Fostering the ability of patients to self-manage their CKD

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The escalating burden of chronic kidney disease (CKD), [1] and ultimate end-stage kidney disease (ESKD), is widely acknowledged [2] and, thus, CKD presents itself not only as a very potent cause of mortality and morbidity but also as a very serious economic challenge around the world [3, 4]. It is therefore disappointing that while the prevalence in CKD is increasing, few measurable patient outcomes seem to be improving. ESKD is a disease with a particularly poor prognosis with average mortality rates of dialysed patients of around 15–20% per year [5, 6]. For dialysis-dependent patients, mortality rates (adjusted for age and gender) are up to 100 times the rates of the general population [5]. Perhaps the most important point about CKD at all stages is the recognition of the massively increased risk it imposes for cardiovascular disease and associated events and early death. More than half of the deaths in patients on maintenance dialysis are related to cardiovascular disease [4, 6].

In nephrology, the lack of clinical research in CKD is well documented with the number of quality randomized control trials in particular being noticeably less than virtually every other medical sub-specialty [7]. Qualitative research also seems to be relatively novel in nephrology, with clearly much more required. Research of this type would for instance help to increase our understanding of how patients (and patient carers) perceive their illness or disease across the spectrum of CKD, the importance of which may well be underestimated by clinicians [8]. For instance, patients with CKD seem to have different priorities than clinicians. Their choices of treatment might be based much more on ‘lifestyle, family impact, and physical comfort’ [9], than on specific or traditional clinical outcomes such as blood pressure and serum creatinine estimations. It has therefore been suggested that rather than concentrating on clinical endpoints of importance to clinicians, greater emphasis should be given to providing information and psychosocial and practical support to optimize outcomes of importance to patients and their carers [9, 10] as has been demonstrated in other chronic disease states [11–13].

It also follows that if patients with CKD think in these ‘broad-based themes’ and quality of life outcomes, then some translation of this needs to be considered in ‘research priority-setting and resource allocation’ [8]. These qualitative findings also suggest that there may be substantial potential to improve ‘health literacy’ at all levels in CKD (disease detection, prevention and management), and to perhaps help inform investigators to move forward with newer and improved research endeavours [14].

Optimizing health literacy might also lead to greater ‘self-efficacy’, i.e. a person’s perception of his/her ability to plan and take action to reach a particular goal, and lead to improved self-management behaviours [15] that could in turn possibly influence the progression of CKD. Considering the burden of CKD and the priorities of patients and carers, it seems totally reasonable to explore ways of improving self-management skills as there are links between self-management interventions and making other life style changes, and the slowing of progression of CKD [16]. In the article ‘The Chronic Kidney Disease Self Efficacy (CKD-SE) Instrument: Development and Psychometric Evaluation’ by Liu et al in the current issue of the journal, the authors have developed an instrument to measure ‘disease-related self-efficacy’ of patients with early CKD for the purpose of early identification of those with low disease-related self-efficacy skills (a ‘discriminative’ tool). If there were effective interventions that could improve self-efficacy and improve self-management behaviours in an early phase of CKD, this could favourably influence the course of the disease.

If such instruments are going to perform adequately for their given purpose, two types of rigour are required to develop them—rigour in the process of conceptualization of the underlying construct to be measured, and definition and identification of a range of indicators to measure the construct’s validity; and rigour in the psychometric analysis of the tool. Ideally, the development of a new tool should be based upon an underlying conceptual framework developed from the ground up [17–19]. The development of the instrument in this case was based almost entirely on literature review and subsequent advice of ‘experts’ who assessed whether or not the chosen items

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were relevant and comprehensive (content validity), although the precise details of how the domains and items were initially chosen for inclusion or exclusion was not entirely clarified. While the concepts in the instrument seem to all ‘ring true’ (face validity) for what others have found to be relevant to the concept of disease-related self-efficacy, perhaps one key thing that is missing is an underlying conceptual understanding of what patients think is needed for maximal self-efficacy. While patients’ views were sought on the clarity, comprehension and ease of response of included items in the instrument, no documented attempt was made to seek their opinion about the relevancy of items for the underlying construct of self-efficacy from their perspective.

After identification of a relevant pool of items for the tool and pilot testing of the clarity of items, the authors translated the items from Chinese into English with steps taken to ensure semantic equivalence although no formal back translation of the tool was performed. Using exploratory factor analysis, the authors identified four distinct subscales (autonomy, self-integration, problem-solving and seeking social support), each subscale, consisting of between four and eight items (total 25 items), and the total scale and subscales were demonstrated to have good internal consistency. Responses to each item are recorded on an 11-point scale (from 1: not at all confident to 10: totally confident), but it is not actually stated how the subscales are scored and whether or not an overall score is calculated. The test–retest reliability of the tool was assessed in 26 patients who completed the tool twice over an interval of 2 weeks on the assumption that patients were stable over time. Only a single Pearson’s correlation coefficient of 0.720 is reported, which can be interpreted to mean that there was a moderate linear correlation between the score being assessed (possibly an overall score) at each time point. However, this statistic does not detect systematic bias, and intra-class correlation coefficients, which overcome this limitation, are the preferred metric for assessing reliability [20].

While the new disease-specific self-efficacy scale for early CKD appears to be a promising new tool with results reported in this article providing preliminary support for its validity and temporal stability over time, additional evaluation is needed to refine it further. Ideally, confirmatory factor analysis should be performed in an independent sample of patients to confirm item unidimensionality, lack of measurement bias and overall fit with the scale; and Rasch analysis would determine how well the emergent scales capture the full range of potential scores across each subscale [21]. Further research is also needed to evaluate its construct validity with respect to established measures of similar concepts; and, if the tool is planned to be used as an ‘evaluative’ tool (for example to measure the effect of intervention) then its ability to detect change over time (responsiveness) is also required. It is important to recognize that validation of a tool is not a ‘one-off’ endeavour. As the authors acknowledge, while the instrument may have satisfactory psychometric properties in measuring disease-related self-efficacy of Taiwanese patients with early stage CKD, if it is to be applied to other populations (e.g. in other countries or in other disease stages), then empirical evidence of its applicability in these populations is needed.

The development of valid and reliable measurement tools are essential if we are to make further impact in improving outcomes of relevance for patients with CKD. For many chronic diseases, capturing the patient’s perspective via use of patient-reported outcome measures (PROMs) has received greater emphasis in recent times due to the increasing expectation that patients play a greater role in decision-making and managing their illness. The use of PROMs in clinical research may inform of the development and evaluation of novel interventions not previously considered while their use in clinical care may provide clinicians with a better understanding of issues that are influencing patient treatment choices and adherence [22]. PROMs are also being increasingly used, alongside more traditional measures, to assess the outcomes of service delivery. For example, in the UK since 2009, providers of NHS-funded elective procedures such as hip and knee replacements are required to collect PROMs to assess the effectiveness of the procedures from the patient’s perspective [22].

The development of instruments to measure patient attributes such as the one described in this issue of the journal is to be very much encouraged and greatly applauded. Among nephrologists, it may be necessary to develop almost a whole new culture and literacy with respect to these tools as so few of them have been used in nephrological research to date. One would expect to see not only an increase in the number of these tools in nephrology, but also a consistent and rapid improvement in the quality of any new instruments developed over time and where valid and appropriate, their application as not only ‘discriminative’, but also as ‘predictive’ and evaluative tools in both research and routine care settings. There is no doubt that other questions need to be answered such as whether we need to have CKD-specific measures or would generic self-efficacy instruments suffice. Either way, these tools should help add value to research endeavours, but there is still a need for much more and much better research across the spectrum of clinical nephrology acknowledging in particular the needs and priorities of patients and carers [8, 23]. Only research will help fill in evidence gaps, improve the quality of clinical practice guidelines and clinical care and thus hopefully provide some improvement in outcomes for patients with CKD.


References

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