

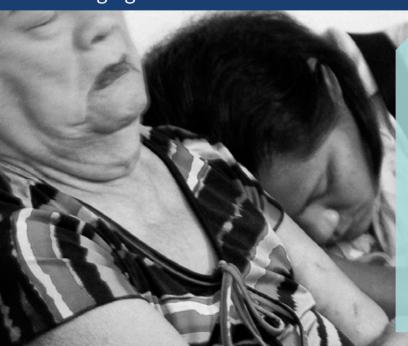


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A bite-sized summary of a piece of research supported by NIHR ARC West Midlands

May 2020

Managing Distress in Patients with End-Stage Renal Disease



Background:

- Patients who have end-stage renal disease (where kidneys function less than 10% compared to normal) often suffer distress.
- This can include a reduction in quality of life, and poor clinical outcomes.
- Although existing guidelines specify that emotional and psychological support should be provided for patients, there is little information about what is required or the challenges staff may experience in identifying and responding to distress.
- To investigate, our researchers carried out cross-sectional studies in the renal units of four West Midlands NHS Trusts.

Damery S, Sein K, Nicholas J, et al. The challenge of managing mild to moderate distress in patients with end stage renal disease: results from a multi-centre, mixed methods research study and the implications for renal service organisation. *BMC Health Serv Res.* 2019; **19**: 989.

Study:

- We carried out surveys and semi-structured interviews of both patients and renal unit staff
- Patients were asked about their experiences of distress, anxiety, depression, anger and need for help, as well as their strategies for coping.
- Patients were assigned to one of three groups, depending on their scores (low, moderate, or severe distress).
- Staff were questioned about their attitudes towards patient distress and perceptions about their own roles, responsibility and capacity.

Results:

- Around one-third of patients reported mild to moderate levels of distress.
- Distress was most often felt in those who were younger (less than 50 years old), female, or from black and minority ethnic backgrounds.
- Patients who had recently started dialysis also needed particular support.
- Both physical (e.g. tiredness, pain) and emotional (e.g. worry, depression) problems were often reported.
- Many staff reported a lack of confidence in recognising and responding to patient distress, due to a significant training/skills gap.
- Staff could generally be split between three groups:
 - *Enthusiasts*, who consider dealing with patient distress as a large part of their role, and who are proactive in identifying and managing distress.
 - *Equivocators*, who believed that they lack skills or confidence to deal with distress, even though they felt it was part of their role.
 - Avoiders, who thought dealing with distress was vital, but did not see it as part of their role, going as far to actively avoid the issue of patient distress.

Conclusions:

We need to **normalise discussions** about patient distress in renal units, and the key to this may be in providing emotional support. All renal staff should be offered **training** to proactively identify and reactively manage distress. **Support for staff** is also needed to ensure that managing distress does not increase staff burnout



1 Long-term Conditions

What is NIHR ARC West Midlands?

The National Institute of Health Research (NIHR) Applied Research Collaboration (ARC) West Midlands is a partnership between universities (Birmingham, Warwick, and Keele) and health and social care organisations in the West Midlands. Our mission is to create lasting and effective partnerships in order to improve care services across the West Midlands.

For further information, visit: arc-wm.nihr.ac.uk

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