

# Functional Status of Patients on Maintenance Haemodialysis and Burden of Their Caregivers: An Example from a Tertiary Referenz Hospital in Cameroon

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## Abstract

**Background:** Patients on maintenance hemodialysis (MHD) often depend on caregivers due functional status impairment (FSI). We evaluated the functional status of patients on MHD and the burden on their caregivers in Douala.

**Material and methods:** A fourth month cross-sectional study including consenting adult patients on MHD in Douala general hospital and their caregivers. Functional status of patients was assessed using the overall functional status scale. A FSI score between 1-5/13 was considered moderate, and severe when above 5/13. Caregiver burden was assessed with the Zarit caregiver burden scale; a score between 21 to 40 was considered light to moderate burden, and severe if >41. Logistic regression was used to look for associated factors to FSI and caregivers burden ( $p < 0.05$ ).

**Results:** In 184 patients, the mean age 47.29 (13.75) years. FSI was moderate in 60.33% (111/184) and severe in 8.69% (16/184). Caregiver burden was light to moderate in 48.91% (90/184), severe in 38.59% (71/184). Factors associated with FSI were: older patients, low patient and caregiver income, diabetes, longer duration on dialysis and being accompanied by his child. Factors associated with caregiver burden were: male gender, patient's age  $\geq 70$  years, low patient's income, inability to do shopping and laundry, age of caregiver  $\geq 50$  years, and caregiver being a student. Patient functional dependence increased the caregiver's burden by 3.87 times ( $p=0.001$ ).

**Conclusion:** FSI and caregiver's burden were relatively high with many associated factors. The caregiver burden increased with the degree of patient dependence.

**Keywords:** Functional status; Hemodialysis; Burden; Caregivers; Douala

## Introduction

Chronic kidney disease (CKD) is a major public health problem and progresses to kidney failure (KF) [1,2]. Patients with KF require kidney replacement therapy (KRT) of which maintenance hemodialysis (MHD) is the main modality used in the world [3]. Hemodialysis (HD) reduces significantly the death of patients with KF but results in significant lifestyle changes [4]: reduces the patient's energy level; affects their ability to work and perform everyday activities with the frequent need to be hospitalized; disrupts the normal lives of patients and their caregivers [5]. This is due to a decrease in the patient's functional status (ability of the patient to perform essential activities for independent living) [6-9]. Also, carrying for a patient on MHD is stressful and can affect the physical and psychological well-being of the caregiver [10]. Caregivers are the people most involved in the care of patients in helping them adapt and manage their disease [4,11-14]. Therefore, it appeared that both, the patient and caregiver are affected by the effects of a disease's treatment.

Goto NA, et al. in the Netherlands found a 40% decline in the functional status of patients on MHD, six months after the initiation of dialysis, while caregiver burden increased from 23% to 38% [9]. Kavanagh NT, et al. in the United States found that stroke, systolic blood pressure and cognitive impairment were associated with an increased prevalence of functional status impairment (FSI) in patients on MHD [15]. In Iran, studies have found that 72.5 to 86% of caregivers experienced moderate to severe burden [6,11,16]. A significant relationship was observed between male gender and low income with a high caregiver burden score [11].

In sub-Saharan Africa, access to dialysis is limited by the lack of infrastructure and the high out of pocket cost [17]. Adejumo OA, et al. in Nigeria found that 49.1% of caregivers of patients on MHD had mild to moderate burden and 33.3% had high burden [13]. In Cameroon, HD is the main modality and the country has 11 public dialysis centres [18-20]. Data on the burden to caregivers of patients on MHD are rare in a setting where the one-year outcome of patients is influenced by comorbidities at dialysis initiation [21]. We were

interested in assessing the functional status of patients on MHD and the burden to their caregivers in a dialysis unit located at Douala, the socioeconomic capital of the country.

## Methods

### Study setting

This was a cross-sectional study from February to May 2021 (3 months), carried out at the nephrology-HD unit of the Douala General Hospital (DGH), one of the main tertiary referral hospitals in Cameroon. The DGH haemodialysis unit is the unique public center founded by the government in the littoral region of the country and it serves the needs of the majority of patients with KF. An average of 220 chronic patients is registered. This study was approved by the Ethics Committee of the Faculty of Medicine of the Douala University Cameroon number 2534 CEI-UDo/06/2021/T and participants provided a written consent.

### Study participants and data collection

All consenting adult patients 18 years or more who had been on HD for at least 3 months and their caregivers were included in the study. Socio-demographic data of participants were recorded (sex, age, occupation, marital status, educational level, monthly income and the caregiver's relationship with the patient). Clinical data on the patients that was collected were: comorbidities (hypertension, diabetes mellitus, history of stroke, HIV, viral hepatitis (B and C), baseline nephropathy and dialysis parameters (dry weight, height, body mass index and blood pressure).

For each patient, functional status was assessed by the Global Functional Status Scale combining the 5 activities of daily living (ADL) with each scored from 0 to 1 for a total of 13 points [9]. Functional status impairment was considered as moderate for a score between 1 to 5/13 and severe for a score >5/13 [9]. Caregiver (people most involved in the care of patients and helping them adapt and manage their disease) burden was assessed by the Zarit scale consisting of 22 questions with each scored from 0 to 4 for a total of 88 points [22]. A score between 0 and 20 points corresponded to little or no burden, a score between 21 and 40 corresponded to a mild to moderate burden and a score of above >40 was considered as severe [22].

### Data analysis

Statistical analyses were performed using SPSS statistical software v.25 for Windows. Categorical variables were reported as frequency and percentages in which comparisons were performed using Chi-square test or Fisher's exact test when appropriated. Continuous variables were summarized using means (with standard deviations), and medians where necessary. Independent variables associated with functional status impairment and high caregiver burden were analysed by multiple logistic regression. A p-value less than 0.05 were considered statistically significant.

## Results

### General characteristics of study population

A total of 184 patients were included, with males accounting for 65.22 % (120/184), and the mean age (SD) was 47.29 (13.75) years. The median (IQR) duration on HD was 28 months (range 3-242); the main causes of KF were hypertension 36.41 % (67/184), undetermined 22.28% (41/184) and chronic glomerulonephritis 16.30 % (30/184). A total of 38.59% (71/184) had a monthly income less than 35,000 FCFA (Table 1).

We included 184 caregivers with 74.46% (137/184) being female. Their mean age (SD) was 43.84 (13.75) years. The caregiver-patient relationship was; spouses 47.28% (87/184), child 17.93% (33/184), sibling 17.93% (33/184), or parent 13.59% (25/184) (Table 1).

### Functional status of patients

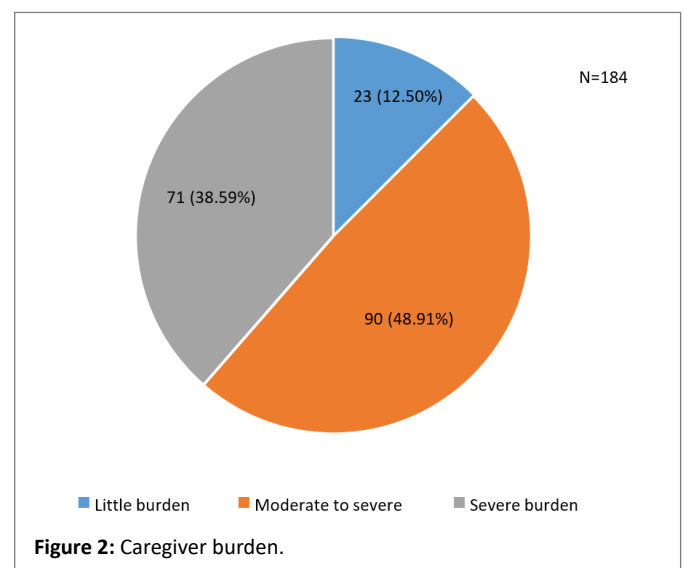
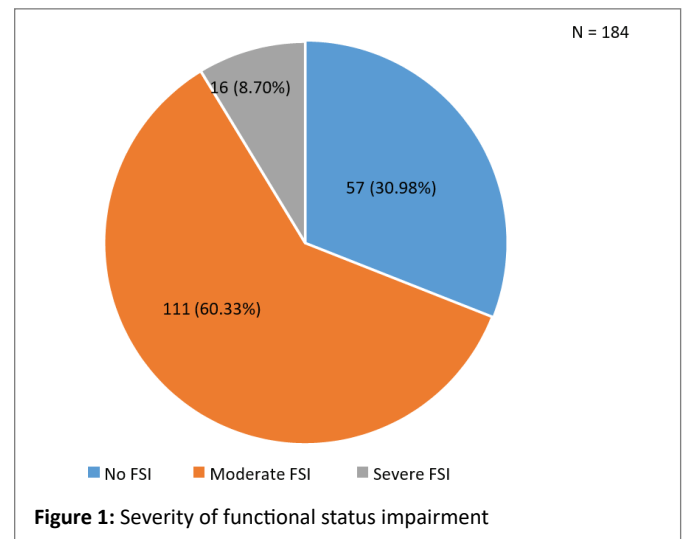
The median functional status of patients was 1 (Range 0 to 11). A total of 69.02% (127/184) had FSI with 60.33% (111/184) of them were classified as moderate impairment and 8.69% (16/184) as severe impairment (Figure 1).

### Caregiver burden

The average caregiver burden scale was 36.85 (14.36) points. In total of 48.91% (90/184) of caregivers had mild to moderate burden and 38.59% (71/184) of caregivers had severe burden (Figure 2).

### Factors associated with FSI

In multivariate analysis, factors associated with FSI were: age  $\geq$  50 years, patient and caregiver monthly income <35.000 XAF (53.5 euro, 60.52 USD), presence of diabetes, dialysis duration  $\geq$  15 years and a child as the caregiver (Table 2).



**Table 1:** General characteristics of patients on MHD and their caregivers (N=184).

Variables	Numbers (n=184)	Percentages (%)
Male	120	65.22
<b>Mean age (SD)</b>	47.29 ( 13.75)	
Unemployed	69	37.50
<b>Monthly income in XAF</b>		
<35000	71	38.59
<b>Etiology of KF</b>		
Hypertension	67	36,41
Unknown	41	22,28
Chronic glomerulonephritis	30	16,30
Diabetes mellitus	23	12,50
CIN	14	7,60
Others (Systemic lupus, ADPKD, HIVAN)	9	4.89
Median dialysis vintage IIQ; in months	28(14-64)	
<b>Socio-demographic characteristics of caregivers</b>		
Female	137	74.46
<b>Mean age (SD)</b>	43.84(13.75)	
<b>Monthly income in XAF</b>		
<35000	59	32.07
<b>Caregiver-patient relationship</b>		
Spouse	87	47.28
Child	33	17.93
Parent	25	13.59
Sibling	33	17.93
Others family relatives	6	3.26

SD: Standard Deviation; ESKD: End-Stage Kidney Disease; CIN: Chronic interstitial nephritis; ADPKD: Autosomal dominant polycystic kidney disease; HIVAN: HIV associated nephropathy; HD: Haemodialysis; Fcfa: Franc cfa; KF: Kidney failure; XAF: code for the central Africa; CFA: African financial community.

### Factors associated with caregiver burden and the relationship between FSI and caregiver burden on multivariate analysis

Factors associated with caregiver burden and the relationship between FSI and caregiver burden were: male patient, patient's age  $\geq$  70 years, patient's monthly income <35000, inability to do shopping and laundry, caregiver's age  $\geq$  50 years, and the caregiver being a student (Table 3). There was a relationship between patient's FSI and caregiver burden (p-value <0.001), in fact the patient's FSI increased the risk to caregivers to develop a burden by 3.87 times (Table 4).

### Discussion

The aim of this study was to evaluate the FSI of patients on MHD and the burden to their caregivers at the DGH. The prevalence of FSI in this study was 69.02 % (127/184) and the caregiver burden was 87.5 % (161/184). Age, diabetes, dialysis vintage, monthly outcome and the relationship with caregiver were factors affecting either FSI or caregivers burden.

FSI is highly prevalent in the dialysis population, with a range of 32 to 95% [8,9,15,23-28]. Our prevalence of 69% was similar to the reported findings of Tamura MK, et al. in the United States, Jassal SV, et al. in Europe and Gutiérrez-Peredo GB, et al. in Brazil [8,24,28]. This high

**Table 2:** Factors associated with functional status impairment on multivariate analysis.

Variables	ORa (CI 95%)	p-value
<b>Patients related factors</b>		
Male patient	2.82 (0.78-14.30)	0.014
Age between [40-50]	11.23 (0.67-55.28)	0.367
Patient's age $\geq$ 50 years	18.94 (5.18-69.17)	<0.001
<b>Monthly income in XAF</b>		
<35000	80.17 (6.89-231.70)	<0.001
[35,000-100,000]	45.86 (0.78-347.90)	0.137
[100,000- 200,000]	7.50 (0.71-79.44)	0.051
Diabetes	4.09 (1.78-9.39)	<0.001
Chronic Glomerulonephritis	0.69 (0.16-2.88)	0.318
Dialysis vintage ( $\geq$ 15) years	4.51 (1.65-12.35)	0.001
<b>Caregivers related factors</b>		
Male caregiver	2.08 (0.17-14.92)	0.296
<b>Monthly income in XAF</b>		
<35000	10.83 (3.23-36.28)	<0.001
[35,000-100,000]	6.93 (0.49-24.92)	0.391
[100,000- 200,000]	9.21 (0.32-21.96)	0.344
Child of the patient as caregiver	8.64 (3.35-22.28)	<0.001

ORa: odds ratio adjusted; CI=Confidence interval; XAF: code for the central Africa; CFA: African financial community.

prevalence could be explained by the chronic nature of KF, multiple comorbidities, physical inactivity, anaemia, persistent uraemia, and the repeated need for hospitalization [25]. Our prevalence is lower than the 95% of Cook et al. in Canada [28] probably due to the aging Canadian population (75 vs 47.29 years). Our results were high from those of Akash N, et al. in Jordan and Ifudu O, et al. in the United States, who found a prevalence of 32% and 38.8%, respectively [23,25]. This difference could be explained by the fact that compared to our study population their patients had a longer duration on dialysis and also had 3 dialysis sessions per week, which is known to improve the quality of life in patients.

The prevalence of caregiver burden was 87.5%, which is close to the results of Adejumo OA, et al. in Nigeria who reported a prevalence of 82.7% [13]. This prevalence could be explained by the combination of physical labour, emotional pressure, social restrictions and economic demands by the caregivers. Our prevalence was however higher than the 23% found by Goto NA, et al in the caregivers of patients initiating dialysis in the Netherlands [9]. The difference in care organization with the use of social workers in developed countries did not compare to our setting where the care depends more on family members [9].

Factors associated with FSI were: patient's age  $\geq$  50 years, patient and caregiver monthly income <35000, presence of diabetes, longer duration on dialysis  $\geq$  15 years and being accompanied by a child. Older age and diabetes were also reported by Carlson DM, et al. Ifudu O, et al. in the United States and Nabil et al. in Jordan [23,25,26]. The dialysis population is increasingly aging and has an increased risk of physical deterioration that affects their mobility and ability to care for themselves [25]. Diabetes is responsible of many micro and macrovascular complications that can lead to an alteration of the functional status of affected patients [29]. Monthly incomes <35000 of patients and their caregivers were also associated to FSI. This could be explained by the fact that in our context, despite the state subsidy for dialysis sessions, the out of pocket payment for dialysis care in

**Table 3:** Factors associated with caregiver burden on multivariate analysis.

Variables	ORa (CI 95%)	p-value
Male patient	2.11 (1.13-6.23)	<0.001
Patient's age ≥ 70 years	6.12 (2.24-19.60)	<0.001
Patient's monthly income <35000 XAF	6.24 (2.29-43.80)	0.001
Patient's monthly income [35,000-100,000 XAF]	9.50 (0.68-132.00)	0.001
Inability to do shopping	2.45 (1.39-15.25)	0.065
Inability to cook	2.50 (0.47-17.33)	0.001
Inability to do laundry	5.13 (1.06-23.40)	0.001
Male caregiver	0.56 (0.09-2.89)	0.028
Caregiver's age between [40-50]	1.46 (0.43-5.03)	0.238
Caregiver's age ≥ 50 years	4.88 (1.75-13.61)	0.276
Caregiver being a student	6.72 (1.97-22.93)	0.001
Caregiver's monthly income <35000 XAF	5.11 (0.80-31.00)	0.051
Child of the patient	3.46 (0.89-13.40)	0.038

ORa: odds ratio adjusted; CI=Confidence interval; XAF: code for the central Africa; CFA: African financial community.

**Table 4:** Relation between functional status and caregiver burden.

	Yes	No	OR (CI 95%)	p-value
Caregiver burden	17 (73.91)	110 (68.32)	3.87(1.86-16.19)	<0.001
Functional status impairment	6 (26.09)	51 (31.68)		

OR: odds ratio; CI=Confidence interval.

Cameroon is very high and commonly out of reach for most patients [30], increasing the burden on patients and family.

Factors associated with caregiver burden were: male patient, patient's age ≥ 70 years, patient's monthly income <35000, inability to do shopping and laundry, caregiver's age ≥ 50 years, and the caregiver being a student. Caregiver's age ≥ 50 years and male gender was also reported by Zhang et al. in China [31]. Middle-aged caregivers and men are generally more concerned about missed work days, work interruptions, and decreased productivity due to care giving. Low monthly income was also associated with caregiver burden in this study and implies that the high cost of care is difficult to access [31]. Mashayekhi F, et al. in Iran and Zhang R, et al. in China also reported similar results [11,31].

Caregivers of patients who require greater assistance with daily living experience greater a greater burden [32]. In our study, we found that functional dependence increases the caregiver burden by 3.87 times. Providing long-term daily care to patients on MHD leads to physical and psychological exhaustion which increases with the level of dependency of these patients [32]. Caregivers feel less responsible and burdened if monthly income is high and if patients are independent in their daily activities and complain less about their dialysis treatment.

## Conclusion

In this study two out of three patients had a FSI and seven out of eight caregivers had a burden. A patient with FSI increased the odds of the caregiver's burden. It is therefore necessary to identified patient with FSI systemically and to provide psychosocial support to their caregivers with the aim to reduce the burden associated with the disease.

## Competing Interests

The authors declare that they have no competing interests.

## Author's Contribution

HMP, TL, KFF: Study conception and design; TL, EC, MJ: data collection and supervision; TL, MJ, NV, MM, FH: data analysis and interpretation; HMP, TL: drafting of the manuscript; MJ, NV, MM, FH, KKF: critical revision of the manuscript. Authors read and approved the final manuscript.

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