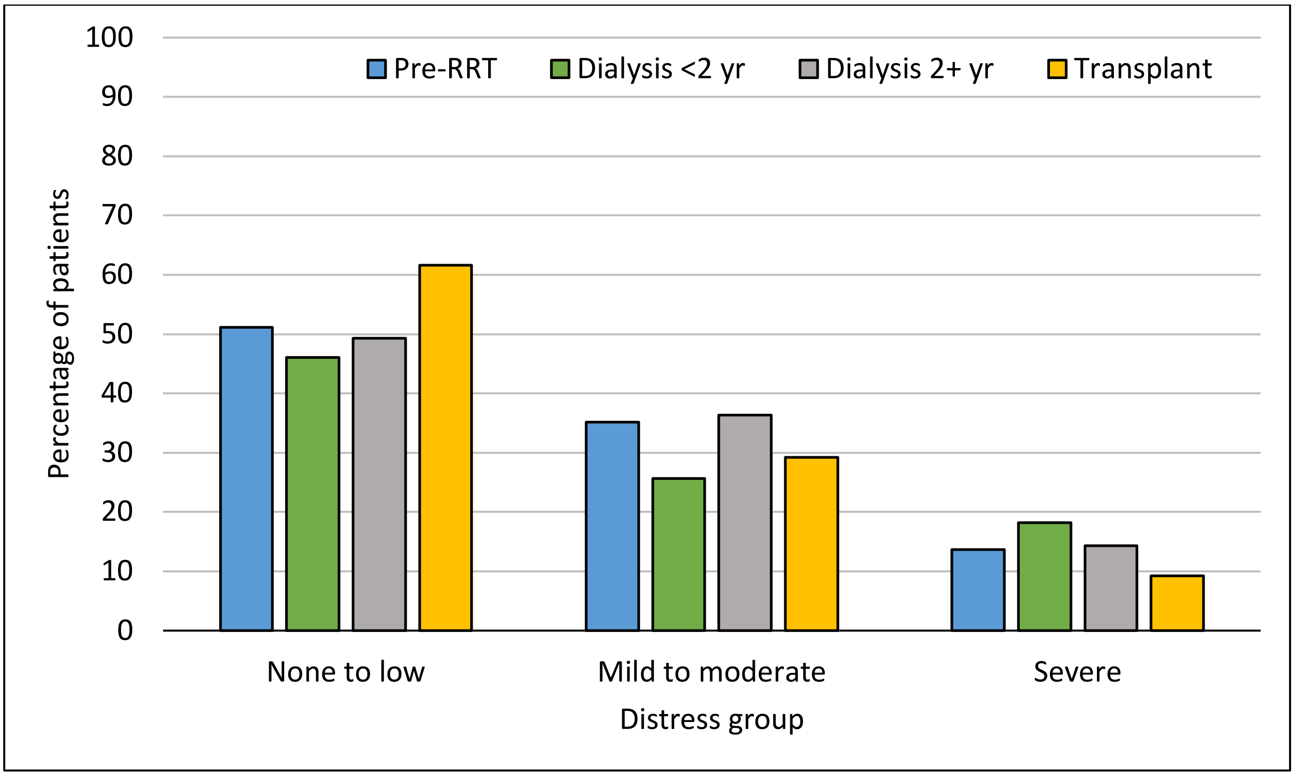
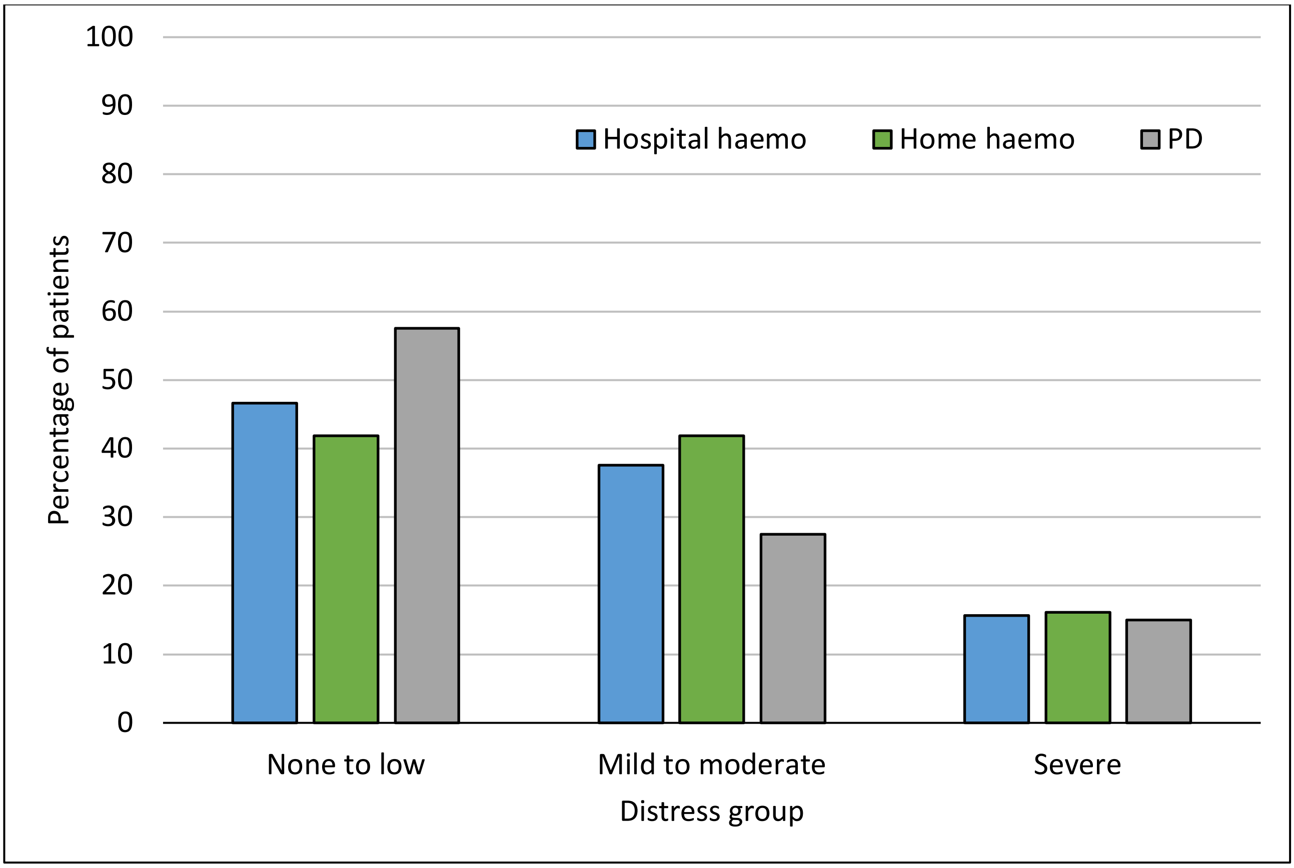


Figure A1.3: Distress groupings by dialysis type



PD = peritoneal dialysis

Figure A1.4: Distress groupings by age

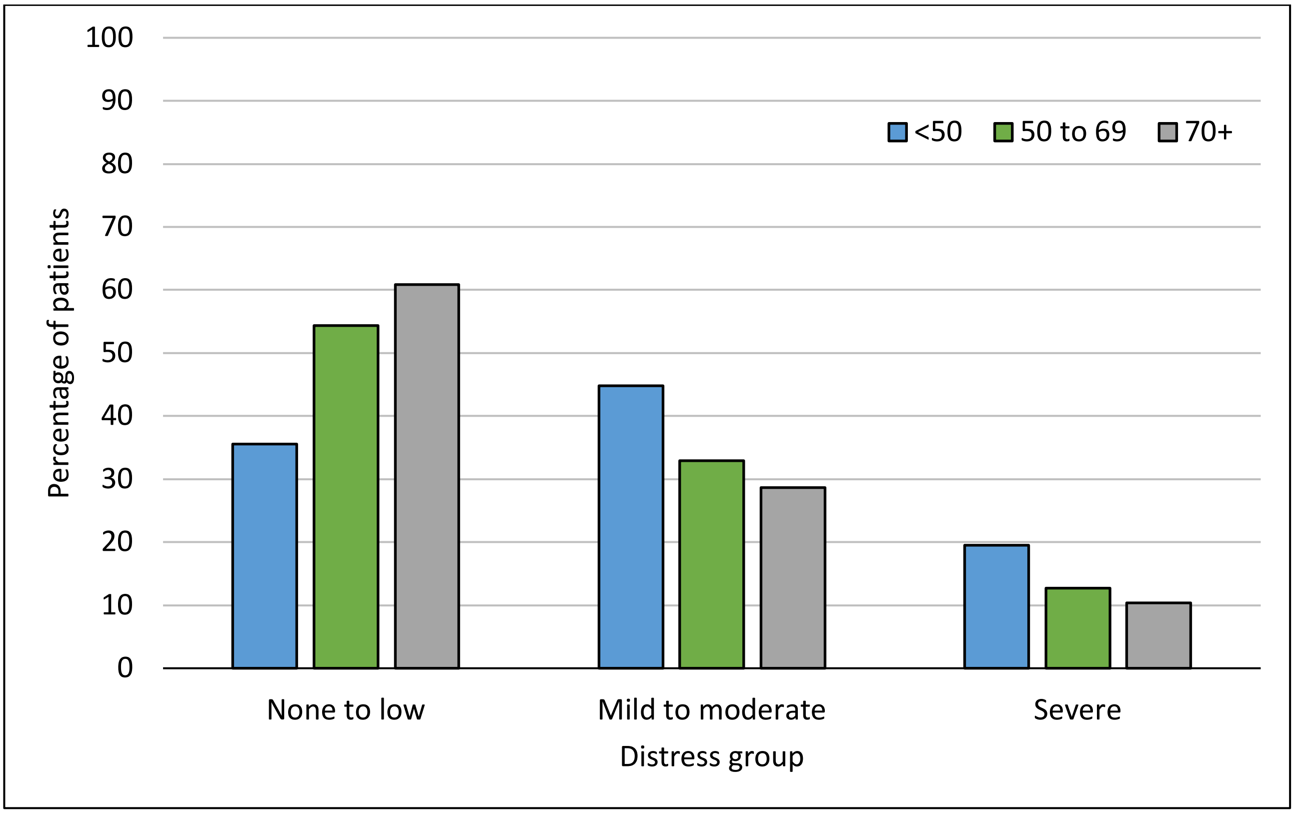


Figure A1.5: Distress groupings by gender

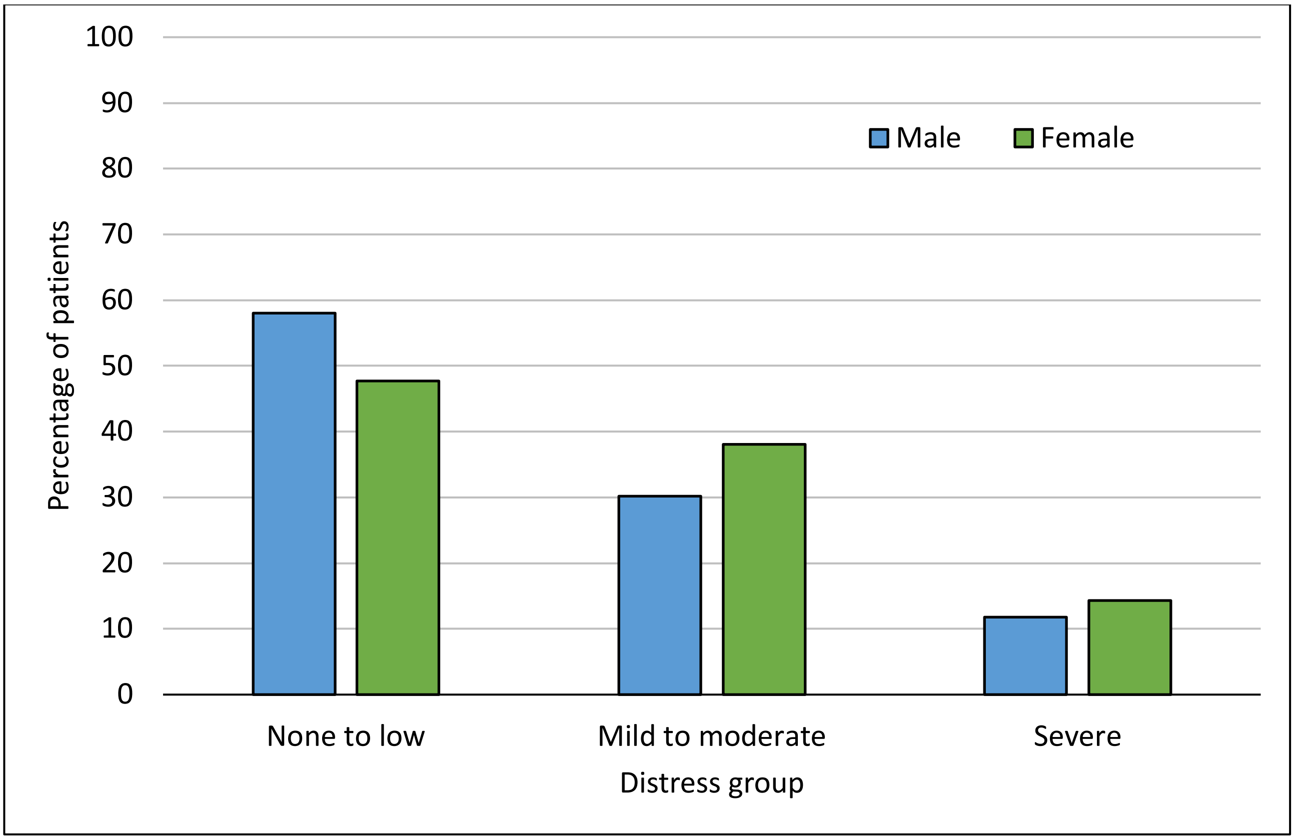
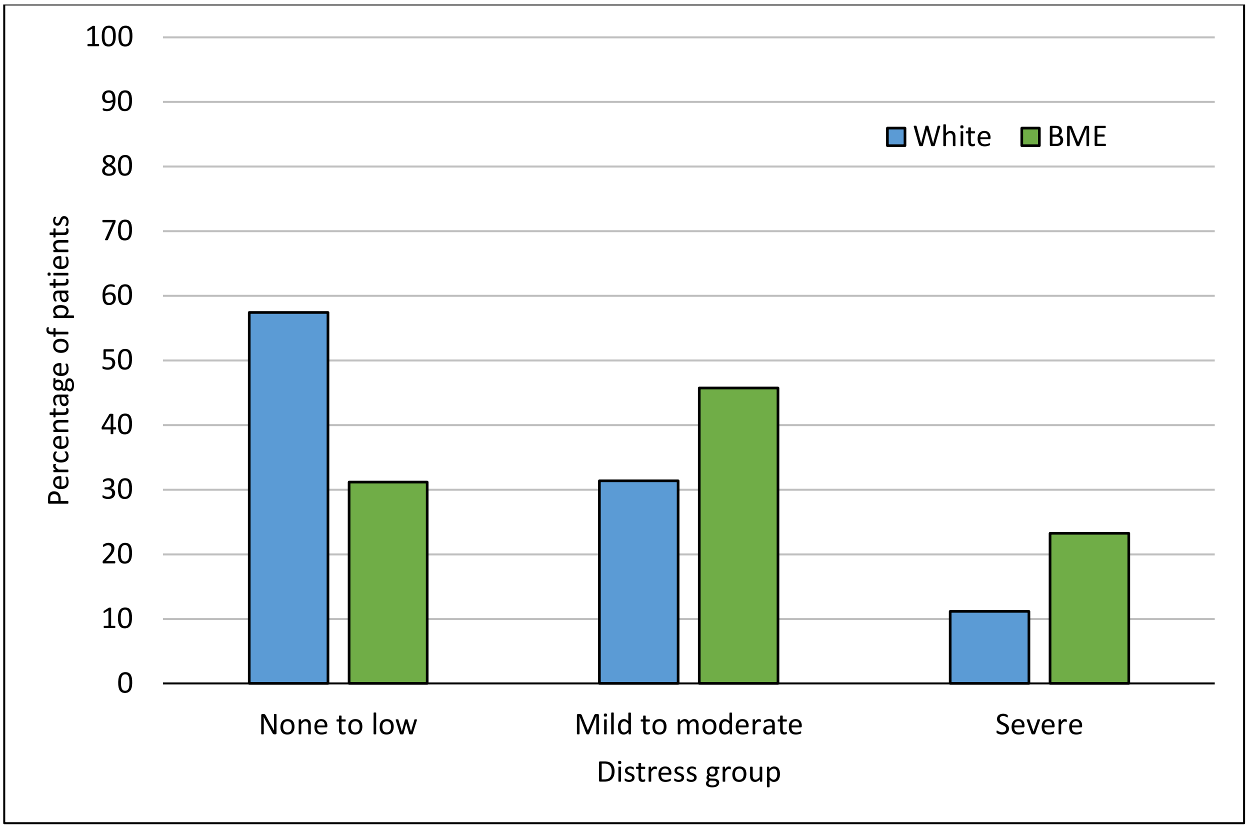


Figure A1.6: Distress groupings by ethnicity



BME – Black and minority ethnic

APPENDIX 2: PATIENT SURVEY PANAS SCORES BY SUB-GROUP (MILD TO MODERATE DISTRESS)

Figure A2.1: Comparison of PANAS scores by hospital site

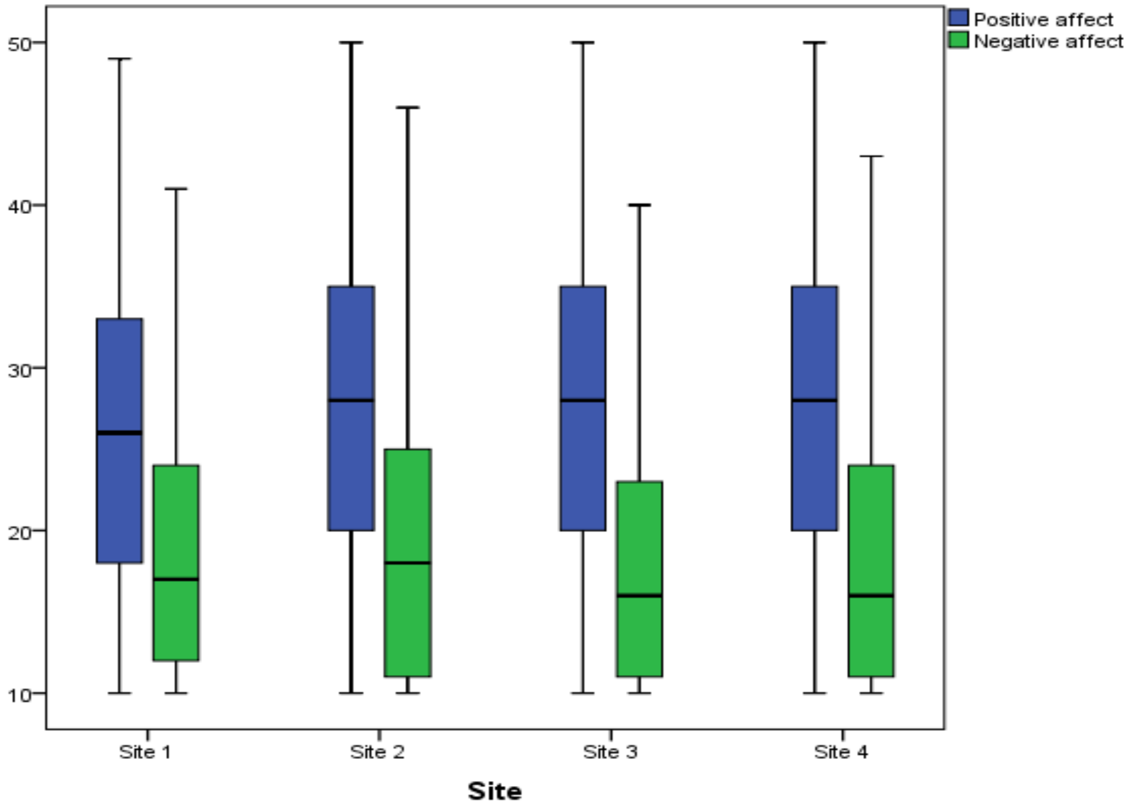


Figure A2.2: Comparison of PANAS scores by ESRD pathway stage

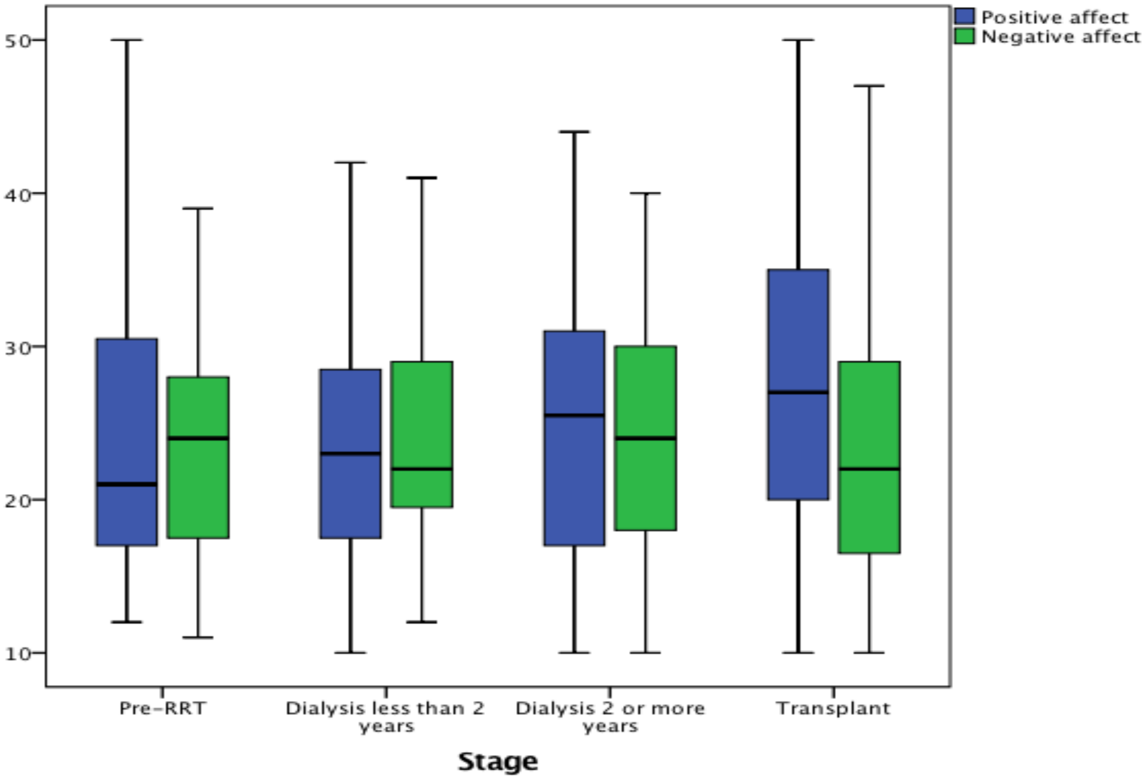


Figure A2.3: Comparison of PANAS scores by dialysis type

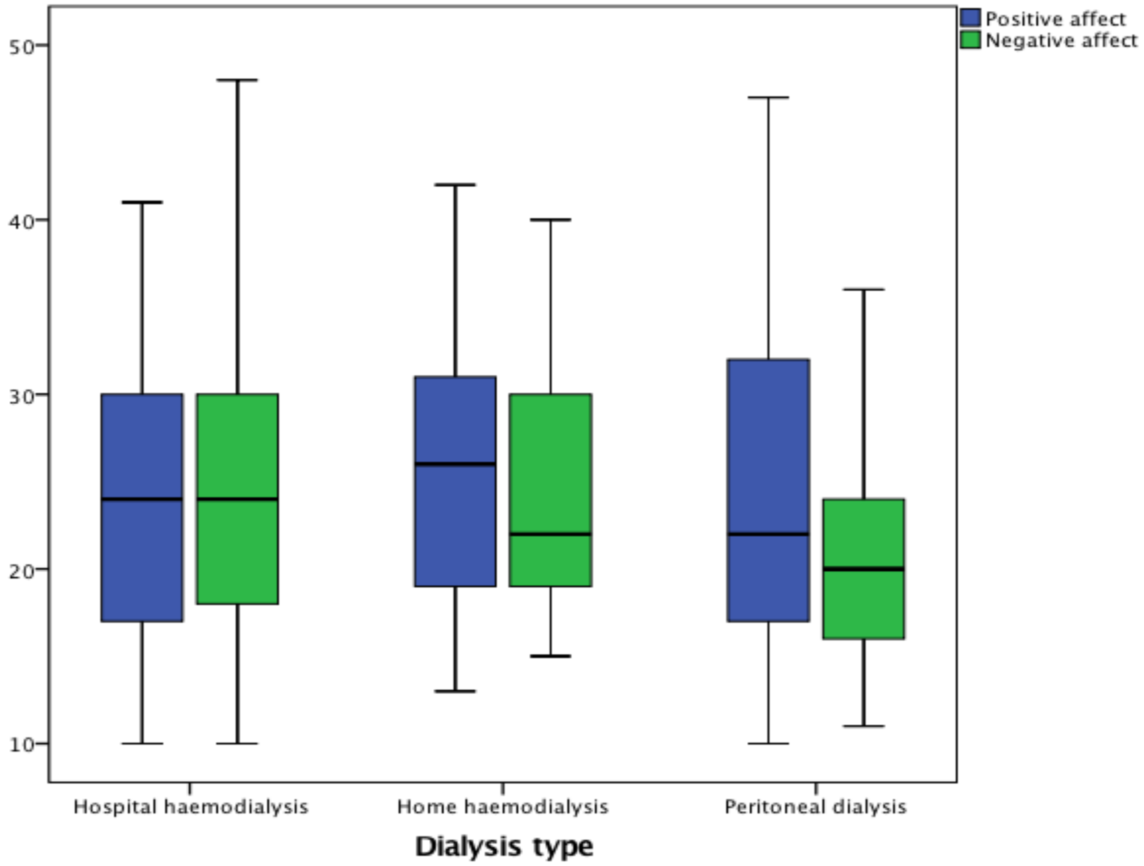


Figure A2.4: Comparison of PANAS scores by patient age group

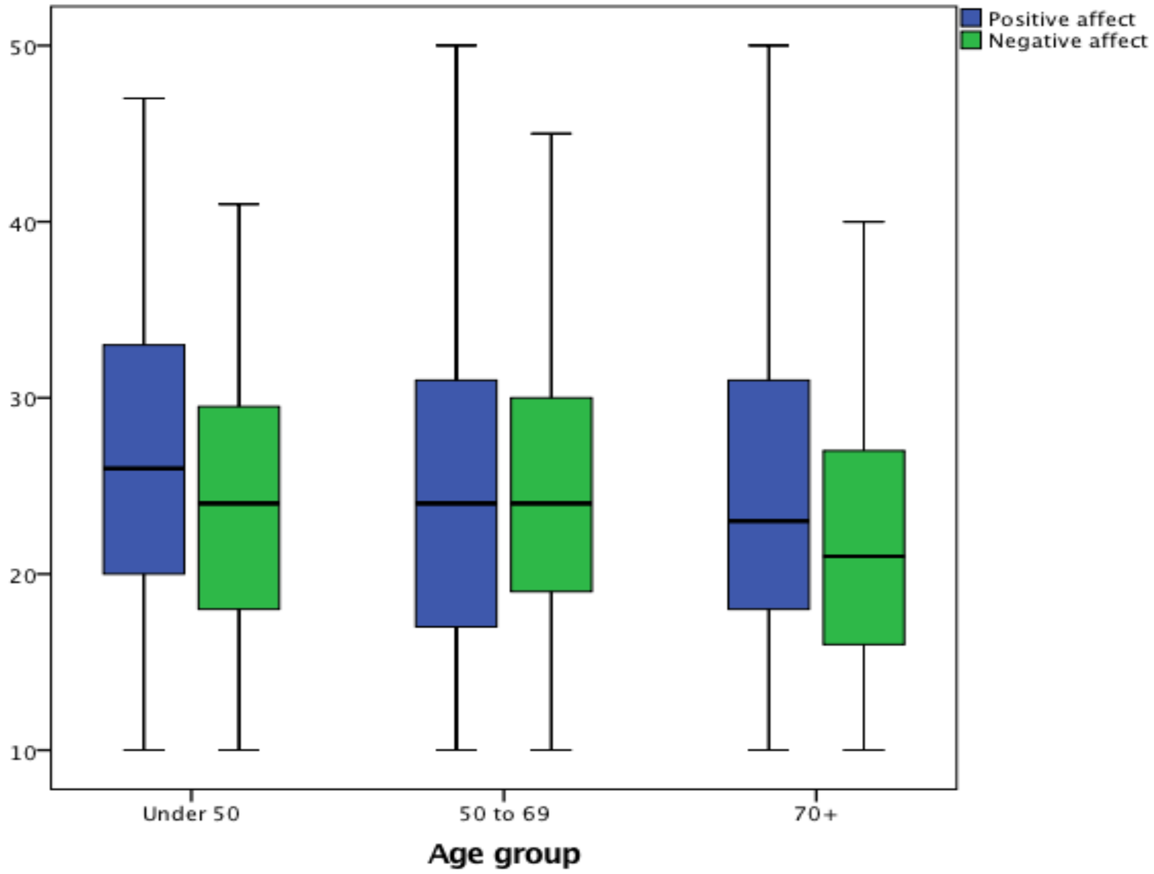


Figure A2.5: Comparison of PANAS scores by gender

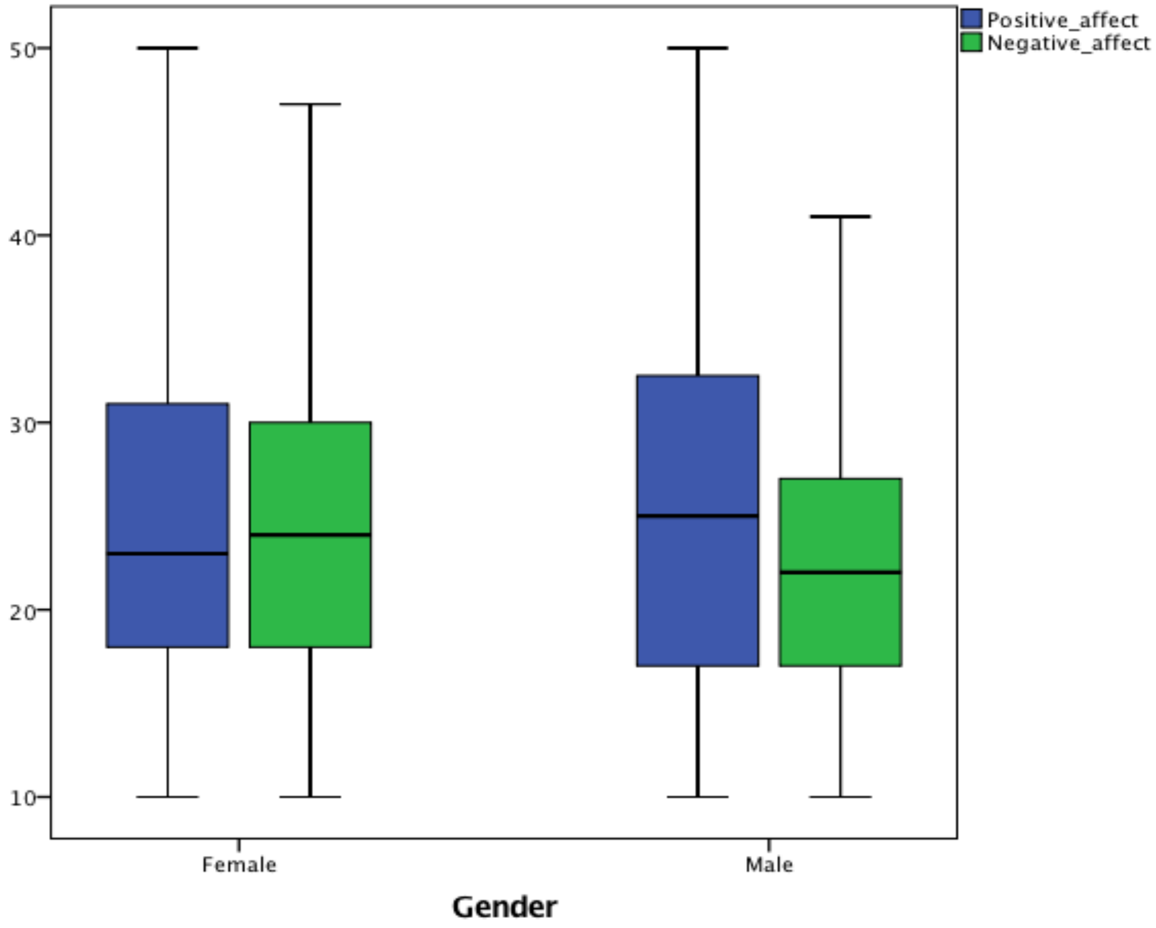


Figure A2.6: Comparison of PANAS scores by ethnicity