Letters and Replies

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Disease classification: a pitfall of the ERA/EDTA registry?

Sir,

We read with great interest the expert editorial comment by Prof. Ronco [1] which discussed the paper by Tsakiris et al. on the incidence and outcome of patients starting renal replacement therapy for end-stage renal disease due to multiple myeloma (MM) or light-chain deposit disease (LCDD) using long-term data from the ERA–EDTA Registry [2]. Prof. Ronco noted the lack of diagnostic detail available in the existing ERA–EDTA Primary Renal Diagnosis (PRD) codes, and he gave constructive suggestions for the subclassification of diseases currently included in PRD code 82, which includes MM and LCDD.

In the paper, Tsakiris et al. acknowledged the important limitations imposed by the inclusion in PRD code 82 of a constellation of what are now recognized as distinct diseases. We agree that improvements in the coding scheme are required but nevertheless feel that important insights can be gained by examining these rare conditions using the unique and extensive data which have been collected by the European renal community and collated by the ERA–EDTA Registry. The coding scheme used has existed almost unchanged since the 1980s. It has been widely adopted with only minor modifications by nephrologists and renal registries around the world. The type of epidemiological analysis presented by Tsakiris et al. can only be done by a registry, and it is not possible at this stage to generate details which were not specified in the original codes.

The classification of plasma cell disorders is still evolving. The new ERA–EDTA PRD codes, which were launched during the 2009 WCN/ERA–EDTA Congress in Milan, take account of many new disease subdefinitions and include a wider choice of plasma cell disorders. The new codes are currently being mapped to SNOMED and will therefore also have accurate mapping to ICD codes. As soon as this mapping is completed, the new ERA–EDTA PRD coding system will be distributed to all national and regional renal societies and registries affiliated to the ERA–EDTA, and it will be submitted for publication in print and on the internet. We hope that it will be universally adopted and then maintained with international consensus.

For all coding and classification schemes, there is a tension between detail and brevity. A detailed system allows a precise classification but is inevitably complex, large, difficult to use and expensive to maintain. Training and strict definitions are required so that cases can be assigned accurately and consistently. Frequent pleas from nephrologists to ‘keep codes simple and workable’ convey their view that staff will not cope with complex systems without introducing coding errors and omissions. The new ERA–EDTA PRD codes have had to achieve a balance between these valid but conflicting views.

We acknowledge that definitions and diagnostic criteria were limited during the period reflected in the study by Tsakiris et al. However, if used with care and mindful of recent developments, even limited information about the incidence and prognosis of these rare disorders can be extremely useful when planning treatment and helping patients to make informed choices. We agree with Prof. Ronco’s plea for expansion and improvement in PRD code 82, and we hope that the new ERA–EDTA PRD codes will provide that.

Editorial Note: Dr Ronco had no further comments on this letter.

Conflict of interest statement. None declared.

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