

SYMPTOMS IN END-STAGE RENAL DISEASE – A SYSTEMATIC REVIEW

F Murtagh
Kings College Hospital, London

Problem In the UK, the dialysis population is increasing by 10% per annum, with this increase containing disproportionate numbers of elderly, dependent patients with multiple co-morbidities. Dialysing these dependent patients, who often have several co-morbid conditions, may not improve their survival and may adversely affect their quality of life. Growing numbers of patients with end-stage renal disease (ESRD) are therefore being managed conservatively (without dialysis). In order to plan services for this group of patients, it is important to understand the extent of symptom burden.

Purpose The aim of this systematic review is to describe the prevalence and severity of symptoms in patients with ESRD, with particular attention given to those following a conservative management pathway (not for renal replacement therapy).

Design Studies reporting the prevalence and/or severity of symptoms in adult patients with ESRD, on haemo-dialysis, peritoneal dialysis, discontinuing dialysis, or having conservative management (without dialysis), were included. Studies of renal transplant patients were excluded, as were case reports or case series. Extensive database, hand, and grey literature searching was undertaken to identify studies, and those fulfilling these pre-defined inclusion/exclusion criteria were then formally included. Data extraction from these studies was standardized, and each study assessed for both content and quality (quality criteria adapted from Rinck et al¹).

Findings Fifty-two studies in haemo-dialysis and peritoneal dialysis populations fulfilled the inclusion criteria. Just one study of patients discontinuing dialysis, and no studies describing symptoms in conservatively managed patients fulfilled the inclusion criteria. All of the included studies were service rather than population based, and all but two used patient rather than proxy data. The prevalence and severity of symptoms in this population was found to be comparable to other populations with advanced disease. The range of prevalence reported for each symptom varied widely, but much of this variation can be related directly to:

- Variation in the definition of the symptom concerned
- Variation in the period over which prevalence was measured
- Variation in the level of severity included in prevalence data, and
- Whether screening or diagnostic tools were used to identify the symptom

In addition, only twelve papers explored the whole range of symptoms experienced by this population – all of the remaining studies sought one symptom alone or a small group of related symptoms.

Conclusions ESRD patients suffer considerable symptom burden, but exact quantification of prevalence and severity is difficult, because of extensive variations in the way symptoms are defined, identified and quantified. Most importantly, very few studies explore the whole range of symptoms, and even fewer use ‘open fields’ to allow patients to report for themselves what symptoms they experience. This constrains the studies from identifying and describing under-recognized symptoms, which may be considerable in this population. There is no evidence on symptom burden in conservatively managed patients, who might be expected to have the greatest symptom burden, increasing as their disease progresses towards death.

Relevance This review highlights the limitations in the available evidence on symptoms in ESRD, particularly the absence of evidence in the conservatively managed population. It indicates how this gap could best be addressed:

- by the use of symptom assessment tools which have been validated in other advanced disease or end of life populations
- by addressing the whole range of symptoms, and
- by inclusion of ‘free fields’

All these approaches would facilitate more standardized evaluation of symptoms, and enable useful comparisons to inform service development.

1. Rinck GC, Van den Bos GAM, Kleijnen J, De Haes H, Schade E, Veerhof C. Methodologic issues in effectiveness research on palliative cancer care: a systematic review. *Journal of Clinical Oncology*, 15 (4): 1697-1707.