

‘I feel weak, useless and dependent on others’ South Asian patient experiences of haemodialysis

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OBJECTIVE: Much of what is known about patient experiences of haemodialysis (HD) has been gleaned from research with White English speaking groups. People from South Asian backgrounds- originating from India, Pakistan and Bangladesh- have a three to five fold greater risk of needing treatment for renal failure. Owing to language and cultural barriers, less is known about how patients from specific ethnic minorities experience HD, although such knowledge would help shape efforts to provide suitable support. In this study, we invited those who communicate predominately or exclusively in Gujarati, Punjabi or Urdu to participate in focus groups and with the aim of exploring thoughts and feelings related to HD and its impact on day-to-day life.

METHOD: Seven focus groups were held and across four NHS Trusts with high representation of patients from South Asian backgrounds. They were facilitated by a team of bilingual researchers with experience of working in healthcare contexts. Twenty-eight patients participated (15 males and 13 females; mean age 57.4 years). Focus groups were transcribed verbatim and translated into English, paying attention to retaining meaning as opposed to literal interpretation. Thematic Analysis was used to elucidate emerging themes, and using NVivo 10- a software programme designed to aid robust analysis of qualitative data.

RESULTS: Patients reported numerous aspects of the ‘imposition of treatment’ that altered their sense of self and left them feeling as though they were ‘living in limbo’. Various ‘support mechanisms’ were seen as crucial in helping maintain some form of normality and these were both internally and externally derived. Hope for optimising outcomes was constrained by awareness of cultural barriers to ‘access to transplantation’ with patients’ conscious that their current situation added to ‘family stress’. Furthermore, perceptions of the ‘patient-clinician relationship’ often compounded the overall experience of HD- leaving the majority feeling trapped by their situation.

CONCLUSION: Our findings highlight communalities in patient experiences of HD across different ethnic and cultural groups- delineating the aspects of treatment that patients struggle to contend with. Unique to our sample, we also expose concerns about access to kidney transplantation, with cultural factors limiting hope for improving quality of life. Targeted organ donation campaigns have a role to play here in furthering patient optimism for the future. It is apparent that patients require support in managing their altered sense of self and this can be facilitated in many ways including strengthening personal resources for coping alongside peer support.