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# Contributing Factors to Non-Adherence among Chronic Kidney Disease (CKD) Patients: A Systematic Review of Literature

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## Abstract

**Background:** Non-adherence to comprehensive management of Chronic Kidney Disease (CKD) remains a significant barrier to effective management of the population. Interventions to improve adherence need to target the contributing factors to enhance the quality of life.

**Objective:** To highlight the factors contributing to non-adherence in CKD patients.

**Methods:** Articles were identified from online data bases namely Medline, PubMed, Cinahl, Google scholar and Grey literature. A comprehensive search was done to identify articles which highlight the factors contributing to non-adherence in CKD patients. The following words were used for this search: Adherence & non-adherence, factors contributing to non-adherence to dialysis, medication, diet and fluid, CKD patients. 96 of them were identified.

**Results:** Six categories of factors contributing to non-adherence were identified. These were patient related, socioeconomic factors, psychological factors, therapy related factors, pathophysiological related factors and health care system related factors.

**Conclusion:** Non adherence remains a major obstacle in the effective management of CKD population. There is need for collaborative approach to devise measures that eliminate relevant contributing factors to non-adherence in CKD patients.

**Keywords:** Chronic Kidney Disease (CDK); Adherence; Non-adherence; Medication; Haemodialysis; Continuous Ambulatory Peritoneal Dialysis (CAPD); Dietary and fluid restriction

## Introduction

Patients undergoing treatment for Chronic Kidney Disease (CKD) are required to follow this multifaceted and comprehensive treatment that is complex and difficult to comprehend [1]. Comprehensive management of CKD patients includes dialysis, medication, fluid and dietary restriction [2]. The provision of CKD comprehensive patient care in terms of dialysis plan, medication, fluid and dietary restriction is crucial in slowing the progression and complications of CKD. However, evidence indicated that a substantial proportion of CKD patients were found to deviate from prescribed dialytic, medication, dietary and fluid recommendations [3] causing ongoing challenges in the health care.

Non-adherence rates to dialysis among CKD patients found in previous studies range from 2% to 98% [3-8]. Low rates of adherence to fluid restriction ranging from 9.7% to 72%, have been found in previous studies [9-12]. Similarly, poor adherence to medication and dietary restriction has been documented among CKD patients, ranging from 3% to 80% and 2% to 81% respectively [11,13-15].

Non-adherence to dialysis is a cause for concern as it leads to several life-threatening complications. Tolkof-Rubin [16] emphasises that poor adherence to haemodialysis increases the risk of complications in CKD patients. Complications include chronic anaemia, brain dysfunction, congestive heart failure, decreased function of white blood cells, excessive bleeding, infections, weakness of bones and pulmonary complications.

Mortality rates for individuals with CKD remain high because of nonadherence and without adequate dialysis, death occurs from build-up of fluids and waste products in the body [17]. According to the 2010 Global Burden of Disease Study, CKD ranked 27<sup>th</sup> in the list of causes of total number of global deaths in 1990, with age standardised annual death rate of 15.7 per 100,000, but rose to 18<sup>th</sup> in 2010, with annual death rate of 16.3 per 100,000 [18].

Non-adherence to CAPD is the leading cause of peritonitis in CKD patients. Peritonitis remains a significant problem in peritoneal dialysis and contributes to mortality. In India, Mawar et al. [19] did an observational study to find the prevalence of noncompliance to the CAPD procedure and its influence on the incidence of peritonitis. Peritonitis occurred in 60% of non-adherence patients and fully compliant patients had no peritonitis.

These findings indicate that poor compliance in performing CAPD procedure is a modifiable risk factor for peritonitis. Other complications of non-adherence to CAPD include pulmonary oedema, hypertension, hospital readmissions and septicaemia. In addition, poor adherence to dialysis has been reported as the most common cause of failure to respond to medication and of additional and unnecessary tests, dosage adjustment, changes in treatment plans, emergency department visits and hospitalisations, which ultimately increase the costs of medical care [20].

Consequences of excessive fluid intake and associated chronic fluid overload include treatment-related fatigue and dizziness, lower-extremity oedema, ascites, left ventricular hypertrophy and congestive heart failure, hypertension, shortness of breath, and pulmonary vascular congestion or acute pulmonary oedema [8,21,22]. Excessive fluid overload contributes to increased morbidity [8,23] and high mortality [8,21] in CKD patients.

In a study of more than 3000 patients with CKD, medication non-adherence has been associated with uncontrolled hypertension, which is associated with increased risk of CKD stage 5, and intensified blood pressure control may slow progression of CKD [20]. Inability to adhere with dietary restriction results in a faster progression of kidney disease into kidney failure and the need for transplant. Observational data from epidemiologic studies provide evidence that dietary protein intake is related to the progression of renal disease [24].

Non-adherence to dietary and medication regimes can result in chronically elevated serum levels of phosphate, which play an important role in the development of secondary hyperparathyroidism and renal osteodystrophy. Further, elevated levels of phosphate may increase coronary artery disease even in young patients, leading to significantly increased risk for mortality. Elevated blood phosphorus concentrations are associated with increased mortality in ESRD patients [25] and increase the risk for cardiovascular events, at least in part by contributing to vascular calcification [26]. Cozzolino et al. [26] show that mortality risk increases when the serum phosphorus levels chronically exceed 6.5 mg/dl as a result of nonadherence to dialysis and diet restriction.

Non-adherence carries a huge economic burden and yearly expenditure for the consequences of non-adherence has been estimated to be in the hundreds of billions of US dollars [27]. Estimation of hospitalisation costs due to medication nonadherence is as high as 13.35 billion dollars annually in the United States alone. It is clear that non-adherence results in a combination of wasted medical care dollars, wasted time and

energy for patients and health care providers as well as frustration and dissatisfaction all the parties involved [28].

The Australian Institute of Health and Welfare estimated that the total expenditure on kidney failure disease in 2001 was 647 million dollars and the corresponding figure for the UK National Health Service in 2010 was 1.45 billion pounds, which is about 1.3% of all health spending [29]. These figures are for adhering patients; for non-adherent cases, the cost of care will be three times the normal spending on the kidney failure population. Thus it is clear that non-adherence often results in wasted medical-care dollars [27,30].

The detrimental effects of non-adherence with dialysis, medication, fluid and dietary restriction need serious consideration as these impacts on the quality of life of CKD patients. Therefore, in order to formulate effective strategies that combat non-adherence in CKD patients, there is a need to systematically review the contributing factors in all four modalities since this is a comprehensive treatment. An understanding of these contributing factors will therefore inform the overall planning of CDK management. Despite the evidence that indicates factors contributing to non-adherence in dialysis, medication, dietary and fluid restriction in CKD population, there are no summative reviews on these factors in all four management modalities.

## Purpose of the Review

The purpose of the review is to highlight the contributing factors to non-adherence among CKD patients.

## Methodology

Articles from 1993–2015 were identified from online data bases namely Medline, PubMed, Ebsco Host, CINAHL, google scholar and grey literature. A comprehensive search was done to identify studies that identify and explore the factors contributing to nonadherence in CKD.

The following words were used for this search: Adherence & non-adherence, factors contributing to non-adherence to dialysis, medication, diet and fluid, consequences of non-adherence in CKD patients. The review included articles written in English only as there were some which covered non-English speaking countries. Qualitative and quantitative studies were included as the review used studies that identifies and explore factors contributing to non-adherence in CKD population. Excluded were studies with factors contributing to non-adherence in comments, editorials and studies with no outcome of interest were excluded from the systematic review (**Figure 1**) shows the search strategy.

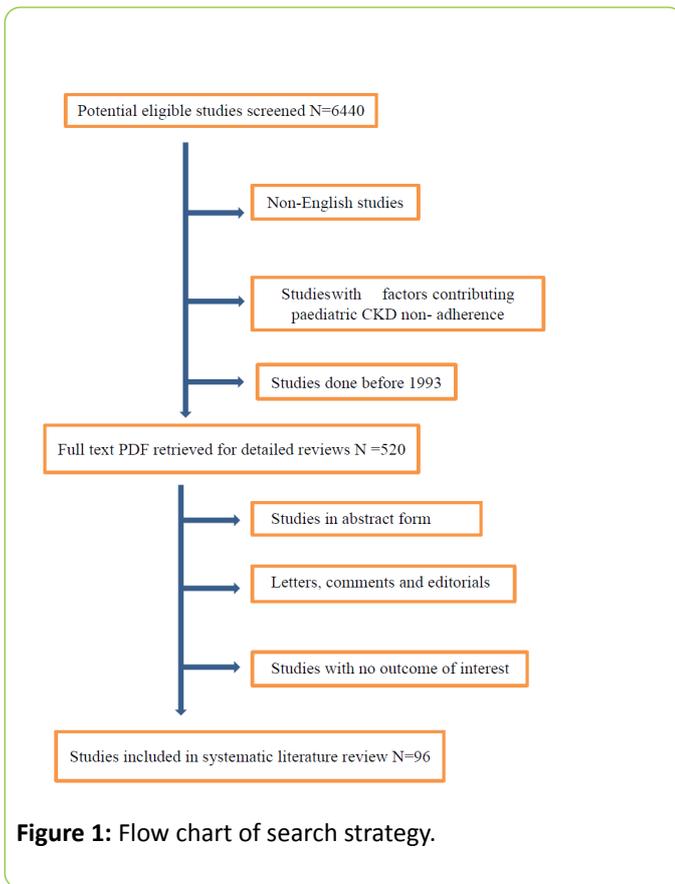


Figure 1: Flow chart of search strategy.

category which contributes to non-adherence as shown in Table 2.

Table 2: Categories and specific factors contributing to non-adherence in CKD patients.

Categories of factors contributing to non-adherence	Sub factors for each category
Patient related factors	Age Gender Level of education Health beliefs Interpersonal communication
Socioeconomic status	Income status Employment status Social support of families Peer support
Psychological factors	Depression Stress Irrational thoughts Perceived physical health Disturbance in self-concept
Health care related factors	Availability of dialysis centres Accessibility of dialysis centres Strict selection criteria Economic resources
Therapy related factors	Muscle cramps Intra dialytic Hypotension Chest pain Physical fatigue
Disease related factors	Gastrointestinal problems Uraemia

## Results

Six categories of factors contributing to non-adherence in CKD patients were identified. They include socio-economic factors, therapy-related factors, patient-related factors, psychological factors, disease-related factors and health care system-related factors. Table 1 reveals the categories of factors contributing to non-adherence in CKD patients.

Table 1: Categories of factors contributing to non-adherence in CKD patients.

Identified categories of factors contributing to non-adherence in CKD patients
Patient related factors
Socioeconomic factors
Psychological factors
Health care related factors
Therapy related factors
Disease related factors

## Discussion of Results

Six categories of factors contributing to non-adherence in CKD patients are patient related, psychological, disease related, socioeconomic, therapy related and health care system related factors. There are different sub factors for each

## Patient-Related Factors

Patient-related factors appear to affect adherence of CKD patients. Age has been found to be a determinant in adherence issues. Younger patients and those diagnosed as having chronic illnesses are less adherent. Higher adherence behaviour is found in older patients [9,10,20,31]. Kutner et al. [7] reported similarly that young age is associated with non-adherence in the CKD population. In addition, being male is consistently associated with non-adherence [9,10]

Level of education has also been cited as a determinant in adherence behaviour in chronic illnesses such as CKD. Low education has been found to cause decreased adherence due to poor correlation with knowledge of disease and treatment [32]. Knowledge appeared to be the chief facilitator of positive adherence to fluid restriction, with accurate self-assessment, positive psychological factors and supportive social contacts are also playing a role [33]. Low health literacy has been reported in dialysis patients and this factor, combined with regimen complexity, may contribute to non-adherence [10,34].

Those with low levels of health literacy find it difficult to follow instructions on how to care for themselves or to adhere to treatment regimens such as taking their medicines [35].

In addition, low health literacy is associated with more hospitalisations, greater use of emergency care, less adherence to treatment recommendations, worse health status, and higher mortality rates [36]. People with good basic literacy and numeracy skills, on the other hand, may struggle to understand and interpret health information in a way that prompts them to act appropriately to protect or enhance their health [37].

Health belief and culture influence how a patient adapts to treatment requirements and have been found to influence phosphate binder adherence in six of nine studies that evaluated health beliefs [38]. In a Chinese population, perceived barriers showed associations with compliance measures, implying that patients who perceived fewer barriers in following the dietary restrictions showed better compliance [39]. Studies have repeatedly shown that forgetting to take medications is a major contributor to non-adherence [40,41].

The interpersonal dynamics of health care and the patient play an important role in determining a variety of patient outcomes including patient adherence to their treatment recommendations. Patients who feel that their physicians communicate well and actively encourage them to be involved in their own care tend to be more motivated to adhere [42-44]. Empathetic communication, involving a thorough understanding of patient's perspective, improves adherence. Patients who are informed and effectively motivated are also more likely to adhere to their treatment recommendations [45].

## Socio-economic Factors

Employment status and income have been investigated in relation to socio-economic status among the CKD population. Low socio-economic status has been reported among CKD patients by Magacho et al. [14], Chironda et al. [4] and Assounga et al. [46] and where the majority of the CKD patients were unemployed. Poverty increases the risk of disorders that predispose CKD to progress and worsens outcomes in those who already have CKD. Prosperity increases access to renal replacement therapy. People in the lowest socio-economic quartile are at a 60% greater risk of CKD than those who are in the highest quartile [47].

The ability of CKD patients to work and lead a productive life is hampered by CKD as they no longer work and are unable to provide for their families [48,49]. Kaitelidou et al. [49] have reported similar findings and highlight unemployment due to CKD as a significant stressor for CKD patients. In their study, more than half of patients receiving dialysis were not able to maintain their profession and some had to retire after the beginning of dialysis. Furthermore, consistent associations with non-adherence were identified for being unemployed [10,50,51].

Admittedly dialysis is an expensive treatment, ranging from 30,000 US dollars to 60,000 US dollars annually in developed countries and from 6000 US dollars to 40,000 US dollars in developing nations [52]. Cost has been implicated in non-adherence in several studies of dialysis patients [4,53]. Most patients in developing countries have no access to health insurance and this makes care for CKD unaffordable and consequently affects their adherence rates to prescribed treatment regimen. According to World Kidney Day [54], the majority of patients commencing dialysis in low income countries die or stop treatment within three months of initiating dialysis due to cost constraints. Limited economic resources of patients in developing countries results in reduced frequency of dialysis and eventually discontinuation of therapy [55].

In addition to a debilitating and disruptive chronic illness, the treatment regimen is complex and demanding, which also this affects personal and social life [56]. Social support of friends, family and renal health professionals as well as family dynamics have been found to influence medication adherence among kidney failure patients [38,57]. Emotionally or genetically related family members of patients can have significant influence on the patient's engagement in their own care [58]. Excellence in care requires more than just the best care in diagnosis and treatment; it also requires care that addresses every aspect of a patient's experience. CKD and its treatments can restrict daily activities, employment, family life, and social relationships. This can lead to feelings of isolation. Feeling socially isolated can be stressful and anxiety provoking. Social support has been shown to improve survival and quality of life in dialysis patients [59].

Living with a chronic illness requires emotional support to help make the changes needed to cope and adapt. Peer support is reported to be beneficial to patients with kidney disease and in long-term dialysis therapy [60,61]. Research shows that people often cope better when they interact with peers with whom they identify and share common experiences [62]. In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalised. Peer mentoring has been shown to be highly effective in helping CKD patients adjust to dialysis and approach end-of-life planning [60,61]. It also improves depression, social isolation, self-esteem, and self-management and consequently better adherence, health and survival.

## Psychological Factors

The rate of psychiatric disorders in a population of CKD patients is considerably higher than in any other population with other chronic illnesses [63]. Depression is the most common psychological problem in CKD patients and is associated with both mortality and morbidity [64]. Biochemical imbalance, physiological changes, neurological disturbances, cognitive impairment are additional stressors which contribute to depression in CKD patients [65].

According to Leung [66], diagnosis of CKD creates a turmoil that reaches into all aspects of the patient's life and precipitates emotions, fear, anger and despair. Consequently, life with CKD becomes challenging, forcing the patient to confront it in a very personal way. Numerous psychosocial stressors affect CKD patients and their families, and their response to such stressors impact negatively on adjustment and response to treatment regimen. Smith et al. [33] cite psychological factors as the most common barriers to fluid restriction, predominantly involving lack of motivation.

Chilcot et al. [67] reported that 20–30% of CKD patients have significant depressive symptoms compared to lifetime prevalence of depression of approximately 16% in the general population. Depressed patients are found to be three times more likely to be non-adherent with treatment recommendations than non-depressed patients [68]. Kimmel et al. [63] investigated the impact of psychosocial factors on behavioural compliance and survival in urban haemodialysis patients and depression was related to decreased adherence to treatment regimen.

In a study which employed a descriptive cross-sectional design to examine the relationship between depressive symptoms and adherence to fluid and dietary restrictions in patients with CKD, common depressive symptoms were identified that were contributing to non-adherence to fluid and dietary intake in the study population [69].

Irrational thoughts such as mental shortcuts (ignoring some medical conditions), altered risk perceptions of behaviours, cognitive trickery (distorted views about controlling conditions) and using denial as form of coping have also been reported to contribute to non-adherence [70]. The challenges associated with living with CKD are significant and may contribute to patients feeling that they have lost control of their lives [71]. Disturbance in self-concept may lead to depression, with associated suicidal thoughts and poor self-esteem manifested by poor self-hygiene, excessive dependency and lack of adherence to treatment requirements [65]. Perceived physical health has also been reported to cause reduced adherence to treatment regimen among CKD patients [4]. Elsevier [72] states that patient's beliefs about their physical health are important because they influence adherence and adjustment to dialysis.

## Health Care System-related Factors

Availability and accessibility of dialysis centres affect adherence to prescribed treatment regimen among CKD patients. The lack of health care resources in low and middle income countries makes renal replacement therapy unavailable, with consequently low adherence to this therapy [73]. In the United States, patients with kidney failure have access to life-saving dialysis treatments paid for by Medicare, while in less affluent countries like South Africa, medical professionals rely on rationing dialysis services [74]. Public hospitals in South Africa strictly limit the number of patients for dialysis to save money for other pressing health priorities [46].

This situation is similar to that of the United States and other developed nations in the 1960s when dialysis first became available. Demand for the procedure was far greater than the supply, and hospital-based committees quietly rationed dialysis much as they do in South Africa and other African countries. In Nigeria, the majority of patients live far from existing dialysis centres and have to travel long distances to receive dialysis, resulting in dialysis inadequacy and frequent disruption of work that leads to job losses and consequent non-engagement with treatment regimen. Problems of transport are one of the most common reasons for absence or late appearance at the scheduled time for dialysis sessions [75].

## Therapy-related Factors

Side-effects of haemodialysis are therapy-related factors that affect adherence of CKD patients to the procedure. These include muscle cramps, hypotension and chest pain. Lynch et al. [76], Fidan et al. [77] and Figueiredo et al. [78] all note that muscle cramps are very common and lead to non-adherence to haemodialysis treatment. Muscle cramps is a well-known and distressing adverse effect that may arise during a haemodialysis session, closely related to the volume of ultrafiltration needed, which can reach an occurrence of 10–20% [79].

Muscle cramps associated with haemodialysis can be debilitating and often affect the patient's adherence with the haemodialysis treatment. Previous studies have reported that 17.9% of patients had early sign-offs of haemodialysis treatment because of muscle cramps [80]. These cramps frequently occur towards the end of the dialysis sessions, sometimes precede hypotension, and are associated with higher fluid removal during HD. Recurrent muscle cramps frequently lead to non-compliance with the prescribed haemodialysis treatment [80] and impact patients' quality of life [77]. Intradialytic hypotension is a major common complication which has been reported to occur in 16–30% of dialysis sessions [81–83]. Intradialytic hypotension is defined as a fall in systolic or mean arterial pressure of 20 mmHg or greater, in combination with clinical symptoms requiring intervention [82]. Such hypotension event will occur if the rate of fluid removal in the dialyzer exceeds the plasma refilling rate in the patient [84]. In addition, repeated episodes of intradialytic hypotension may cause cardiac fibrosis and cerebral ischemia leading to development of lacunar infarcts [82]. A higher rate of fluid removal is associated with an increased risk of both intradialytic hypotension and mortality [85]. According to the same authors, the safe rate of fluid removal at dialysis should be less than 10 mL/h/kg dry body weight.

Pain is a major health problem in CKD, affecting half of the dialysis patients, and most experience moderate to severe degree of pain [81]. Nevertheless, the impact of chronic pain and its consequences are often underestimated [86]. Again, being on treatment for a longer period of time [10] is associated with non-adherence among CKD patients.

Physical fatigue is one frequently experienced problem among CKD patients on haemodialysis, with approximately 90% of CKD patients reporting lack of energy and feeling tired. Harilall [87] did a study in KZN where CKD patients on dialysis were found to experience physical symptoms such as tiredness, lack of energy, nausea and cramps post dialysis and these were causing limitations in activities of daily living. People with CKD report a reduced capacity to engage in regular activity [88] and difficulties with being able to undertake routine living activities [4]. Athienites et al. [89] found that 25–30% of peritoneal dialysis and haemodialysis patients had mild-to-moderate physical and cognitive impairment due to comorbidity.

## Disease-related Factors

Herselman [90] indicates that attempts to convince patients to actively participate in diet and medical regimens do not produce desired outcomes because it is difficult to manage. Previous studies have implicated gastrointestinal complaints as a major contributor to problems of decreased intake and malnutrition [47,91] and suggest that addressing GI issues in patients with renal failure may improve nutritional status [91]. Furthermore, patients with CKD have increased serum leptin and elevated serum acute phase mediators. These mediators decrease oral intake of food. Again, the presence of uremia is a more obvious factor that adds to decreased appetite and nutrient intake [92] contributing to non-adherence. Moreover, CKD patients regard renal diet as tasteless and are continually tempted to continue eating non-renal diet like the rest of the family, as Gordon [91] have noted.

## Conclusion

The provision of CKD comprehensive patient care in terms of dialysis plan, medication, fluid and dietary restriction is crucial in slowing the progression and complications of CKD. Non-adherence to comprehensive treatment is a cause for concern as it leads to several life-threatening complications. Excellence in care of CKD patients requires more than just the best care in diagnosis and treatment. It also requires the identification of factors that contribute to non-adherence as this is the cornerstone for management of CKD. Therefore, there is need to formulate effective strategies that combat factors contributing to non-adherence in CKD patients.

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## Competing Interest

Geldine Chironda and Busisiwe Bhengu declare that there is no financial or personal interest or belief that could affect our objectivity. No potential conflicts of interest exist.

## Author Contribution

All authors have contributed to development and writing of the manuscript.

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