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# Family support, social and demographic correlations of non-adherence among haemodialysis patients

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**Abstract:** Non-adherence to treatment is an increasing problem for patients with end stage renal disease under haemodialysis. Aim: This study aimed to review the basic literature mentioned to the correlation between haemodialysis patient demographic characteristics and non-adherence to their treatment regimen. Method: Studies written in English published in 2002-2013 were identified through PubMed, PubMed Central, Dove press, Scopus. Clinical trials and review articles were excluded. Key- words used for search included a combination of adherence / non-adherence and haemodialysis in titles. Results: According to the literature, patient demographic characteristics are important factors for patient adherence to treatment regimen. Generally, factors associated with increased level of non-adherence to haemodialysis treatment regimen included young age, sex, race and educational level. Conclusions: Early identification of risk factors, inclusion of patients in the health care team and participation in clinical decision making, can lead to behavior adherence.

**Keywords:** Haemodialysis Patient, Non-Adherence, Demographic Characteristics, Factors

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## 1. Introduction

Center for Disease Control classifies Chronic Kidney Disease (C.K.D) as the ninth cause of death in the U.S [1].

Haemodialysis (HD) is the most common type of renal replacement for patients with End Stage Renal Disease (ESRD) [2]. Patients undergoing chronic haemodialysis have multiple problems such as sodium and water retention, hyperphosphatemia, hypertension, anemia, and heart disease. Almost half of the patients under haemodialysis suffer from diabetes mellitus which leads to further complications. To deal with all these problems, limitations are required on fluids intake, receiving antihypertensive drugs, hypoglycemic agents, erythropoietin, and iron supplements [3]. The management of these health issues requires multiple variations in the patient's lifestyle. Treatment success depends heavily on patient adherence in strict recommended regimens [4].

According to the National Kidney Foundation and Kidney Disease Outcomes Quality Initiative (N.K.F. K.D.O.Q.I.) non-adherence (NA) for haemodialysis patients includes: a) skipping or shortening of haemodialysis session,

b) excessive fluid intake and foods containing potassium and phosphorus and c) medication NA [1]. Non-adherence in these areas can have unpleasant effects on quality of life, health costs and increase the risk of cardiovascular events [2,6-8]. Nevertheless, it is estimated that approximately 50% of HD patients adhere poorly to their treatment [9].

According to the WHO [10] "adherence" is: "the extent to which a person's behavior (taking medications, following a recommended diet and/or executing life-style changes) corresponds with the agreed recommendations of a health care provider".

According to Reach [11] non-adherence is a "disorder". Trying to explain the mechanisms of this disorder, Reach highlights that NA is a manifestation of the syndrome of "weakness of will", as philosophers call, and liken non-adherence with gambling, drug addiction or procrastination.

According to several studies, factors that influence patient adherence are varied [12]. WHO [10] has categorized potential factors of NA into five fields: therapy-related, condition-related, healthcare-team, system related and finally, social/economic. Causes of non-adherence may include

patients' beliefs [13], complexity of the regimen [14], poor relationship between therapist and patients, [15] adverse effects [16], lack of social support [16], patient personality [17], educational level [16], or economic reasons [18]. Most of these studies agree that all potential determinants should be examined in order to improve the ability of HD patients to follow their treatment regimen [10].

The purpose of the present study was the literature investigation of studies reporting on patient demographic factors of HD patients' non-adherence. This template, created in MS Word 2000/2007/2010 and saved as "Word 97-2000 & 6.0/95 – RTF" for the PC, provides authors with most of the formatting specifications needed for preparing electronic versions of their papers. All standard paper components have been specified for three reasons: (1) ease of use when formatting individual papers, (2) automatic compliance to electronic requirements that facilitate the concurrent or later production of electronic products, and (3) conformity of style throughout a journal publication. Margins, column widths, line spacing, and type styles are built-in; examples of the type styles are provided throughout this document. Some components, such as multi-leveled equations, graphics, and tables are not prescribed, although the various table text

styles are provided. The formatter will need to create these components, incorporating the applicable criteria that follow.

## 2. Methods

The search covers the period 2002-2013 and made through electronic data-bases PubMed, PubMed Central, Dovepress, and Scopus. Keywords used were: "Haemodialysis patient", "non-adherence", "demographic characteristics", "factors". Review articles, case reports and clinical trials were excluded. Clinical and observational studies were considered. Articles which were reviewed specified the effect of demographic characteristics in haemodialysis treatment regimen.

## 3. Results

Many determinants have been found to be associated with non-adherence in HD. Some of them are age [4,6,7,19-22,26,27,28,36], race [4,6,7,19,23], sex [4,7,22,26,27], educational level [6,22,23], work [27,34], marital status [18,33,34,36]. Studies that have analyzed the demographic characteristics and correlated them with adherence in HD are summarized below (Table 1).

**Table 1.** Demographic factors affecting adherence

Author	Positive effect	Negative effect	Neutral effect
Kauric-Klein 2013	Female gender elderly	Young age, black race	High educational level
Hain, 2008		Young age	
Murray 2008		Young age	
Barazet al 2010	Young age, high educational level		Family status, gender
Saran et al 2003		Young age, African American race, female gender, employment	Educational level
Bland et al 2008	High educational level	Black race	
Barnett et al 2008		Female gender	
Chan et al 2012	Female gender	Young age, employment	
Kugler et al 2011	Female gender, high educational level	Young age	
Unruh, 2005		Young age, black race	
Theofilou, 2012	Male gender	Young age	
Zrinyiet al 2003	Family support		
Smith et al 2010		Employment, lack of family support	
Theofilou 2011	Family support		
Kugler et al 2005			Family support
Untas et al 2011		Lack of family support	

### 3.1. Demographic Characteristics

Although studies do not indicate clear relationship between NA and demographic characteristics of HD patients, some factors seem to be associated with non-adherence to a treatment regimen.

Most of the studies found that age, sex, race, marital status, educational level and employment status are important factors of adherence in HD.

Literature suggests that young people may have lower

adherence levels than older.

Kauric-Klein [19] found a significant negative correlation between young age and NA in antihypertensive agents and fluid restriction. Older adults were more adherent in medication and attendance in dialysis session, black race was a predictor for skipping sessions, while females were more adherent in fluid restrictions. No relationship was found between educational level and adherence in antihypertensive drugs.

Similar are the results of Hain et al [20] and Murray [21]

regarding age. Opposite are the results in the study of Baraz et al [22] in which young patients were found more compliant than older after an educational intervention. High educational level predicts high rates of adherence. No association was found between adherence and gender or marital status.

Saran et al [4] studied adherence levels in an international study using data from Dialysis Outcomes and Practice Patterns Study (DOPPS). Determinants of high rates of NA were young age (for hyperphosphatemia, fluid overload, shortening or skipping sessions), African American race for skipping and shortening dialysis sessions, females for increased weight and employment for hyperphosphatemia. Neutral correlation was found between highly educated (college) patients and adherence in HD regimen.

Bland et al [23] found black race as a predictor of NA in medication taking. HD patients with high level of education were more informed about their condition and thus more adherent. This study comes in agreement with previous studies [24,25].

Barnett et al [26] studying the effectiveness of an educational program in fluid adherence found that women had an important decrease in the fluid consumption. No correlation was found between adherence and other demographic characteristics.

Chan et al [27] studied adherence levels using self-report methods and biochemical parameters among 188 patients from 14 different dialysis centers in Malaysia. Younger patients were less adherent to the therapeutic treatment compared to the older. Females were statistically more adherent to dietary and fluid restriction. Searchers did not find any difference between male and females on medication adherence ( $r = 0.172$ ,  $p > 0.05$ ). Patients who were employed were more likely to be less adherent to dietary and fluid restrictions.

This search comes in agreement with the study of Kugler et al [6] as far as age and sex are concerned. Especially, in their international comparison study among 456 HD patients, searchers using Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ) found that high educational level among US group was associated with high level of adherence in diet whereas among German group low educational level was associated with high degree of diet NA.

Black race and young age were associated with skipping dialysis in the study of Unruh et al [7]. Skipping treatments was associated with high potassium levels and therefore, increased risk of death.

In Theofilou study (2012) [28], which conducted in six general hospitals in Athens between 168 HD, patients were administered questionnaires regarding medication adherence and beliefs medicine. This study comes in contrast to the previous studies referred above as well as the results show that men and young patients are more adherent in medication than women and older respectively. Theofilou explains that the number of pills in elderly is greater than in young patients leading in NA. Similar results are mentioned in other studies [29-31]. Searcher argues that women are more vulnerable to mental disorders.

Other searchers found no correlation between age, sex [23, 32], or marital status [32].

Ambiguous are the findings about the effect of employment in patient adherence. Employment showed to be no associated with adherence levels with the dietary regimen in the study of Zrinyi et al [33] in contrast to the results of Chan et al [27] as we referred above. Smith et al [34] refers to employment as a social bar to adherence.

### 3.2. Marital Status

Because marital status includes not only demographic characteristics but also has a social character we found it useful to refer on it emphasizing in the social role of family.

In Theofilou study [18] conducted in six general hospitals in Athens between 168 HD patients, levels of patient adherence correlated with the family support. Married patients, because of the support they have from their spouses / companions, showed better adherence levels than unmarried, widows / widowers and divorced as well as better mental and physical health.

Similarly, Smith et al [34] studying patient perspectives in fluid management found that patients do not comply with fluid restrictions due to lack of support from family.

However, Kugler et al [35] did not find any correlation between adherence behavior and family support whereas according to Zrinyi et al [33] the larger the family, the less adherence level with phosphorus and fluid restrictions.

Untas et al [36] in a study among 32.332 patients in 12 countries concluded that in North America, patients without family support time were more likely to skip or shorten a HD session. In Europe-Australia/New Zealand, patients who had the sense of a burden to family had greater possibilities to shorten a HD session and to have hyperkalemia. It is useful to emphasize that patients from Japan had the lowest rates of skipping session. Searchers link this with the marital and employment status as well as most of the patients were married or lived with family or employed.

These patterns of associations are consistent with those of other studies [37, 38]. Other studies [39, 40] highlight the negative effect of being single or divorced in adherence levels whereas others the positive effects of being married [41] or living with someone. [42]. Several searches concluded in neutral results about the relationship between the two variables [43, 44].

## 4. Discussion

Most of the studies [4,6,7, 19-22, 27] showed that young age is related to non-adherence in haemodialysis.

Some researchers use only demographic characteristics (age, race, and marital status) to find out HD patients who are likely to be NA to 1 or more fields of treatment. In a large multicenter study of 1230 HD patients, searchers tried to measure adherence with phosphate binders. Only 2 demographic factors (young age and being a widow) correlated with medication non-adherence.<sup>45</sup> In a large study conducted by Legatt et al [46] young adult age was the

greatest factor of NA in fluid restrictions. Some studies try to explain why older HD patients are more adherent than young. Kutner et al [47] explain that lifestyle of the elderly is such that it can adopt the requirements regimen unlike young people who consider themselves less vulnerable to the negative effects. Kauric-Klein [19] argues that young people may have not accepted that they suffer from a chronic disease and additionally have many family and work tasks. Thus, young people are stressed because of duties in their everyday life so it is more possible not to comply with being in HD sessions or following fluid restrictions. Another explanation is that older patients may have espoused to some self-care behaviors as well as they have been under HD for a long time. Also, older HD patients follow a program of their life adjusted to HD.

As far as gender is concerned, results are fuzzy. However, some studies [4, 26-27, 48] show that women are more adherent in fluid restriction. Kugler et al [35] explain the fact that women are more aware of their health status than men. Gender may not be a good predictor of non-adherence because of the inconsistent conclusions. The way that gender determines adherence level is unknown so more research should be suggested.

As far as employment status is concerned is a predictor if NA. Patients who are working have difficulties on following diet restrictions leading in uncontrolled interdialytic weight gain. Also, working patients may eat, for the most part, "fast foods". These foods may contain a high amount of sodium or potassium [22]. This fact could lead to increased sodium and potassium levels. It is, also, possible that life style of workers is associated with low adherence rates in phosphate binders having to be taken during meals [27].

Race as a factor associated with non-adherence behavior has been studied in the USA and European countries [48]. According to some studies [49, 50], Caucasians are showed to be more compliant whereas African Americans less adherents. A possible explanation is that for minorities is difficult to follow the treatment regimen due to low income and socioeconomic status. Also, language is a barrier of the minorities [48]. Curtin et al [51] found race (black) and ethnicity as the one factor associated with NA to antihypertensive and phosphate binders. Therefore, ethnicity may not be an objective predictive factor of low adherence. However, literature [7, 19, 20] suggest that this population is at higher risk for NA to the dialysis regimen and fluid restriction.

Marital status might influence patients' adherence with medication positively [4, 52, 53]. However, marital status was not found to be related to patient adherence in three recent studies [54-56]. Lack of social/family support is sometimes a barrier to adherence in HD according to the reviewed literature [29, 32, 34, 37-42]. Friends and family offers an incentive for learning and complying with the life changes. However, social support affects positively outcomes and is a link between HD patient and adherence to treatment regimen. Especially, older HD patients usually ask for help and support for transportation or meal time. The concern among

HD older patients is the fear of missed love and acceptance from the family. The significance of family role is related to the cultural character of the country as it is showed in two studies [28, 57]. According to Tezel et al [57] help coming from family might be emotional (improving quality of life) or practical (transportation, meal preparation, economic).

Several studies found that the high educational level predict better rates of adherence, [6, 22, 23, 32] while some studies found no correlation [4, 19], Baraz et al [22] claims that the higher the educational level the better knowledge and better adherence. Baraz et al [22] argues that a high educated patient might understand more easily the usefulness of the treatment whereas Grierson et al [58] mention that it is difficult for high educated patients to be adherent because of their business and their professional status [58].

## 5. Conclusions

This study reviews the literature mentioned to non-adherence in haemodialysis. Studies which were reviewed showed that non-adherence in HD is a big problem. This study highlights the importance of demographic factors affecting adherence. Various factors such as gender, young age, negatively or positively are correlated with adherence to treatment.

Haemodialysis as a process is a lifesaving procedure. Haemodialysis patients after their accession in HD have to adhere to many lifestyle changes as well as diet and fluid restriction, taking of a great number of medication and attendance in dialysis session.

Plenty of demographic factors are involved in adherence HD. As listed above, determinants such as age, sex, race, educational level are related to adherence in HD regimen.

For healthcare professionals of dialysis centers the best way to convince the patient is to "touch" patient needs. Most importantly, in addition to medical knowledge and techniques, is communication. Therefore, all barriers must be confined in order to persuade HD patients and bring them into adherence behaviors.

Interventions can lead to increased levels of adherence are:

- Early identification of non-adherence risk factors [6, 16, 23, 27].
- Increased attention and supervision [23].
- Strategies focused on patient age.
- Counseling education and patient information [22, 23, 26, 27].
- More available time for information, especially for patients with low educational level.
- Educational interventions to increase knowledge about the significance and implications of non-adherence to regimen [22].
- Inclusion of patient in health care team and in clinical decision making [18, 44].
- Techniques of active listening and interview
- «Simple» «and practical» messages, re amplification of messages and frequent training sessions [27].
- Cognitive-behavioral therapy.

- Simplifying the therapeutic regimen (reducing the number of tablets and the size of them). New technologies like reminders via mobile phones, personal digital assistants and pill boxes with paging system can be applied to patients with more difficulties in achieving goals [23].

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