**Managing distress in people with ESRD: people’s ability to cope with ESRD is impaired by a combination of smaller problems and larger worries.**

Background: The prevalence of depression and anxiety among people with end stage renal disease (ESRD) is known to be around four times higher than in the general adult population. A recent study found that distress is often unrecognised, particularly when not diagnosed as a psychiatric problem, and is prevalent in the ESRD population. This study sought to identify what causes distress and what additional support is required by people with ESRD.

Method: Semi-structured interviews were conducted with 48 people with ESRD receiving renal replacement therapy, awaiting transplant, or on conservative care. Interviews were conducted across four mixed urban and rural NHS Trusts. Interviews were transcribed verbatim and analysed using thematic analysis.

Results: Most participants reported emotional and psychological distress directly related to their renal replacement therapy and their medication regimen. Some participants became visibly upset, angry, and frustrated during interview. There tended to be a collection of smaller problems that would combine with distressing feelings, e.g. a fear of dying. Practical difficulties, such as being unable to cope with gardening or being exhausted after dialysing (particularly at first), increased distress. Participants tended not to have developed coping strategies to deal with the distress they were feeling. The most common coping strategy was a passive attempt to ignore the distress, which often left participants frustrated and seemed to increase distress. Participants attempted to hide distress from healthcare professionals (HCPs), would often report refusing offers of support, but still wanted support to be an option regularly offered to them. This was usually because HCPs were perceived as too busy (particularly nursing staff) or not trained enough to help with distress.

Discussion: Participants tended to praise HCPs alongside suggesting ways in which renal units could improve dealing with distress. The varied nature of the problems that caused participants distress is a challenge to all renal unit staff. The problems and concerns (e.g. pain, lack of time, exhaustion, transport issues, fear of death or worsening ESRD) that people with ESRD on dialysis face must be recognised and small steps taken to alleviate these wherever possible. This would leave people with increased emotional resource to cope with the psychological burden of things like a fear of dying. Increased access and offers of emotional and psychological support was cited as a potential improvement, although participants were unsure who is best placed to deliver the support. People with ESRD receiving dialysis seem to suffer distress frequently and a culture of refusing support for anything other than physical problems seems to exist. A clearly defined pathway that regularly signposts people to appropriate services, even if they have refused support in the past, would begin to foster a more supportive culture.