Burden of disease and quality of life of first degree relatives and other caregivers of patients with chronic kidney disease

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Abstract

Background: Chronic kidney disease (CKD) poses enormous burdens to the individual affected. Caregivers are usually not considered to share in this disease burden (DB). The study aimed to assess the burden of disease in relatives and non-relative caregivers of patients with CKD.
Methods: Analytical descriptive study of caregivers of patients with CKD. The research instruments used were in four parts, the sociodemographic data and 3 DB instruments that include World Health Organization Quality of Life Questionnaire in Brief (WHOQOL–BREF), Caregivers Guilt Questionnaire (CGQ) and Zarit Burden Interview (ZBI)
Results: Of the 305 caregivers enrolled, 258(84.6%) and 47(15.54%) were relatives and non-relatives, respectively, while 225 (73.8%) caregivers were less than 45 years in age. The mean scores of DB were 90.1±12.7, 21.5± 6.1 and 24.5 ± 13.6 for WHOQOL-BREF, CQG and ZBI, respectively. Increased burden of CKD on caregivers were reported in 47.5%, 59.0% and 62.3% for WHOQOL-BREF, CQG and ZBI, respectively. Durations of dialysis (OR:1.50),) and caregiver (OR:2.36) were factors independently associated with increased DB.
Conclusion: Majority of the caregivers were young relatives of patients with CKD and reported high burden of disease. Durations of dialysis and caregiving associated with high DB.

Fardeau de la maladie et qualité de vie des parents au premier degré et autres soignants de patients atteints d'insuffisance rénale chronique

Titre du fonctionnement courant : Le fardeau des soignants de patients atteints d'insuffisance rénale chronique

Résumé

Contexte de l'étude : L'insuffisance rénale chronique (IRC) représente un fardeau énorme pour la personne concernée. Les soignants ne sont généralement pas considérés comme partageant ce fardeau de la maladie (FM). L'étude visait à évaluer le fardeau de la maladie chez les proches et les soignants non apparentés de patients atteints d'IRC.
Méthode de l'étude : Étude descriptive analytique des soignants de patients atteints d'IRC. Les instruments de recherche utilisés étaient divisés en quatre parties : les données sociodémographiques et 3 instruments DB, dont le questionnaire sur la qualité de vie de l'Organisation mondiale de la santé (WHOQOL-BREF), le questionnaire sur la culpabilité des soignants (CGQ) et l'entretien sur le fardeau de Zarit (ZBI).
Résultats de l'étude : Sur les 305 soignants inclus, 258 (84,6 %) et 47 (15,54 %) étaient respectivement des parents et des non-parents, tandis que 225 (73,8 %) soignants avaient moins de 45 ans. Les scores moyens de DB étaient de 90,1 ± 12,7, 21,5 ± 6,1 et 24,5 ± 13,6 pour les scores WHOQOL-BREF, CQG et ZBI, respectivement. Une augmentation du fardeau de l'IRC sur les soignants a été signalée chez 47,5 %, 59,0 % et 62,3 % pour les scores WHOQOL-BREF, CQG et ZBI, respectivement. Durées de dialyse (OR : 1,50) et de soins (OR : 2,36)
Conclusion : La majorité des soignants étaient de jeunes parents de patients atteints d'IRC et ont signalé une charge de morbidité élevée. Les durées de dialyse et de soins étaient associées à une DB élevée.

Mots-clés : Fardeau de la maladie, aidants, maladie rénale chronique, maladie rénale terminale, parents au premier degré

INTRODUCTION

Chronic kidney disease (CKD) is a disease of public health importance that poses enormous burdens to the individual affected and the economy of most nations of the world (1).

The prevalence of CKD varies in different parts of the world. The global prevalence is estimated to be between 11 - 13% and it is on the rise (2). In 2017 the Global Burden of Disease (GBD) study reported that CKD was responsible for 1.2 million deaths, 35.8 million disability-adjusted life-years (DALYs) and 25.3 million years of life lost due to cardiovascular diseases (CVD) (3,4).

CKD is associated with a tremendous economic burden. Most high-income countries tend to spend more than 3% of their annual healthcare budget on the treatment of end stage kidney disease (ESKD) (5). In 2010, 2.62 million people received dialysis worldwide and the need for dialysis was projected to double by 2030 (6). In 2015, in the United States of America the Medicare expenditures on CKD and ESKD were more than $64 billion and $34 billion (7).

In Nigeria, CKD accounts for 8-10% of all medical admissions in most of the tertiary healthcare centres (8,9). Although there is no nationwide data, recent epidemiological studies from the different regions of the country estimated the prevalence of CKD in the community to be between 18 - 27% (10-12).

The disease burdens in patients with CKD is beyond the huge cost of care for the affected but also include its total effects on psychological, economical, functional ability, lifestyle changes, and independent status (13). These burden domains are usually taken into consideration in the overall management of the patients with CKD (14,15).

In most clinical practice, a lot of attention is often given to the affected individuals, whereas the caregivers are usually not considered to share in the burden of CKD (16,17). The informal caregivers consist of relatives and non-relatives. This group of caregivers are different from the formal caregivers encountered in the healthcare facilities. Patients with advanced CKD require assistance of informal caregivers in administration of medications, diets, transportation to and from the hospital, psychological and financial supports, these services are often rendered free by the family and friends. These responsibilities of care increase the burdens on the informal caregivers. Few studies from West Africa suggest increasing burden of disease among the caregivers (18,19), although the coping mechanisms employed by these caregivers have only been superficially examined, these studies employed only one quality of life instrument and fewer domains in most cases.

The members of the family as caregivers do not only have increased risk of CKD due to shared environmental and genetic factors but also shared in the economic, lifestyle and psychological burden of CKD in the affected individuals. It has been shown that the wellbeing of caregivers may have direct influence on care received by the patients (20-22). Assessing the burden of CKD on the informal caregivers will inform strategies and policy for attending to the health needs of this group of individuals. The objective of the study was to examine the burden of disease in first degree relatives (FDRs) and non-relative caregivers of patients with CKD.

MATERIALS AND METHODS

Study Design

This is a cross-sectional analytical descriptive study of informal caregivers of patients with CKD and consisted of the FDRs of patients with CKD and other caregivers. Informal caregivers were defined as individuals who provide some type of unpaid, ongoing assistance with activities of daily living (ADL), e.g., toileting, feeding, bathing, walking, clothing; or instrumental activities of daily living (IADL), e.g., shopping, meal preparation, house cleaning, and managing finances, for individuals with a chronic illness or disability (23). The participants were caregivers of patients with CKD and ESKD who were attending the Renal Clinic of the Medical Outpatient Department and Dialysis Centre of the University College Hospital, Ibadan, Nigeria. The study was carried out between 16th May 2019 and 29th February 2020. To be included in the study, the individual must have been a caregiver of patient with CKD for at least 3 months, aged 18 years and above. Those with history of mental illness and caregivers of patients with other chronic illnesses were excluded from the studies.

Instruments

The research instruments were in four parts and it include the sociodemographic data and 3 disease burden instruments. The 3 disease burden questionnaires include World Health Organization Quality of Life Questionnaire in Brief (WHOQOL–BREF), Caregivers Questionnaire (CGQ) and Zarit Burden Interview (ZBI) questionnaires (24-26).

World Health Organization Quality of Life Questionnaire in Brief (WHOQOL–BREF)

WHOQOL-BREF was used for the QOL in this study (24). The WHOQOL-BREF is a 24-item version of the WHOQOL-100 assessment. The WHOQOL-BREF questionnaire contains 24 items of satisfaction that is divided into four domains: Physical health with 7 items (DOM1), psychological health with 6 items (DOM2), social relationships with 3 items (DOM3) and environmental health with 8 items (DOM4). Each of the items on the WHOQOL-BREF is rated on a 5-point Likert scale. Raw domain scores obtained were transformed to a 4-20 score in accordance with the guidelines (24). The domain scores were scaled in a positive direction (i.e., higher scores denote higher QOL) and the mean score of items within each domain was used to calculate the final score for each domain. The computed scores were subsequently transformed linearly to a 0-100-scale (27,28). High disease burden using WHOQOL-BREF was defined as score above 90 based on the mean score of 90.1±12.7 among the participating caregivers.

Caregivers Guilt Questionnaire (CGQ)

The Caregivers Guilt Questionnaire (CGQ) is a 22-item self-report measure (25,29). Participants rate how frequently they have experienced specified thoughts or feelings of guilt over the past two weeks. Response options range from 0 (“never”) to 4 (“nearly always”). The instrument has been shown to have good internal consistency in different populations (Cronbach's $\alpha = 0.88$). The cut-off of 22 was used for this study based on finding by Roach et al (23) that the cut-off score of 22 on the CGQ showed the optimal balance between sensitivity (80%) and specificity (61.5%), with a positive predictive value (PPV) of 70.2%.

The Zarit Burden Interview (ZBI)

The Zarit Burden Interview (ZBI) consists of 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores ranging between 0–88. Higher scores indicate greater burden. A score of 17 or more was considered high burden (26,30). The ZBI's psychometric proprieties have been extensively examined in caregivers of patients with dementia, cancer and brain injury and demonstrate strong evidence for reliability and validity in those population (30-33). The reported Cronbach's alpha for the ZBI in caregivers of patients with cancer and dementia ranged between 0.85 and 0.93 (34-37). Evidence for criterion validity of the ZBI has been demonstrated in caregivers of patients with dementia in whom the ZBI was highly correlated with the Burden Assessment Scale (38). A ZBI cut-off of 24 was used based on report that it correctly identified 72% of caregivers with probable depression (38). A score of 0–20 indicated little or no burden; 21–40 means a mild to moderate burden; 41–60 moderate to severe burden; while 61–88 means a severe burden.

Data Collection

Data was obtained through researcher-administered questionnaire on all the participating caregivers who gave informed and satisfied the inclusion criteria. The administration of research instrument lasted average of 90 minutes per participant. The information obtained were socio-demographic details that include age, gender, occupation, income, relationship to the patient and duration of taking care of the patient. The 3 instruments of disease burden described above were also administered.

Ethical approval

Ethical approval was obtained from the University of Ibadan and University College Hospital, Ibadan Joint Institutional Review Board (IRB) with the approval number: UI/EC/19/0111. All participants (caregivers) gave written informed consent.

Data analysis

The data were analyzed using the IBM SPSS Statistics version 22 (IBM Corporation, Armonk, NY, USA). Continuous variables were represented as mean (standard deviation) while categorical variables were summarized as percentages. The prevalence of burden of disease among the FDRs and non-relative caregivers were determined using WHOQOL -BREF, CGQ and ZBI scores. In addition, multiple logistic regression was carried out to identify factors associated with caregiver burden in all the psychometric domains. We also carried out correlation statistics of various disease burden scores with other variables, such as age, income, duration of caring for patients. A 2-tailed p value < 0.05 was considered statistically significant in all situations.

RESULTS

A total of 305 caregivers were enrolled in the study, the mean age was 39.8 ±9.6 years while 173 (56.7%) were females. Two hundred and fifty-eight (84.6%) participants were relatives of patient with CKD while 47 (15.4%) were non-relatives. The relatives were mostly FDRs (68.6%) and spousal relatives 52 (17.1%), (Table1). Most caregivers were married 203 (66.6%) and employed 204 (66.9%) and were mostly traders (29.2%) or civil servants (31.8%). Two-third (65.9%) of the participants were caring for patients who were on maintenance haemodialysis and 80 (26.2%) had been taken care of patients with CKD for 6 months or more (Table 1).

The mean disease burden scores for the 305 caregivers for CGQ, WHOQOL-BREF and ZBI were 21.5±6.1, 90.1±12.7 and 24.5±13.6, respectively. The mean CGQ scores for FDR and non- relatives were 21.7±5.9 and 21.3±6.1, respectively ($p<0.56$)., The mean WHOQOL-BREF scores for FDR and non-relatives were 90.7±13.7 and 89.1±11.0 respectively ($p<0.29$) while the mean ZBI scores for FDRs and non-relatives were 24.9±14. and 23.7±12.6, respectively ($p<0.45$), (Table 2). The burden disease using CGQ, WHOQOL-BREF and ZBI were observed in 180 (59.0%), 160 (52.5%) and 190 (62.3%) caregivers, respectively (Table 2). There were no significant differences in the prevalence of burden of disease between FDR and non-relatives using all the 3 disease burden instruments: CGQ (59.1%) and 58.8%, $p < 0.96$), WHOQOL-BREF (54.8% and 48.7%, $p < 0.30$) and ZBI (62.4% and 62.2%, $p < 0.97$), (Table 2). Physical health [mean (SD): 27.2 (5.4)] and psychological health [mean (SD): 25.1(4.7)] were the two top leading domains that contributed to the mean WHOQOL-BREF score (Table 3). There were no significant differences in the mean scores across the WHOQOL-BREF domains between FDRs and non- relative caregivers; physical health [27.4±5.4 versus 26.9±5.1, $p < 0.12$], psychological health [26.3±6.3 versus 24.5±5.9, $p < 0.09$], social relationship [18.1±3.7 versus 18.5±4.1, $p < 0.51$] and environmental health [20.1±5.3 versus 19.0±5.1, $p < 0.23$], (table 3).

The factors associated with high CGQ score were being a caregiver taking care of patients on maintenance dialysis (Odd Ratio (OR) 0.51: 95% Confidence Interval (CI) 0.3125 - 0.8183, $p < 0.01$), duration of caregiving ≥ 6months (OR 0.45, 95% CI 0.2575 – 0.7838, $p < 0.01$), high WHOQOL-BREF (OR 0.58, 95% CI 0.3417 – 0.9830, $p < 0.04$) and ZBI scores (OR 2.36, 95% CI 1.4665 - 3.7922, $p < 0.0$), (Table 4). Being a caregiver taking care of CKD patients on maintenance dialysis was the only factor independently associated with high CGQ score (OR 1.50, 95% CI 1.5847 – 4.8183, $p < 0.01$).

On univariate analysis, the factors associated with high WHOQOL-BREF score were being a caregiver taking care of patients on maintenance dialysis (OR 3.52: 95% CI 1.5486 - 4.1033, $p < 0.01$ 0.3125 - 0.8183, $p < 0.01$), duration of caregiving ≥6months (OR 0.19, 95% CI 0.1013 – 0.3418, $p < 0.01$). high WHOQOL-BREF (OR 0.58, 95% CI 0.3417 – 0.9830, $p < 0.04$) and ZBI scores (OR 2.36, 95% CI 1.4665 - 3.7922, $p < 0.0$), (Table 5). Being caregiver taking care of CKD patients on maintenance dialysis was independently associated with high WHOQOL-BREF score (OR 1.50, 95% CI 1.5847 – 4.8183, $p < 0.01$).

On univariate analysis, the factors associated with high ZBI score were being a caregiver taking care of patients on maintenance dialysis (OR 2.99: 95% CI 1.8278 – 4.8914, $p<0.01$), duration of caregiving ≥6months (OR 0.52, 95% CI 0.3125 – 0.9121, $p<0.02$), high CGQ (OR 2.36, 95% CI 1.4665 - 3.7922, $p<0.01$ and high WHOQOL-BREF (OR 0.58, 95% CI 0.3417 – 0.9830, $p<0.04$ (Table 6). Being a caregiver taking care of CKD patients on maintenance dialysis (OR 0.58, 95% CI 0.3567 – 0.5934, $p<0.03$ was independently associated with high ZBI score.

DISCUSSION

The current study demonstrated high disease burden among caregivers of patients with CKD using 3 different instrument that assessed several domains. The prevalence of burden of disease among the caregivers of patients with CKD using CGQ, WHOQOL-BREF and ZBI were 59.0%, 52.5% and 62.3% respectively. The domains commonly affected were the physical and psychological health. The findings in this study are similar to report from other researchers. Adejumo et al [18] using ZBI reported that 49.1% and 33.3% of the caregivers of patients on maintenance haemodialysis had mild- moderate and high disease burden respectively. Mashayekhi et al (39) reported 72.5% of caregivers of patient with ESKD on maintenance haemodialysis reported moderate severe levels of caregiver disease burden. Mashayekhi et al (39) employed the use of Caregiver Questionnaire developed by Elmstahl et al (40). Similarly, Shah et al (41) reported that 65% and 13% caregivers of patients on dialysis were having mild-moderate and moderate- severe burden of disease respectively, using ZBI as the instrument of assessment similar to the index study.

Caregivers of patients with CKD particularly those on maintenance dialysis shared in the disease burden of their patients and the effects of the disease burden include physiological, functional ability, lifestyle changes, and independence status. This is because of the prolonged duration of care required by patient with chronic illness like CKD and ESKD. The wellbeing of caregivers is directly related to the health and health outcomes of patients with chronic illnesses. However, there are no structured programmes and policies in most of the low and medium income countries (LMICs) for caregivers of patients with chronic illness, particularly those who care for patients with ESKD. In the index study, the physical and psychological health were the disease burden domains that were mostly affected and this finding is similar to that reported by Mashayekhi et al (39) who observed that the general strain, isolation, emotional involvement, disappointment, and environmental were domains that contributed to the increased disease burden (72.5%) observed in their cohort.

Majority of the caregivers were females which is in tandem with reports from similar studies from other LMICs (42,43). The socio-cultural practices and acceptance in LMICs may explain why majority of the caregivers were females. In addition, female gender tends to show more affection and empathy towards a sick relative compared to the male gender. Studies have also reported that females tend to develop appropriate coping strategies that allow them to be willing and effective caregivers in most instances (43). Furthermore, 57.8% of the patients with CKD who agreed to their caregivers taking part in the study were males, which may suggest that most of the caregivers would be either wives or daughters.

Examining the distribution of caregivers in this study, more than 80% were either FDRs (68.6%) or spousal relatives (17.1%), this finding supports the hypothesis that relatives do not only share in the risk of chronic diseases but also shared in the burden of disease in affected relatives. The shared burdens observed in this study include economic, lifestyle, social and psychological burden of disease. In this study, 71.8% of participants contributed financially to the care of their sick relatives. This was in addition to other responsibilities that include transportation of the affected patients to and from the hospital, prepare meals, medication administration, and psychological supports among other caregiving responsibilities. The caregivers 'multiple roles and commitments to the patient may put strain on the health and wellbeing of the caregivers. Hence, sub-optimal u caregiver health and reduced income by caregivers may affect patient's outcomes and prompt family members relinquishing the caregiving role, despite their willingness to help the affected family member. Thus, understanding the need to provide structured and effective healthcare for caregivers becomes increasingly important to healthcare providers and health policy makers.

Using the three different instruments (CGQ, WHOQL-BREF and ZBI), we examined caregiver attributes that may be associated with high burden of disease and these include caregivers' age, gender, education, family relationship, employment status, dialysis status of the patient and duration of caregiving. Only being a caregiver to patients on maintenance haemodialysis and being in caregiving role for at least 6 months were factors independently associated with high burden of disease among the caregivers. The burden on caregivers of patients on maintenance haemodialysis were higher, as patients on maintenance haemodialysis need to be in the hospital for at least thrice a week for dialysis and anaemia treatment. The financial implication of each session of dialysis also contributes significantly to the excess burden of disease observed among the caregivers of patients on maintenance haemodialysis. Furthermore, it has been previously demonstrated that the longer the duration of caregiving role, the more likely it is for the caregivers to experience burnt out (44). Several factors have been associated with increased burden in caregivers and they include the age of the caregiver, length of caregiving time, type of caregiving tasks, family stressors, and extent of disability by the care recipient (45,46). Our study finds no association between high burden of disease with age of the caregivers and relationship with the person affected with CKD/ESKD. This might be because most of the caregivers in our study were young individuals with their ages being less than 45years, and also the fewer numbers of non-relatives as caregivers may explain the lack of association between high burden of disease and relationship of the caregivers to the affected persons. The findings of this study bring to bear the need for appropriate policies and strategies to support the caregivers of patients with CKD/ESRD, with the aim of preventing, and alleviating the burden of care through psychological, medical, social, and financial supports.

This study is not without limitations which include participation of fewer spousal relatives in the study and the non-inclusion of the general population as controls. This makes it impossible to ascertain if the high burden of disease observed in the study will be similar or different in the general population. However, the study included a large cohort of FDRs of patients with CKD, and caregivers of both dialysing and non-dialysing patients with CKD, in addition to employing three different quality of life instruments to assess the burden of disease in the caregivers.

CONCLUSION

Majority of the caregivers in this study were young people, first degree relatives of patients with CKD/ESRD and reported high burden of disease with all the three instruments of quality of life. The duration of caregiving and dialysis status were factors independently associated with high disease burden in caregivers of patient with CKD/ESRD.

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Authors' contributions: YRR conceptualized the study idea, participated in the design, acquisition and analysis of data, interpretation of data and drafting and revising the manuscript. SOA and OU participated in acquisition and interpretation and revising the manuscript. BLS participated in data interpretation and revising the manuscript. All authors read and gave the final approval of the version to be published.

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Table 1: Demographic characteristics of the caregivers

Variables	FDR as Caregivers n = 186	Other Caregivers n = 119	Total Caregivers n = 305	P - Value
Mean Age (Years)	38.6± 11.6	41.4± 10.4	39.8 ±9.6 and	0.07
Age > 45 years	55 (29.6%)	25 (21.0%)	80 (26.2%)	0.10
Gender				
Female	101 (54.3%)	72 (60.5%)	173 (56.7%)	0.29
Male	85 (45.7%)	47 (39.5%)	132 (43.3%)	
Marital Status				
Married	98 (54.3%)	105 (88.2%)	203 (66.6%)	0.01
Single	84 (45.2%)	13 (10.9%	97 (31.8%)	
Widowed	4 (1.5%)	1 (0.9%)	5 (1.6%)	
Employment				
Employed	110 (59.2%)	94 (79.0%)	204 (66.9%)	0.01
Unemployed	20 (10.8%)	12 (10.1%)	32 (10.5%)	
Student	48 (25,8%)	10 (8.4%)	58 (19.0%)	
Retired	8 (4.3%)	3 (2.5%)	11 (3.6%)	
Occupation				
Trading	42 (22.6%)	47 (39.5%)	89 (29.2%)	0.01
Civil Service	53 (28.5%)	44 (37.0%)	97 (31.8%)	
Others	91 (48.9%)	28 (23.5%)	119 (39.0%)	
Contribute financially to the care of the patient.				
Yes				
No	137 (73.7%)	82 (68.9%)	219 (71.8%)	0.37
	49 (26.3%)	37 (31.1%)	86 (28.2%)	
Enrolled on NHIS				
Yes	15 (8.1%)	4 (3.4%)	19 (6.2%)	0.98
No	171 (91.9%)	115 (96.6%)	286 (93.8%)	
Duration of caring for patients				
< 6months	131 (70.4%)	94 (79.0%)	225 (73.8%)	0.10
> 6months	55 (29.6%)	25 (21.0%)	80 (26.2%)	
Dialysis status of patients that is being cared for				
Non-dialysing	63 (33.9%)	41 (34.5%)	104 (34.1%)	0.92
Dialysing	123 (66.1%)	78 (65.5%)	201 (65.9%)	

FDRs – First Degree Relatives, NHIS – National Health Insurance Scheme

Table 2: Burdens of disease using three psychometric instruments

Variables	FDR as Caregivers n = 186	Other Caregivers n = 119	Total Caregivers n = 305	P - Val
Mean CGQ Score	21.7±5.9	21.3±6.1	21.5±6.1	0.56
Mean WHOQL-BREF Score	90.7±13.7	89.1±11.0	90.1±12.7	0.29
Mean ZBI Score	24.9±14.1	23.7±12.6	24.5±13.6	0.45
High burden of disease with CGQ Score	110 (59.1%)	70 (58.8%)	180 (59.0%)	0.96
High burden of disease with WHOQL-BREF Score	102 (54.8%)	58 (48.7%)	160 (52.5%)	0.30
High burden of disease with ZBI Score	116 (62.4%)	74 (62.2%)	190 (62.3%)	0.97

CGQ – Caregivers Guilt Questionnaire, FDR – First Degree Relatives, WHOQL-BREF – World Health Organiz Quality of Life in Brief, ZBI – Zarit Burden Interview

Table 3: The scores across the WHOQOL-BREF Domains

WHOQOL Domain	First Degree Relatives	Non-Relatives	Total	P - value
Physical health	27.4	26.9	27.2	0.12
Psychological health	26.3	24.5	25.1	0.09
Social relationship	18.1	18.5	18.2	0.51
Environmental health	20.1	19.0	19.5	0.23

WHOQL–BREF - World Health Organization Quality of Life Questionnaire in Brief

Table 4: Factors associated with high burden of disease using Caregivers Guilt Questionnaire Score.

Variables	Participants with high burden of disease using CGQ score n = 180	Participants with low burden of disease using CGQ score n = 125	Odd Ratio (95%Confidence Interval)	P - value
Age				
Age < 45years	125 (69.4%)	80 (64.0%)	0.78 (0.4822-1.2688)	0.32
Age = 45years	55 (30.6%)	45 (36.0%)		
Gender				
Female	104 (57.8%)	69 (55.8%)	0.90 (0.5683-1.4266)	0.63
Male	76 (42.2%)	56 (44.2%)		
Marital Status				
Married	117 (65.0%)	86 (68.8%)	0.82 (0.5176-1.3703)	0.54
Single	61 (33.9%)	36 (28.8%)		
Widowed	2 (1.1%)	3 (2.4%)		
Employment				
Employed	118 (65.6%)	81 (64.8%)	1.03 (0.6405 – 1.6688)	0.89
Unemployed	19 (10.6%)	16 (12.8%)		
Student	39 (21.7%)	22 (17.6%)		
Retired	4 (2.2%)	6 (4.8%)		
Register on NHIS				0.06
Yes	15 (8.3%)	4 (3.2%)	2.75 (0.8905-8.4929)	
No	165 (91.7%)	121 (96.8%)		
Dialysis status				
Dialysing	130 (72.2%)	71 (56.8%)	0.51 (0.3125 - 0.8183)	0.01
Non-dialysing	50 (27.8%)	54 (43.2%)		
Relatives				
FDR	110 (61.1%)	76 (60.8%)	1.01 (0.6347 - 1.6173)	0.97
Non- FDR	70 (38.9%)	49 (39.2%)		
Duration of caring for patients				
< 6months	122 (67.8%)	103 (82.4%)	0.45 (0.2575 – 0.7838)	0.01
= 6months	58 (32.2%)	22 (17.6%)		
WHOQOL-BREF				
High	122 (76.8%)	98 (78.4%)	0.58 (0.3417 – 0.9830	0.04
Low	58 (33.2%)	27 (21.6%)		
ZBI score				
High	127 (70.6%)	63 (50.4%)	2.36 (1.4665 - 3.7922)	0.01
Low	53 (29.4%)	62 (49.6%)		

CGQ – Caregivers Guilt Questionnaire, FDR – First Degree Relatives, NHIS – National Health Insurance Scheme, WHOQOL-BREF – World Health Organization Quality of Life Questionnaire in Brief, ZBI – Zarit Burden Interview.

Table 5: Factors associated with high burden of disease using World Health Organization Quality of Life Questionnaire in Brief Score (WHOQOL-BREF)

Variables	Participants with high burden of disease using WHOQOL-BREF score n = 160	Participants with low burden of disease using WHOQOL-BREF score n = 145	Odd Ratio (95%Confidence Interval)	P - value
Age				
Age < 45years	113 (70.6%)	92 (63.5%)	0.72 (0.4470 - 1.1663)	0.18
Age = 45years	47 (29.4%)	53 (36.5%)		
Gender				
Female	83 (51.9%)	90 (67.1%)	1.51 (0.9614 - 2.3972)	0.08
Male	77 (48.1%)	55 (32.9%)		
Marital Status				
Married	100 (65.0%)	103 (71.0%)	0.68 (0.4202 -1.0992)	0.54
Single	58 (33.9%)	39 (26.9%)		
Widowed	2 (1.1%)	3 (2.0%)		
Employment				
Employed	118 (65.6%)	81 (64.8%)	1.13 (0.7062 – 1.8107)	0.60
Unemployed	19 (10.6%)	16 (12.8%)		
Student	39 (21.7%)	22 (17.6%)		
Retired	4 (2.2%)	6 (4.8%)		
Register on NHIS				
Yes	10 (6.3%)	9 (6.2%)	1.0 (0.3975-2.5532)	0.98
No	150 (93.7%)	136 (93.8%)		
Dialysis status				
Dialysing	121 (76.6%)	80 (55.2%)	3.52 (1.5486 - 4.1033)	0.01
Non-dialysing	39 (24.4%)	65 (44.8%)		
Relatives				
FDR	102 (63.8%)	84 (57.1%)	1.28 (0.8053- 2.0252)	0.30
Non- FDR	58 (36.2%)	61 (32.9%)		
Duration of caring for patients				
< 6months	96 (60.0%)	129 (89.0%)	0.19 (0.1013 – 0.3418)	0.01
= 6months	64 (40.0%)	16 (11.0%)		
CGQ score				
High	122 (76.3%)	98 67.6%)	1.54 (0.9804 – 2.5475)	0.09
Low	38 (23.7%)	47 (32.4%)		
ZBI score				
High	98 (61.3%)	92 (50.4%)	0.91(0.5725 1.4484)	0.60
Low	62 (39.7%)	53 (49.6%)		

CGQ – Caregivers Guilt Questionnaire, FDR – First Degree Relatives, NHIS – National Health Insurance Scheme, WHOQOL-BREF – World Health Organization Quality of Life Questionnaire in Brief, ZBI – Zarit Burden Interview.

Table 6: Factors associated with high burden of disease using Zarit Burden Interview (ZBI) Questionnaire Score

Variables	Participants with high burden of disease using CGQ score n = 190	Participants with low burden of disease using CGQ score n = 115	Odd Ratio (95%Confidence Interval)	P - value
Age				
Age < 45years	132 (69.5%)	42 (36.5%)	0.76 (0.4682 1.2458)	0.28
Age = 45years	58 (30.5%)	73 (73.5%)		
Gender				
Female	110 (57.9%)	63 (54.8%)	0.88 (0.5525 - 1.4051)	0.59
Male	80 (42.1%)	52 (45.2%)		
Marital Status				
Married	126 (66.3%)	77 (67.0%)	0.82 (0.5176-1.3703)	0.54
Single	63 (33.2%)	34 (29.6%)		
Widowed	1 (0.5%)	3 (2.4%)		
Employment				
Employed	126 (66.3%)	73 (66.5%)	1.13 (0.6978– 1.8385)	0.61
Unemployed	21 (11.1%)	14 (12.2%)		
Student	40 (21.1%)	21 (18.3%)		
Retired	1 (0.5%)	7 (6.0%)		
Register on NHIS				
Yes	15 (7.9%)	4 (3.5%)	2.38 (0.7697 - 7.3508)	0.16
No	175 (92.1%)	111 (96.5%)		
Dialysis status				
Dialysing	143 (75.3%)	58 (50.4%)	2.99 (1.8278 – 4.8914)	0.01
Non-dialysing	47 (24.7%)	57 (49.6%)		
Relatives				
FDR	116 (61.0%)	76 (60.8%)	1.01 (0.6269 1.6198)	0.93
Non- FDR	74 (40.0%)	49 (39.2%)		
Duration of caring for patients				
< 6months	125 (65.8%)	91 (78.3%)	0.52 (0.3125 – 0.9121)	0.02
= 6months	65 (34.2%)	24 (21.7%)		
CGQ				
High	125 (66.8%)	53 (46.1%)	2.36 (1.4665 3.7922	0.01
Low	63 (33.2%)	62 (53.9%)		
WHOQOL-BREF				
High	125 (65.8%)	88 (76.5%)	0.58 (0.3417 – 0.9830	0.04
Low	65 (34.2%)	27 (23.5%)		

CGQ – Caregivers Guilt Questionnaire, FDR – First Degree Relatives, NHIS – National Health Insurance Scheme, WHOQOL-BREF – World Health Organization Quality of Life Questionnaire in Brief, ZBI – Zarit Burden Interview.