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How to tackle non-compliance among patients undergoing maintenance haemodialysis: Role of educational interventions, a review of literature

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Review article

How to tackle non-compliance among patients undergoing maintenance haemodialysis: Role of educational interventions, a review of literature

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Abstract

End stage renal disease is a major, chronic, non-communicable, and irreversible health problem that affects people all over world including India. Being one of the worst inevitable complications of diabetes mellitus, diabetic nephropathy ranks first among the causes of end stage renal disease. There are only limited options for the patients with end stage renal disease; either to wait for a donor kidney or to undergo renal replacement therapies. Even though the definite treatment is renal transplantation, patients have to wait years for a matching donor kidney. Hence, they are forced to undergo dialysis to sustain their lives. Compliance towards haemodialysis treatment regimen is an unavoidable component for those who are undergoing maintenance haemodialysis. There exists a great demand for initiatives and positive attitudes from the part of patients to be compliant towards the treatment. This literature review has tried to identify the gaps between non-compliance among patients undergoing maintenance haemodialysis and educational interventions for solving issues and thereby improving the health related quality of life.

Keywords: End stage renal disease, maintenance haemodialysis, health related quality of life, compliance, non-compliance

Introduction

Like any other chronic irreversible illness, end stage renal disease also places the person and family in great agony, suffering and financial burden. When the renal function goes down to 20-30% of its normal capacity, then it is referred to as End Stage Renal Disease (ESRD). These patients have to be fully dependent on machines with long tubes to get clear of the waste produced from their own body. With plenty of distasting medicines and boring menu plans, they have to tolerate weakness and tiredness throughout the day while they are allowed only a few glasses of water for alleviating thirst. However, they have to strictly adhere to the treatment regimen to sustain their lives (Cummings, Becker, Krischt, & Nathan, 1981). A qualitative study on the live experience of patients on maintenance haemodialysis showed that the patients are greatly affected in almost all the areas of life and are in great need for help from the healthcare professionals, to help them adapt to the situation (Valsaraj, Bhat, & Prabhu, 2014).

The reports from the World Health Organization and Global Burden of Disease project showed that kidney diseases add to the global burden of diseases at a staggering average of 8, 50,000deaths every year, and 15,010,167 Disease Adjusted Life Years (DALY) (Aggarwal, 2005).According to World Health Report and Global Burden of Disease project, kidney diseases contribute to twelfth cause for death and seventeenth cause of disability. National Kidney Disease and Education Program (NKDEP) have planned to give more stress on educating patients on various aspects of renal failure and its management

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(Narva & Briggs, 2009). The program itself is aiming at reducing mortality and morbidity due to the irreversible renal failure.

In India, the disease burden contributed by the non-communicable diseases is increasing in the last few years and accounts for 40% of all the deaths. Even though exact figures for ESRD are not available, its incidence is about 152 million. The major aetiology behind ESRD is diabetes mellitus based on a population study conducted in India (Vivekanand, 2013).

Kidneys perform the vital function of excretion of metabolic wastes from our body and other major organs are really relying on them for the proper functioning of the whole body. The maintenance of homeostasis via the regulation of electrolytes, acid base, and water balance, and the production of erythropoietin are the other crucial roles played by the kidney. Depending on the body's demand, kidneys perform filtration of the plasma and thereby remove the waste substances at a rate that is variable. The treatment modalities for ESRD currently available include either kidney transplantation or a renal replacement therapy *i.e.*, haemodialysis, peritoneal dialysis or continuous renal replacement therapy (Aggarwal, 2005).

Haemodialysis helps the renal failure patient to cover the excretory function and homeostasis that should have been performed by the diseased kidneys, thus it can be named as life saving for them. The patient's blood is exchanged with dialysate fluid on a discontinuous basis depending upon the patient's demand for fluid overload so that there will be appropriate water and solute movements through a semi permeable membrane during the haemodialysis process (Cummings, Becker, Krischt, & Nathan, 1981).

Haemodialysis: compliance and non-compliance

Regular haemodialysis requires great commitment from the side of patient and family throughout the treatment course. Hence, non-compliance remains a major issue though it adversely affects the survival of the patients. The rate of the non-compliance relies greatly on how it is defined. Many research studies show the relationship between non-compliance and various ocio-demographic variables. For example, there is a relationship between age of the patient undergoing haemodialys is and compliance *i.e.*, younger patients on dialysis are less compliant than the older patients (Hailey & Moss, 2000).

The spectrum of compliance includes a range of actions like receiving treatment such as dialysis, chemotherapy or surgical management, having medicines as per prescription like the right dose, the right route, the right way, at the right time, modifying dietary habits, engaging in some activities like exercise, yoga therapy and sometimes abstinence from actions like smoking and alcohol abuse (Rehabilitation, 2007).

Compliance towards the prescribed treatment regimen is crucial for the overall quality of the life of patients undergoing haemodialysis. According to Weitenberg et. al., compliance is a multifactorial phenomenon, and there should be coordination of various methods to quantify the same. A study on evaluation of compliance in home and centre among haemodialysis patients explored biochemical indicators for assessing patient's compliance. The study compared mid-month values of serum potassium, serum phosphorous and blood urea nitrogen and inert dialytic weight gain (Susan, Edward, Guy, Jerry, & Donald, 1983). The analysis of the findings revealed that poor control of biochemical variables could affect the actual compliance among patients undergoing haemodialysis.

Another study among end stage renal failure patients on their compliance towards haemodialysis reviewed the current available treatments and found that adult patients are having non-compliance generally. The subjective and objective compliance measures are too weak to prove strong relationship (Wolcott, Maida, Diamond, & Nissenson, 1986).Cameron conducted a study on compliance and found out that compliance is splendidly effective for all treatment regimens. Non-compliance can lead to non-accomplishment of therapeutic goals and thereby poor patient outcome. There is a strong connection between compliance and social and psychological factors. The factors are: (1) basic knowledge and understanding of the disease condition (2) the quality of healthcare

provider and patient relationship (3) social support such as family (4) health belief and attitude towards health, and finally (5) the factors related to illness and the therapy like the complexity and duration of regimen (Cameron, 1996).

Educational interventions and compliance among haemodialysis patients

The efforts to tackle the compliance among haemodialysis patients resulted in a finding that self-administered medication, counseling and written information can really have an effect on compliance and total clinical outcome. They reviewed studies that showed improvements in treatment outcome. The review reported that 16 long-term interventions led to improvements in treatment outcomes. The nature of interventions was complex consisting of routine care, patient information, reminders, self-monitoring, reminders, involvement of family and various other realms of scrutiny and monitoring. The study recommended that the available compliance enhancing modalities are really complex and more research has to be undertaken to solve the problem (Hayne, Mc Donald, Garg, & Montague, 2002).

Another review showed evidence of significant effect of combined dietary, medication, and fluid counseling on overall well-being of haemodialysis patients. The emphasis was given to more objective measurements such as clinical variables like blood urea nitrogen, serum phosphorous and potassium and interdialytic weight gain. The instructions for dietary changes should be given one at a time. The modification of the instruction has to be done only after the demonstration of adequate knowledge level by the patient. Another issue addressed is the multidimensional nature of non-compliance. The author recommended that the interventions for improving compliance must incorporate the issues, which seem to be the greatest concern for the patient (Ouzouni, Kouidi, Sioulis, Grekas, & Deligiannis, 2009). With a simplified treatment regimen, family therapy and clarification to patient regarding instructions are the other interventions found to be effective.

Dietary counseling itself helps maintenance haemodialysis patients to be compliant with the therapeutic regimen. A study was conducted among two hundred maintenance haemodialysis patients, aimed mainly on assessment of factors influencing compliance. Biochemical variables assessed were blood urea nitrogen, serum potassium, and phosphorous and interdialytic weight gain with the help of medical records. The analysis showed that most patients did not have adherence towards fluid restrictions. Non-compliance to potassium, phosphorous and blood urea nitrogen was also present. Educational status of patients was found to have association with blood urea, nitrogen, serum potassium, phosphorous levels, and interdialytic weight gain. Based on the results, educational level of maintenance haemodialysis patients was associated with compliance to fluid restrictions (Finkelstein & Finkelstein, 2000). The study concluded that dietary and fluid adherence could be improved by dietary counseling techniques and patient education.

A study on the effect of psycho-social factors on the outcome of maintenance haemodialysis patients drew attention recently. The most common psychological problem among patients with irreversible renal failure is depression. The clinical symptoms among haemodialysis patients can be feeling of sadness and anhedonia, helplessness, hopelessness, feeling of guilt followed by changes in appetite, sleep, and libido. Based on these findings, a program for dialysis patient was started in the dialysis unit with a screening every six months. The analysis showed that majority of the patients (74.6%) scored 17 or greater and met the DSM-IV criteria for depressive disorders. They concluded that the healthcare personnel, including nurses in the dialysis units, were to be educated regarding the present scenario and the efforts to alleviate the symptoms of depression and thereby decreasing morbidity and mortality (Chilcot , Wellsted , Silva, & Farrington, 2008).

The feasibility of an educational intervention was studied by Curtis *et.al.*, among the patients undergoing maintenance haemodialysis. They developed a stage specific educational intervention for haemodialysis patients with a psycho-social framework of illness adjustment. They recommended that the intervention should correspond to the stage

of adjustment to the disease (Renal, 2000). The study concluded that increased knowledge about the disease, treatment, and self-management might help the patient to comply better with their condition.

Another educational intervention revealed that most of the clinical complications were due to inadequate dietary habits and failure to restrict fluid as per their condition. The intervention they selected mainly focused on oral and/ or video education in order to improve their compliance with dietary and fluid management. The sample size was about sixty three patients having haemodialysis in three different hospital settings in Tehran and Iran. The samples were randomly allocated into two groups for attending oral or video education program. The socio-demographic data was collected. Clinical variables were monitored twice in a month and the average value of blood urea nitrogen, uric acid, creatinine, serum potassium, calcium, sodium, phosphate, and albumin and interdialytic weight gain was taken. Pre and post measures were taken (Baraz, Parvardesh, Mohammadi, & Broumand, 2010). The study findings conveyed the compliance in terms of clinical variables. The interdialytic weight gain was observed among 64.5% and 76.2% of haemodialysis patients. Significant correlation was present between socio-demographic variables like age, occupation, educational level, fluid and dietary compliances ($p<0.001$) but there was no significant difference between the two interventions.

A renal rehabilitation report shows that early information about disease condition, treatment available, survival rates might definitely influence the decision-making capacity among haemodialysis patients. Specific educational interventions focusing on renal failure, treatment options, medications, and dietary management can help them to have a sense of control, a critical factor that in turn influences improved compliance and life satisfaction. Educational interventions were found to be effective for maintaining physical and mental health of haemodialysis patients. Patients who were educated during the initial course of their illness reported to have very few complications and better compliance. Family and dialysis staff involvement in care can contribute towards increase in autonomy, self-control and involvement in the treatment regimen (Renal, 2000).

According to renal rehabilitation report in 2006, many studies showed that haemodialysis patients who are motivated to learn about their disease condition and its various aspects have better outcome and improved health related quality of life. The motivated patients may be ready to take responsibility of things such as physical activity, dietary adherence, medications, etc. that can be under their control. Education and support really help them in careful decision-making while they get a feeling of self-control over certain aspects of their condition. This can indirectly relate their emotional well-being and thereby reduce the chance of being depressed (Callahan, et al., 2000).

An observational prospective interventional study was conducted among haemodialysis patients in Cochin. The aim of the study was to find out the effect of educational counseling on health related quality of life. The main area of counseling included diet and fluid restrictions, medication and physical activity guidelines and stress reduction strategies. Experimental group received the intervention. The confounding variables such as age, gender, co-morbidities were controlled by using comparison groups (Thomas, Joseph, Francis, & Mohanta, 2009). The results bring out the conclusion that educational counseling was effective in improving health related quality of life among maintenance haemodialysis patients.

Conclusion

To prolong life end stage renal disease the patients have to comply with haemodialysis treatment. The dialysis usually takes 2-4 hours on an average but greatly depends upon the patient's condition. The dialysis staff nurses can take initiatives in providing educational counseling for the patients as it serves a great help for those whose lives are dependent on the haemodialysis machines.

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