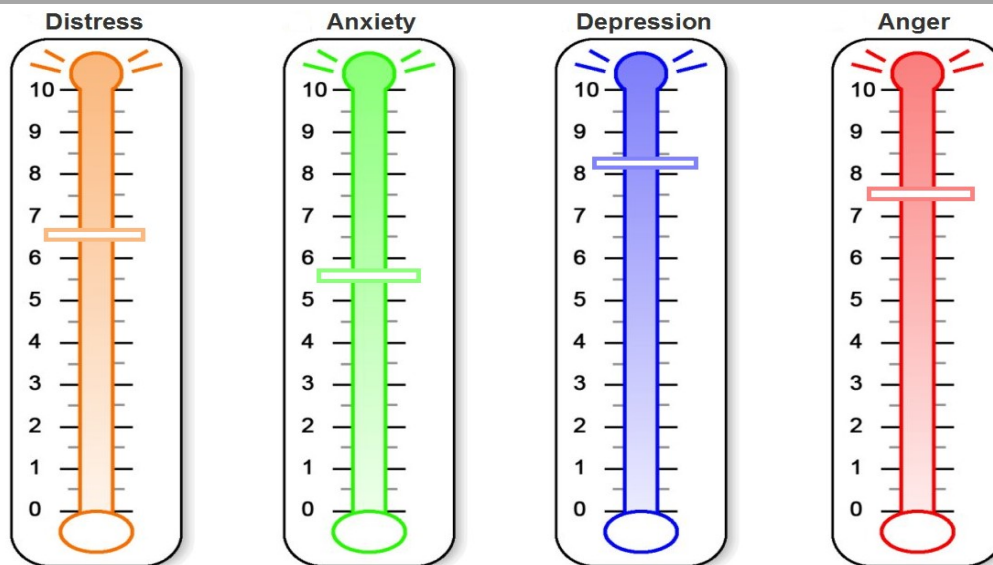


Mild to moderate distress in patients with end stage renal disease

Summary for patients and staff

THE STUDY



A four-year study looked at how many patients with end stage renal disease (ESRD) experience mild to moderate distress and explored the support that patients with distress want. The study also looked at some of the problems renal unit staff experience in being able to recognise and manage patient distress and made recommendations about what needed to improve.

WHAT DID WE DO?

The research was done in four West Midlands hospitals from 2014 to 2018. Over 1000 patients filled in a survey about distress and their support needs. The survey included the emotion thermometers (see front page) for patients to show their distress level, then 46 patients with mild to moderate distress were interviewed. Patients who were interviewed varied in age, gender, ethnicity and the treatment they were having: some were about to start dialysis, others were already on dialysis, and some had received transplants.

Staff at two renal units were sent a survey about the way that they recognised and handled patient distress. A total of 108 surveys were returned from a wide range of staff, including nurses and consultants. After the survey, 31 staff were interviewed about their attitudes and views about distress and to suggest changes that might improve how staff and renal units identified and managed distress.

FINDINGS

WHAT DID WE FIND OUT?

Distress is common and has many negative impacts: One third of patients were distressed, and distress was most likely for patients having dialysis, women, people aged below 50 and patients from black and minority ethnic (BME) backgrounds. Many patients reported emotional problems like 'worry' and 'sadness', and said that ESRD had major impacts on the way they lived their lives.

Who will be distressed and when is hard to predict: Whether or not someone becomes distressed is complex and it may happen to anyone at any time. Most patients said that they tried to keep a positive attitude, but they also talked about being scared that their condition would get worse and that they may not be able to cope.

Patients may hide distress: Many patients avoided talking about distress to staff because they felt they were too busy doing clinical tasks, or that they didn't have time to talk. Some patients also felt staff may not have the right skills to help them with their distress, and that staff deliberately made the renal unit a positive and cheerful place where talking about distress did not seem appropriate.

FINDINGS

Staff often find distress hard to recognise: Most staff felt that emotional support was an important part of patient care, but said it was often difficult to spot when patients needed help, because of:

- **Time:** Staff often needed to give priority to clinical rather than emotional issues for patients
- **Training and skills:** Staff without specific training often lacked confidence about managing distress and felt they were not very good at recognising signs of distress or being able to 'contain' it
- **Renal units:** Whether staff could spot distress often depended on their own skills, personality and individual approach to patients rather than distress management being a key part of care
- **Responsibility:** Some staff felt that dealing with distressed patients was optional or that it was the responsibility of other staff members with specialist skills or training.

Staff fell into 3 groups:

'Enthusiasts' who felt that responding to distress was an important part of their role and who were confident to do this

'Equivocators' who felt that responding to distress should be part of their role but who were not confident enough to do this

'Avoiders' who did not see responding to distress as part of their role, and who prioritised clinical care over emotional wellbeing

Staff may not be able to give appropriate support: Some staff said they needed more training and skills to help them offer emotional support to patients. This was especially important for some clinical staff who felt that emotional problems could be too difficult to solve. It was also difficult to organise support quickly from people like counsellors and psychologists because of the waiting time for appointments. However, patients often just wanted to see a doctor or nurse informally and face-to-face, who would ask about their problems and listen sympathetically.

RECOMMENDATIONS

WHAT DO WE RECOMMEND?

1. Patients should be offered education about distress and emotional support, whatever their stage of treatment for ESRD
2. Education should explain that distress is normal and can be experienced by anyone at any time
3. Support should help patients to cope better with distress and become more resilient. This could include regular, informal drop-in sessions with psychologists or specialist nurses
4. All renal staff should be given training about how to notice the spoken and unspoken signs that a patient is distressed, and develop skills to help them to manage the distress
5. Renal staff should also receive emotional support so that they don't get burnt out from providing support to patients
6. Staff should have clear information about the support available, which should be a mix of formal and informal options that patients can access immediately if necessary
7. Renal unit culture needs to change so that talking about distress is seen as normal and patients are encouraged to ask for help rather than hiding their distress or bottling it up

[Read the Executive Summary and full report here:](https://warwick.ac.uk/fac/sci/med/about/centres/clahrc/research/theme4-integrated-holistic-care-chronic-disease/publications)

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