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P089 -Development of a self-management behaviour scale for people on haemodialysis (HD)

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Introduction

Increased patient engagement in self-management enhances patient outcomes. Such behaviours refer to the daily activities that people do to keep themselves as well as possible medically, physically and emotionally to minimise the impact of illness. Existing measures that look at self-management behaviours among renal patients tend to have a clinical focus. They largely neglect the psychosocial aspects of functioning and everyday living which impact patients' ability to manage. Our study aims to develop a disease-specific scale that builds upon pre-existing measures to address circumstances or patient/staff behaviours that may impact on a patients' ability to manage their kidney disease day to day. Through a series of qualitative interviews, we sought to understand how HD patients manage, what is important to them and their experience of living with kidney disease and haemodialysis. Together with a review of current literature, these interviews will ensure the development of the scale has a focus wider than medical adherence and clinical care, to include a more patient-centred approach to understanding engagement in self-management.

Methods

Haemodialysis patients on dialysis for a minimum of three months were recruited across three sites in London, Hertfordshire and Birmingham and interviewed using a set of open-ended questions. In-centre, satellite and home-dialysis patients were sampled. Patients were specifically asked to talk about their day to day experience of living with kidney disease, beyond the illness and medical management of it. The interview script was developed from a review of self-management and haemodialysis literature.

Interviews were audio recorded, transcribed and analysed using a mixture of inductive and deductive thematic analysis.

Results

Twenty-eight patients across three clinical sites were interviewed, age range; 24 to 89 years with a mean age of 57 years (table 1). Thematic analysis identified sixteen themes relating to psychosocial aspects of self-management, many of which have been identified in the increasing amount of self-management literature published in renal disease (figure 2). Central themes include social support and family, coping strategies and psychological responses to illness, the impact of symptoms, treatment decisions, communication with clinical staff and the impact of multi-morbidity.

Discussion

Despite the many hours patients spend having renal replacement therapy, much more of a patient's time is spent away from the clinical setting, balancing life with dialysis. The qualitative work in phase one of the study has looked at the impact of kidney disease on people and families, at issues beyond only kidney

function. From this work we aim to develop a questionnaire that identifies gaps in support for patients which impact on their ability to manage in the way they would like.

The next step is to refine the list of questions that map to the themes identified in phase one. This will be done through expert consensus by patients, clinicians and methodologists using a content validity index approach. Cognitive testing in phase three will precede full validation involving 600 patients across all clinical sites in phase four.