

Cross-cultural validation of the Portuguese version of the Dialysis Symptom Index for haemodialysis patients

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Commentary on the cross-cultural validation of the Portuguese version of the Dialysis Symptom Index for Hemodialysis Patients

Patient-reported outcomes (PROs) are patients' own reports about how they feel, function, and live their lives, and are a powerful tool to deliver person-centred care. In health care settings, PROs can include a patient's direct report of their symptoms and/or how a disease or treatment (or both) affects their physical, mental, emotional, spiritual, and social well-being as well as overall quality of life (Calvert et al., 2019). This perspective is usually collected via a validated self-report questionnaire designed to measure the construct of interest; a patient-reported outcome measure (PROM). It is increasingly common to collect this information via digital devices such as a smartphone or tablet (ePROs). This information can be used alongside other data including clinician observation/assessment and biomedical results to manage and improve care (Aiyegbusi et al., 2017). Research from other clinical settings suggests PROMs use can improve clinician/patient communication, improve health related quality of life (HRQoL), reduce hospitalisations, and increase overall survival, while demonstrating cost effectiveness (Basch et al., 2018, Lizée et al., 2019). At an aggregate level, these data can be used for audit and benchmarking to improve services (Calvert et al., 2019). However, PROMs have not been implemented routinely and systematically in kidney care settings.

The paper by **XX** reports the 'Cross-cultural validation of the Portuguese version of the Dialysis Symptom Index for Hemodialysis Patients'. It is notable to see an outcomes methodological study being reported in a nursing research journal highlighting the potential use of PROMs in a dialysis population but also reinforcing the role of nurses in PROM development and implementation, as well as the science and research which supports their effective use.

As highlighted by the authors, the haemodialysis population can experience a high symptom burden and associated reduced HRQoL and monitoring of these using PROMs can provide important information to optimise disease and treatment management. However, the plethora of available PROMs, both generic and disease-specific instruments, can be problematic for clinicians and other key stakeholders trying to choose a measure to implement in clinical practice. A systematic review of symptom burden and HRQoL in chronic kidney disease found 68 different symptoms were measured across 54 PROMs (mean number of items per PROM = 22, range 1–90) (Fletcher et al., 2022). This review identified the Dialysis Symptom Index (DSI) as a one of the currently available PROMs with the most comprehensive symptom coverage (Fletcher et al., 2022).

The DSI was developed in 2004 (Weisbord et al., 2004). The authors of this paper chose the DSI as its use was seen as feasible and acceptable. It also allows assessment of multiple symptoms including a free text option to facilitate reporting of unlisted symptoms. These are key factors when considering respondent burden and likelihood of completion. PROs assessment must be inclusive and equitable, capable of meeting the diverse needs of all patients with the condition of interest (Calvert et al., 2022), underlining the importance of the availability of well translated and culturally validated PROMs.

Cross-cultural validity is defined as 'the degree to which the performance of the items on a translated or culturally adapted PRO are an adequate reflection of the performance of the items in the original version of the instrument' (Mokkink et al., 2010). It is vital that any such adaptation is undertaken effectively to ensure we can still have confidence that the PROM measures what they are intended to measure (validity), they are stable over time (reliability) and can detect changes in conditions (responsiveness) (Mokkink et al., 2010). Concepts may differ across cultures,

consequently, when assessing such a concept using a measure developed elsewhere, it is important to test its cultural equivalence. It is important that such adaptations are reported and follow scientific methods for linguistic validation. This study outlines the approach set out by Beaton et al, and these guidelines serve as a template for the translation and cultural adaptation process (Beaton et al., 2000). However, it is worth noting that the Professional Society for Health Economics and Outcomes Research (ISPOR) have also developed Principles of good practice for the translation and cultural adaptation process for PRO Measures (Wild D, 2005)

The paper by XX also reports a methodological study using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) guideline for studies on measurement properties of patient-reported outcome measures (Gagnier et al., 2021). The COSMIN initiative aims to improve the selection of outcome measurement instruments for research and clinical practice by developing methodology and practical tools for selecting the most suitable outcome measurement instrument (COSMIN, 2023). When studies on measurement properties have good methodological quality, their conclusions are more trustworthy. This is important for cross-cultural validation studies and the adoption of the COSMIN guidelines in this study ensures that the measurement properties of the PROM were rigorously assessed with methodological precision. Additionally, the authors then went on to validate their adapted tool in the target population.

Most importantly, this paper really highlights the active role of the nurse in PROMs development, data capture and use. Treatment of end-stage kidney disease with haemodialysis is commonly undertaken in dialysis units that are multi-disciplinary but largely nurse-led. Nurses play a key role in the recognition, assessment and management of symptoms associated with kidney disease and its treatment and any effective implementation of PROs usage needs nursing leadership. The kidney PROMs literature highlights that actioning of PROMs to relieve symptoms is a key challenge; and this paper identifies the need for further studies on interventions/therapies to reduce the burden of symptoms and underscores how PROMs could play an important role. The implementation of the Dialysis Symptom Index as a routine screening tool by nurses could potentially reduce the severity and prevalence of disease and treatment side effects, thereby improving patient's overall HRQoL. Development, validation, and assessment of psychometric properties of PROMs is a first step, the key challenge will be the implementation of such tools so that PROM data is given similar priority and equivalence to other forms of data used to plan and manage care for patients undergoing dialysis.

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