

'HAEMODIALYSIS PATIENTS' EXPERIENCE OF ILLNESS AND TREATMENT'.

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BACKGROUND: The meaning attributed to the illness experience by each individual is likely to have a major impact on behavior, through coping strategies and defense mechanisms and influence how they deal with the illness. Failure to adhere to the complex regime of regular sessions of dialysis and strict fluid and dietary advice can have serious medical consequences.

PURPOSE: To explore patients' experience of renal failure with particular emphasis on patients' beliefs about treatment.

DESIGN: Face-to-face semi-structured interviews were conducted with 8 haemodialysis patients on renal replacement therapy from 2-7 years ranging in age from 32-68. Participants were encouraged to speak freely of their experiences about their experiences of suffering from ESRD, being in renal replacement therapy, about their symptoms, feelings, thoughts and concerns about their illness and their medical regime. Interviews were audio taped and transcribed verbatim.

ANALYSIS: Interpretative phenomenological analysis was chosen as a method of analyzing participants' accounts because it is concerned with the individual's personal perception (Osborn & Smith, 1998). Prominent themes in the participants' accounts were identified. The intensity with which they were described and the frequency of occurrence served as criteria for choosing higher order themes. Quotes from the actual accounts were used to support the strength of each theme.

RESULTS: Results revealed that patients have a range of beliefs about their illness and their treatment and that these are consistent with the core beliefs in the self-regulatory model of illness (Leventhal et al, 1984). These illness representations are structured 5 components: identity, cause, consequences, timeline, and cure. 'TIMELINE' patients were seeing their illness on a time continuum starting with the diagnosis of ESRD and ending with a kidney transplant. During the course of illness, the passage of time integrated the new stricter lifestyle in their routine and brought them closer to the desirable future outcome. 'CURE' getting a transplant was the miraculous cure designating the end of illness course. 'CONTROL' patients realized that they were agents to their own future. Personal gave confidence and feeling of well-being. However, the 'dialysis double bind' forced patients to accept complete dependence to the dialysis treatment. Patients fought to keep the balance between personal and external control. 'CAUSE' patients perceived cause of their kidney failure was often different to the diagnosis their consultant had offered. These differences, reinforced patients' ambivalent feelings towards treatment and staff. 'CONSEQUENCES' patients mentioned the influence of renal failure in all areas of their life. It interfered with their social roles as parents, friends and partners. 'IDENTITY' patients had very clear views about the symptoms accompanying their condition. The final theme was 'ACTIVE NON-ADHERENCE'. All patients admitted they sometimes consciously ignored or did not act in accordance to advice with respect to one or more aspects of treatment. These instances of non-adherence tended to be with those aspects of treatment that patients considered less important or less easy to adhere to.

CONCLUSIONS: Results of the present study indicate that psychological factors and specifically cognitive factors like beliefs and attitudes which patients hold may constitute causal factors for non-adherence and could allow the planning and implementation of interventions targeting non-adherence with treatment.

RELEVANCE: Interventions targeting non-adherence can prove to be ineffective, as the consequences of non-adherent behavior do not have immediate symptoms / adverse effects. Interventions that take into consideration patients' beliefs, attitudes, sense of efficacy and target their modification will be more likely to have a long term effect on adherence as opposed to those interventions targeting behavior or aiming to increase patient knowledge.