

## Carer and patient perspectives of among people treated with home haemodialysis.

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### Introduction

If more people are to dialyse at home then it is necessary to better understand the experience of patients and their carers so that support mechanisms can be focussed and person centred. We designed a pilot study to investigate this further.

### Methods

Home haemodialysis patients and their carers from 6 centres were recruited into the Dialyse@Home study (NIHR portfolio number 38189) and completed instruments to assess their quality of life and experience of care. Patients completed demographic questionnaire, EQ5D quality of life, patient activation, illness intrusiveness, renal satisfaction and vascular access instruments. Carers completed the 40-question Carer Quality of life instrument (AC-QOL) from which low, medium and high carer quality of life for 8 subdomains relating to support, choice, stress, money, personal grown, value, ability to care and satisfaction. Quality of life for carer subdomains were compared to patient responses to better understand the comparability of patient and carer perceptions of topics that these instruments co-explore

### Results

39 carer-patient pairs were consented. Patients were 87.2% white, having received renal replacement therapy for an average of 8.25 years. 79.5% reported being in a relationship. Once scaled to the same range (0-1.0), the patient EQ5D quality of life was 0.72, with the adult carer quality of life scored 0.70 (a level considered high).

45.2% of carers reported little concern over money compared to 74.2% of patients documenting that they spent no time worrying about the financial cost to the care-giver. The majority (67.7%) of carers reported their stress as low whereas 60% of patients worried about the carer over-extending themselves a little, some or most of the time. Both patients (72.4%) and carers (54.8%) reported capacity to care as high. 40.7% of carers reported poor personal growth, however patients of these carers reported low intrusion of their health into their own self-improvement. Although carers felt highly valued (85.2%) fewer felt highly satisfied (7.4%); while patients felt the intrusion of their health into their relationship was low. 55.6% of carers reported delivering 21 hours or more of carer time per week, despite 80.7% of patients reported no or only slight problems with self care.

### Discussion

We found agreement between patient and carer for capacity to care and carer stress, but paradoxical relationships were noted between satisfaction, personal growth and the amount of time caring and capacity to self-care. It is important to systematically explore the differences between patient and carer perspectives in home haemodialysis so that training and support can be directed to promote well-being in the home dialysis environment.

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