PRIMARY CARE DIABETES

Dialysis Distress

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Abstract

This communication conceptualizes and characterizes the phenomenon of dialysis distress, commonly encountered in persons living with end stage kidney disease on dialysis. Dialysis distress can be defined as an emotional state, marked by extreme apprehension, anxiety, despair and/or dejection, due to a perceived inability to cope with the challenges and demands of living with dialysis. This concept can be extrapolated to persons who undergo renal replacement therapy such as renal transplant.

Dialysis distress should be identified in a timely manner, and managed using appropriate support, counselling and education, delivered in an empathic manner.

Keywords: Chronic kidney disease, dialysis, end stage kidney disease, psychosocial aspects, renal replacement therapy

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Introduction

Chronic kidney disease (CKD) is a rapidly increasing clinical as well as public health challenge.[1] Unmanaged and uncontrolled, CKD can progress to end stage kidney disease (ESKD). ESKD management requires renal replacement therapy (RRT). For most person living with ESKD, maintenance dialysis is the first line of RRT. A prescription of RRT brings multiple challenges, both biomedical and psychosocial, with it. With haemodialysis becoming more and more frequent across the world, the time is apt to examine the quality of life of persons on dialysis. In this communication, we conceptualize the phenomenon of dialysis distress (DD) and call for greater attention to it.

Definition and description

Dialysis distress can be understood as an emotional state characterised by extreme apprehension, anxiety, despair and/or dejection, due to a perceived inability to cope with the challenges and demands of living with dialysis. This concept is based upon earlier definitions of diabetes distress.[2,3]

Such extreme reactions are commonly encountered in persons living with kidney disease. Mc Keaveney et al.[4] had described distress in kidney transplant recipients. "Managing ongoing fears of dialysis, distress, and COVID-19", and "dealing with difficult conversations" emerge as two important themes. Yu et al.[5] reported symptoms of depression, anxiety, stress, and insomnia in persons on dialysis, with greater severity in person on haemodialysis (HD) than peritoneal dialysis (PD). Psychological distress is associated with adverse health outcomes and higher mortality in persons with CKD.[6]

While symptom distress scales have been developed for persons on dialysis, e.g., the Haemodialysis Symptom Distress Scale (HSD-22),[7] these do not focus on psychological distress. Similarly, scales are available to assess distress and coping mechanisms in persons with diabetes[2,3] but they have not been validated in persons who have been advised, or are on, dialysis.

It makes sense, therefore to define and discuss dialysis distress.

Etiopathogenesis

Dialysis distress can predate the onset of dialysis, as it can be precipitated by a suggestion or prescription of dialysis. The suggestion may come from a qualified health care professional, a paramedical health care provider, a care giver, or even a friend or colleague. Learning about dialysis as a modality for CKD from social or mass media can also precipitate dialysis distress.

Multiple issues can contribute to dialysis distress. These include a sense of inability to cope with the technical demands of dialysis, to manage acute and chronic complications that may occur, to change one's lifestyle according to dialysis, and to manage the financial stresses and strains of dialysis. Table depicts various facets of dialysis distress. In addition, there is heightened stress in special situations e.g., dialysis patients advised to identify kidney donors from their family members are under stress. When family members decline to offer a kidney, patients are unclear how to manage ongoing or sometimes broken relationships. Female patients on dialysis confess about added distress when going for dialysis during menstrual

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Table: Diabetes fever.

Biomedical challenges
- Muscle weakness and loss of muscle mass
- Anaemia and fatigue
- Impaired dexterity
- Limited activities of daily living
- Higher mortality in dialysis patients compared from general population

Biomedical demands
- Need for arterio-venous access
- Need for repeated investigations
- Need for regular medical check-ups
- Adherence to strict dietary and fluid intake regimen
- Frequency of complications
  - Chronic
  - Acute

Psychosocial challenges
- Impaired quality of life
- Dependence on caregivers
- Chronic nature of treatment (lifelong dialysis or other RRT modality)
- Limited participation in social activities (social isolation)
- Changes in body image and self-esteem (visible access site scars)
- Fear and anxiety related to dialysis process

Psychosocial demands
- Financial burden
- Need to consult multiple health care providers
- Need to visit multiple health care facilities
- Balancing work and daily activities with dialysis appointments
- Dealing with impact of kidney disease on relationships and intimacy

cycles, stress about sexual dysfunction and even pregnancy. Non-adherence to dialysis is an important issue in children on dialysis. Also, parents of children on dialysis face tremendous burden of care, having to adopt dual roles as parents and informal healthcare providers, delivering clinical care, despite lacking proper qualification and training.

Dialysis distress is characterized by various emotions. A vowed denial or apathy, apprehension or anxiety, aggressiveness or anger, dejection or discomfort, and disillusionment or despair any of these can be a sign of dialysis distress. Such emotions are normal, but if they are extreme or all pervasive, they must be addressed. The dialysis caregiver's distress should also be kept in mind while dealing with dialysis distress (Figure).

Management

Persons with dialysis distress will not meet the diagnostic criteria for major depressive disorder or anxiety neuroses, but still need management. Such management is usually non-pharmacological in nature. Dialysis distress is a disorder of perceived inability to cope. The treatment, therefore, is enhancing cognitive coping with skills, and in teaching skills that are required to live with dialysis. Dialysis distress can also be mitigated by offering a slow and step-wise explanation of the need for dialysis, and ensuring that required skills are developed prior to start of dialysis therapy.

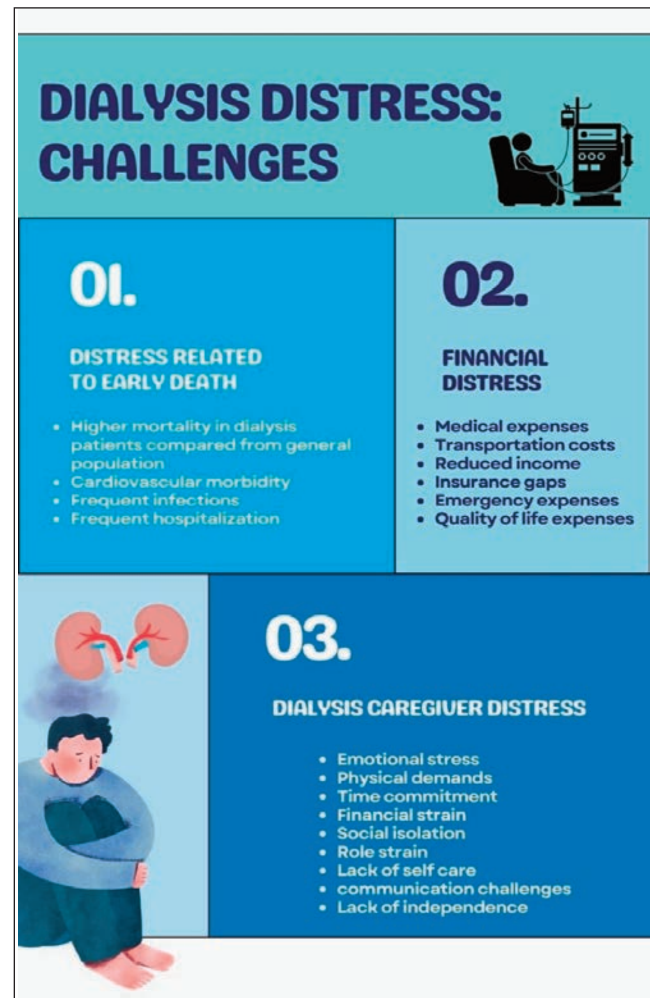

Figure: The challenges of dialysis distress.

Dialysis distress can be mitigated by empathic counselling, which has earlier been termed as "therapy by the ear" Every renal health care provider who discusses dialysis should be equipped to offer psychological first aid (PFA) to the person living with dialysis, and his/her caregivers. While the concept of psychological first aid was created as a response to natural disasters and trauma, it has been accepted for use in diabetes care. Psychological first aid is "*a compassionate and supportive presence, designed to mitigate acute distress, and assess the need for continued mental health care*."[8] In the context of diabetes care, PFA has been defined as " *the empathic support, counselling, and education, to improve coping skills, and optimise self-care, of persons living with diabetes, so that psychological wellbeing can be optimised*" (personal communication). This definition can be adapted for use in persons with ESKD and CKD.

The immediate measures could be having an on-site renal psychologist and peer support. Dialysis staff should be

trained and encouraged to talk about distress as a normal part of the care they provide. Patients feel it is helpful to have someone on the kidney unit they could talk to about their distress. This is true even when there were no solutions. Short term psychotropic therapy may be needed in select persons with severe symptoms suggestive of depression and/or anxiety.

Summary

The first step is to acknowledge that dialysis distress exists. The next step is to present and manage it as a part of standard kidney care. Through this communication, we hope to stimulate debate and discussion, promote inquiry and investigation, and find resources and remedies to address this phenomenon.

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