

Using Patient Reported Outcome measures (PROMs) to promote quality of care in the management of patients with established kidney disease requiring treatment with haemodialysis in the UK (PROM-HD): a qualitative study.

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Introduction:

Patients undergoing renal replacement therapy by haemodialysis (HD) report reduced quality of life (QOL) and often prioritise improvements in overall QoL over long term survival (1). Regular and systematic collection and use of symptom and QoL data through patient reported outcome measures (PROMs) has been shown to be highly beneficial in terms of improvements in QoL, overall survival and cost-effectiveness in other clinical settings (2, 3). However collection of PROM data to manage the symptoms of patients undergoing HD does not routinely occur in the UK. This study aimed to explore the views, perceptions and experiences of patients receiving HD (including Home HD) and members of the multi-disciplinary team (MDT) caring for this group on the implementation and use of PROM data, particularly when collected and fed back electronically (ePROMs).

Methods:

Using qualitative methodology, semi structured interviews were undertaken with 22 patients and 17 members of the HD MDT, which included both professional (nurses/doctors) and non-professional staff (Health care assistants/unit administrators). Before interviews, participants were given sample validated PROMs (IPOS-Renal, KDQOL-SFTM1.3, KDQOLTM-36 1.0) and details of core outcomes identified by the Standardised Outcomes in Nephrology (SONG-HD) initiative to inform discussion. Interviews were steered by a topic guide. Transcripts were analysed deductively using the Consolidated Framework for Implementation Research (CFIR) (4) and inductively using thematic analysis. The CFIR provides a pragmatic structure to report feasibility and acceptability of PROM use in HD settings; it comprises five major domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation and their associated constructs.

Results:

The study identified key practical considerations around: i) frequency (how often PROMs should be completed); ii) timing (around dialysis); iii) setting (completion at home or in unit); iv) preferred mode of administration (electronic or paper versions) and v) interpretation and feedback of the responses. Both patients and the MDT were keen to use PROMs to support the delivery of person-centred care through shared decision making and management in all dialysis settings. The potential advantages of PROM use were generally recognised, primarily in research settings; the complexity of the intervention was highlighted through comments on patient safety and the need for effective electronic systems. Potential barriers to effective implementation included: i) lack of evidence base for use in routine kidney care; ii) perceived time barriers from both staff groups, anxious about work flow interruptions, and patients, who were anxious

about being overburdened by questionnaires; iii) risk of over-medicalising the patient experience; and (iv) health literacy issues for both patients and less experienced staff.

Discussion:

To assess whether PROMs can promote quality of care in HD settings, a coherent and comprehensive implementation strategy needs to be devised, taking into account the best available measures and methodological considerations. The findings from this study can assist implementation planning to address the priorities and concerns of both patients undergoing HD and members of the MDT, including timely understanding of factors which could aid or hinder changes to practice.