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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 – EXECUTIVE SUMMARY

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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.