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Depression and psychosocial burden among caregivers of children with chronic kidney disease



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Abstract

Background: More attention has recently targeted families of children with chronic kidney diseases displaying depressive symptoms and major psychosocial burden due to the long-standing nature of the illness and its alarming complications. A cross sectional comparative study was conducted to assess the rate of occurrence of both depression severity and psychological burden, personal and role strain in a sample of Egyptian caregivers of children with chronic kidney disease.

Results: Thirty caregivers of children with CKD were enrolled compared to 30 matched controls during a 6-month period. A short pre-designed sheet including socio-demographic data, and general medical, psychiatric and family history was used, and Beck Depression Inventory, Zarit Burden Interview, Holmes and Rahe Socioeconomic Stress Scale, and Occupational Stress Questionnaire were answered.

More than half of the caregivers of children with chronic kidney disease reported moderate depression (53.3%), while 30% and 16.7% reported mild and severe depression respectively. The majority of cases 80% had moderate psychological burden. And 70% of cases reported minimal socioeconomic stress compared to 40% in the control. Logistic regression analysis showed that ZBI and SRRS scores were significantly linked to depression and burden found in caregivers of children with CKD (P = 0.001 and 0.031) respectively.

Conclusion: The rate of occurrence of depression and psychological burden is significantly high in caregivers of children with chronic kidney disease; therefore, this population must be assessed and provided with liaison psychological rehabilitation.

Keywords: Depression, Psychological burden, Caregivers, Chronic renal disease

Background

Chronic diseases in children represent a huge burden on family members especially the mothers affecting family relationships and increasing the child's dependency [1]. Chronic kidney disease (CKD) and end stage renal disease (ESRD) and their exacerbations have a major effect on the global health and the DALYs (Disability Adjusted Life-Years) in patients with common cardiovascular related death that warrant more attention especially in the middle and low state insurance countries [2]. Children

with chronic kidney disease have a significantly longer survival rate. However, despite being provided with an increasingly effective treatment, they can never be cured, which means more burden on the caregivers is expected from very long years of treatment and follow up [3]. About 20% of CKD children on hemodialysis are reported a probable psychiatric disorder and poor quality of life [4] which can easily impact the family members' psychological health.

Additionally, children and their caregivers are challenged with the need to navigate multiple health and social care settings, seek treatments and costs, finance their health care, and access educational programs [5]. Challenges may

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be even greater in low income countries with patients suffering from ESRD, as various regions have poor pediatric care centers [6]; simultaneously, this creates burden for the patient as well as their caregivers who are usually not enough prepared to carry this new role which makes them suffer from the negative effects as anxiety, depression, and stress impacting their own health [7]. 33.4% of attendants of patients with chronic kidney disease were found to have moderate to severe depression [8].

Caregivers experience physical and psychological distress, increased workload, limitations to personal and social activities, and financial problems. They are reported to suffer from tiredness, anger, depression, sense of helplessness, guilt, isolation, loss of freedom, fear, vulnerable, and neglect their own health. They face difficulties with dating and marriage and problems with their job [9].

Furthermore, both patients and their caregivers can fall into a loop of psychological ebb being affected by each other as caregivers are reported to experience anxiety and depression if the patients they tend to suffer from the same emotional statuses [10].

Family care partners of patients undergoing different treatment modalities for CKD reflected on their negative treatment experiences they commonly face like unanticipated responsibilities, sleep disruptions, anxiety, the patients' depression, fatigue, and dialysis-related health problems, in addition to treatment logistics obstacles (insufficient information, medication regimen, and logistical inconveniences). Financial incentives, home visits, and assisting peritoneal dialysis at home are recommended to decrease the outsized burden on the patients and their care givers [11].

Caregivers of ESRD patients need to be assessed for burden. Supportive psychosocial interventions should be available to improve the well-being and quality of life of caregivers as well as their ESRD patients throughout this journey of chronic illness. Consequently, both medical and psychosocial aspects must be provided to ensure proper care over pediatric patients with CKD and their caregivers [12]. A study found that different appraisal level among parents of the ill child regarding the income source, taking care of CKD child role, social relations adaptation need, and having to maintain relations with the medical staff, all these without attaining proper support from social workers can create a conflict leading too suboptimal clinical response of the patient [13].

Therefore, our study tackled the burden of caregivers of children with CKD and to highlight the association of caregiver burden with the depression parameter.

Methods

Study design and participants

This was a cross-sectional comparative study. It was approved by Ethics Committee of the Institute of Psychiatry,

Ain Shams University, using a convenient random sampling; the study was conducted at El Demerdash Pediatric Hospital, Faculty of Medicine, Ain Shams University Hospitals, taking a 6-month period from January 2019 till August 2019.

Patients

The total number of the sample recruited was 66 but 6 subjects were excluded due to having current psychiatric diagnosis by SCID-I. Therefore, the 60 participants were divided into 2 groups (case-control), each with 30 subjects.

Case group

Thirty caregivers of children with CKD were recruited by convenient sampling. Inclusion criteria included any age group, both male and female gender and Egyptian nationality only. On the other hand, any caregiver diagnosed with a previous psychiatric illness, or a current general medical or psychiatric illness or having another child with a chronic medical illness was excluded.

Control group

Thirty volunteers were selected from individuals working at Ain Shams University Hospitals after being matched for age, sex, and educational level with the case group.

Sample size

The proportion of cases with depression is used to calculate the sample size. Group sample sizes of 25 and 25 achieve 80% power to reject the null hypothesis of zero effect size when the population effect size is 0.80 and the significance level (alpha) is 0.050 using a two-sided z test.

Tools

This study is approved by the Ethics and Research Committee of the Psychiatric Institute at Ain Shams University. Written informed consent from patients was received prior to data collection. All subjects underwent the following tools:

A short predesigned sheet including data of the caregiver, like age, gender, marital status, education, occupation, residence, past and current general medical history, past and current psychiatric history, history of drug abuse including smoking), clinical data of the child including age, gender, duration of illness, current comorbid illnesses or complications, and whether being on dialysis or not.

The structured clinical interview for DSM-IV (SCID I) [14]

Arabic version was used [15]. It was applied to diagnose major depression and to exclude other current psychiatric disorders apart from depression.

Beck Depression Inventory (BDI) [16]

It is a 21-item scale, viewing depression from a psychodynamic view and its severity grades, each item scores 0 to 63; higher scores indicate greater depressive severity. Key symptoms covered are mood, pessimism, and sense of failure, self-dissatisfaction, guilt, punishment, selfdislike, self-accusation, suicidal ideas, crying, irritability, social withdrawal, indecisiveness, body image change, work difficulty, insomnia, fatigability, loss of appetite, weight loss, somatic preoccupation, and loss of libido. Validity ratings between the BDI and other depression instruments showed 0.77 correlation rating, with high construct validity with medical symptoms measured. Beck's study reported a coefficient alpha rating of .92 for outpatients and .93 for college student samples. The BDI-II positively correlated with the Hamilton Depression Rating Scale, r = 0.71, had a 1-week test-retest reliability of r = 0.93 and an internal consistency $\alpha = .91$. It takes 5–10 min to be answered.

Zarit Burden Interview (ZBI) [17]

It is a popular caregiver self-report measure used by many aging agencies, originated as a 29-item question-naire. The revised version contains 22 items and the short version 12 items. The most frequently used is the two-factor model, addressing personal strain and role strain. The validity and reliability of ZBI has been measured by previous studies. The Crohnbach alpha was found to be 0.93 and the intra-class correlation coefficient for the test–retest reliability of the Zarit burden score was 0.89 [18].

The Social Readjustment Stress Scale (SRRS) [19]

We used the Arabic version [20]. It is a self-administered questionnaire, consisting of a list of 43 life event domains. The more the events included, the higher the score. A total value for stressful life events can be worked out by adding up the scores for each event experienced over a 12-month period. And the higher the score the more likely the patient was to become ill.

Study procedure

The field researcher interviewed caregivers in two separate meeting.

The first interview took an hour, including collecting clinical history data of the patient and the sociodemographic data of caregivers in both the case and control groups, in addition to applying the SCID-I questionnaire.

The second interview included answering the other three scales (BDI, ZBI, and SRRS) by caregivers of both groups. It took an hour to answer the scales.

Statistical analysis

All data were recorded in a statistical package on a compatible computer. Results were tabulated and statistically analyzed by the Statistical Package for the Social Sciences (SPSS) version 20 [21]. Statistical presentation and analysis were conducted using the mean, standard deviation, chi-square, independent t test. For inferential statistics, the independent t test and chi-square test were used. Significance level was set at P < 0.05.

Results

Sociodemographic and clinical data of the case and control groups of caregivers

The whole sample consisted of 60 participants. The mean age of the sample of cases was 38.50 ± 7.21 and in controls was 40.73 ± 7.68 .

Female caregivers represented 27 (90.0%) of the cases and 22 (73.3%) of the controls. Regarding the marital status, the majority of cases 23 (76.7%) and of controls 26 (86.7%) were married.

As for the educational degree, the majority of cases were of average level education (diploma) but most of controls were of primary or preparatory education which was highly significant.

Considering the profession, most of cases were house-wives or unemployed (25 (83.3%)) as for the control group most of them were technical workers (22 (73.3%)) which shows high significance in terms of sample matching.

For the monthly income, the majority of controls reported barely adequate income (12 (40.0%)), as for the cases, most of them (21 (70.0%)) reported inadequate monthly income.

For the residence, the majority of cases (19 (63.3%)) and controls (28 (3.3%)) inhabited urban areas.

Whereas the general medical history showed no significant difference between cases and controls (Table 1).

Descriptive analysis of the clinical data of children with CKD

Among the children with CKD, male and female genders were 50% and 50%, the mean age of the children was 13.30 ± 3.65 . All of them were undergoing dialysis. And their duration of illness ranged from 3 months to 18 years.

Comparison of depression, Zarit burden, and socioeconomic stress scale scores among cases and controls groups

- As regards Beck Depression Inventory, 53.3% of cases reported moderate depression and 43.3% of controls reported minimal depression.
- As for Zarit Burden Interview, the majority of cases 80% reported moderate burden and 60% of controls reported minimal burden.

Table 1 Sociodemographic and clinical data of case and control groups

		Control group	Cases group	Test value	P value	Sig.
		No. = 30	No. = 30			
Age	Mean ± SD	40.73 ± 7.68	38.50 ± 7.21	1.161•	0.250	NS
	Range	23–55	20–50			
Gender of caregiver	Female	22 (73.3%)	27 (90.0%)	2.783 ^a	0.095	NS
	Male	8 (26.7%)	3 (10.0%)			
Marital status	Single	1 (3.3%)	2 (6.7%)	1.850 ^a	0.763	NS
	Married	26 (86.7%)	23 (76.7%)			
	Divorced	2 (6.7%)	2 (6.7%)			
	Widow	1 (3.3%)	2 (6.7%)			
	Other	0 (0.0%)	1 (3.3%)			
Scientific degree	University	10 (33.3%)	2 (6.7%)	28.506 ^a	0.000	HS
	Diploma	0 (0.0%)	12 (40.0%)			
	Primary/preparatory	20 (66.7%)	9 (30.0%)			
	Can read and write	0 (0.0%)	1 (3.3%)			
	Illiterate	0 (0.0%)	6 (20.0%)			
Profession	No	3 (10.0%)	25 (83.3%)	43.571 ^a	0.000	HS
	Manual worker	0 (0.0%)	3 (10.0%)			
	Technical worker	22 (73.3%)	0 (0.0%)			
	Professional worker	5 (16.7%)	2 (6.7%)			
Monthly income	Adequate	8 (26.7%)	2 (6.7%)	8.819 ^a	0.012	S
	Barely adequate	12 (40.0%)	7 (23.3%)			
	Inadequate	10 (33.3%)	21 (70.0%)			
Residence	Urban	28 (93.3%)	19 (63.3%)	7.954 ^a	0.005	HS
	Rural	2 (6.7%)	11 (36.7%)			
General medical history	No	25 (83.3%)	22 (73.3%)	4.525 ^a	0.807	NS
	HTN	1 (3.3%)	2 (6.7%)			
	DM	1 (3.3%)	1 (3.3%)			
	IBS	1 (3.3%)	1 (3.3%)			
	Disc prolapse	1 (3.3%)	1 (3.3%)			
	BA	0 (0.0%)	1 (3.3%)			
	BMT	1 (3.3%)	0 (0.0%)			
	Epilepsy	0 (0.0%)	1 (3.3%)			
	Thyroidectomy	0 (0.0%)	1 (3.3%)			

P > 0.05: NS non-significant; P < 0.05: S significant; P < 0.01: HS highly significant

Age •: independent t test ^aChi-square for the rest variables

• In Social Readjustment Stress Scale, the majority 70% of cases reported minimal stress and the majority 40% of the controls reported minimal stress as well (Table 2).

Beck depression scores in relation to sociodemographic and clinical histories of the parent and child

There was no statistically significant relation between depression, sociodemographic data of caregivers and their clinical history and the child's except for gender of the caregiver relating female gender to have higher depression rate than male counterpart (P = 0.048) (Table 3).

Logistic regression analysis for predictors of psychological burden and depression in the cases group Logistic regression analysis showed that ZBI and SRRS scores were significantly related to burden and depression in caregivers of children with CKD with P value = 0.001 and 0.031, respectively (Table 4).

Table 2 Comparison between scores of the 3 scales among cases and controls

		Control group		Cases group		Test value	P value	Sig.
		No.	%	No.	%			
Beck	Minimal	13	43.3%	0	0.0%	17.651 ^a	0.001	HS
	Mild	6	20.0%	9	30.0%			
	Moderate	10	33.3%	16	53.3%			
	Severe	1	3.3%	5	16.7%			
ZBI	Minimal	18	60.0%	2	6.7%	26.066 ^a	0.000	HS
	Mild	7	23.3%	4	13.3%			
	Moderate	5	16.7%	24	80.0%			
	Severe	0	0.0%	0	0.0%			
SRRS	Minimal	12	40.0%	21	70.0%	6.055 ^a	0.048	S
	Mild	11	36.7%	4	13.3%			
	Moderate	7	23.3%	5	16.7%			
	Severe	0	0.0%	0	0.0%			

^aChi-square is used

Discussion

The current study assessed the degree of depression and psychological burden in caregivers of children with chronic kidney disease compared to caregivers of healthy children. Those caregivers are usually relatives and family members who volunteered to care for the ill child; hence, their responsibility lasts till the end of the child's life, which will affect their lifestyle and daily routine for a long period of time.

Sociodemographic data of caregivers

Regarding the gender of the caregiver, female caregivers represented (90.0%) of the cases and (73.3%) of the controls in our study; this is explained by the fact that women are more concerned about the well-being of the people they provide care for. They also tend to be more emotionally attached to their children as well as the socio-cultural norms that put the responsibility of caregiving in general over the women shoulders; this datum agrees with many previous studies' findings having an ultimatum that the female carries out the primary caregiver role of any sick member in the family [22-24]. On the other hand, a study found no gender differences regarding the responsibility of care, well-being, anxiety, nor stressors perceived by mothers and fathers; a possible interpretation of this fact is that both parents in other subcultures might be presented with similar adaptive experiences and role challenges related to psych sociocultural aspects more than demographic features per se [25].

In this study, most caregivers were parents and from the family members; this is explained by the nature of parenting as parents are always concerned about their off springs, which goes in harmony with a research done by [26] Grapsa and his colleagues in 2014, caregivers were mostly people from within the family environment (98%): 52% of them were spouses, 29% offspring, and the rest were relatives. These findings are in accordance with research from Brazil on caregivers of patients undergoing dialysis, as well as researches coming from Europe and America [27, 28].

Regarding the marital status; the majority of cases (23 (76.7%)) and of controls (26 (86.7%)) were married. As for the scientific degree, the majority of cases were of average level education (diploma) but most of controls were of primary or preparatory education which was highly significant. As regards profession, most of cases were housewives or unemployed (25 (83.3%)); as for the control group, most of them were technical workers (22 (73.3%)) which shows high significance in terms of sample matching. As regards monthly income, the majority of controls reported barely adequate income (12 (40.0%)); as for the cases, most of them (21 (70.0%)) reported inadequate monthly income. For the residence, the majority of cases (19 (63.3%)) and controls (28 (93.3%)) inhabited urban areas.

With regard to the socio-demographic factors, these results are consistent with most cases involved in a research where married mothers with basic schooling who were homemakers, lived in a nuclear family, and had low income and whose main support network was the family [29]. Also, the profile identified in Latin America and the Caribbean by [30, 31] where long-term care represents a type of unpaid work performed by women, as required by the multiplicity of psychological and family demands.

Comparison of rate of depression and psychological burden among caregivers in case and control groups

The current study showed that caregivers of children with chronic kidney disease have significantly more

Table 3 Bivariate analysis of Beck depression and sociodemographic and clinical histories of the parent and child

		SRRS			Test value	P value	Sig.
		Minimal	Mild	Moderate			
Gender of caregiver	Female	20(95.2%)	4(100.0%)	3 (60.0%)	6.085 ^a	0.048	S
	Male	1 (4.8%)	0 (0.0%)	2 (40.0%)			
Marital status	Single	2 (9.5%)	0 (0.0%)	0 (0.0%)	5.474 ^a	0.706	NS
	Married	16(76.2%)	3 (75.0%)	4 (80.0%)			
	Divorced	1 (4.8%)	0 (0.0%)	1 (20.0%)			
	Widow	1 (4.8%)	1 (25.0%)	0 (0.0%)			
	Other	1 (4.8%)	0 (0.0%)	0 (0.0%)			
Scientific degree	University	2 (9.5%)	0 (0.0%)	0 (0.0%)	2.804 ^a	0.946	NS
	Diploma	8 (38.1%)	1 (25.0%)	3 (60.0%)			
	Primary/preparatory	6 (28.6%)	2 (50.0%)	1 (20.0%)			
	Can read and write	1 (4.8%)	0 (0.0%)	0 (0.0%)			
	Illiterate	4 (19.0%)	1 (25.0%)	1 (20.0%)			
Profession	No	18(85.7%)	4(100.0%)	3 (60.0%)	6.808 ^a	0.146	NS
	Manual worker	1 (4.8%)	0 (0.0%)	2 (40.0%)			
	Technical worker	0 (0.0%)	0 (0.0%)	0 (0.0%)			
	Professional worker	2 (9.5%)	0 (0.0%)	0 (0.0%)			
Monthly income	Adequate	2 (9.5%)	0 (0.0%)	0 (0.0%)	2.844 ^a	0.584	NS
	Barely adequate	6 (28.6%)	0 (0.0%)	1 (20.0%)			
	Inadequate	13(61.9%)	4(100.0%)	4 (80.0%)			
Residence	Urban	14(66.7%)	1 (25.0%)	4 (80.0%)	3.230 ^a	0.199	NS
	Rural	7 (33.3%)	3 (75.0%)	1 (20.0%)			
General medical history	No	15(71.4%)	4(100.0%)	3 (60.0%)	13.091 ^a	0.519	NS
	HTN	2 (9.5%)	0 (0.0%)	0 (0.0%)			
	DM	0 (0.0%)	0 (0.0%)	1 (20.0%)			
	IBS	1 (4.8%)	0 (0.0%)	0 (0.0%)			
	Disc prolapse	1 (4.8%)	0 (0.0%)	0 (0.0%)			
	ВА	0 (0.0%)	0 (0.0%)	1 (20.0%)			
	BMT	0 (0.0%)	0 (0.0%)	0 (0.0%)			
	Epilepsy	1 (4.8%)	0 (0.0%)	0 (0.0%)			
	Thyroidectomy	1 (4.8%)	0 (0.0%)	0 (0.0%)			
Gender of the child	Females	10(47.6%)	2 (50.0%)	3 (60.0%)	0.248 ^a	0.884	NS
	Males	11(52.4%)	2 (50.0%)	2 (40.0%)			
Need for dialysis	No	0 (0.0%)	0 (0.0%)	0 (0.0%)	NA	NA	NA
	Yes	21(100.0%)	4(100.0%)	5(100.0%)			

^aChi-square used

 Table 4 Predictors psychological burden and depression

•	В	S.E.	Wald	P value	Odds	95% C.I.	
	В	3.E.	waiu	P value	ratio	95% C.I.	
					(OR)	Lower	Upper
Beck	0.551	0.475	1.344	0.246	1.735	0.684	4.406
ZBI	1.78	0.524	11.519	0.001	5.927	2.121	16.563
SRRS	-1.062	0.492	4.65	0.031	0.346	0.132	0.908

Chi-square test

depression compared to their matched controls reported more in females (P = 0.048), as 53.3% of them showed moderate depression while only 43.3% of controls showed minimal depression when assessed using Beck Depression Inventory. The majority of cases 80% reported moderate burden and 60% of controls reported minimal burden in Zarit Burden Interview so our findings support the hypothesis that caregivers of children with CKD are affected by depression and psychological burden more than caregivers of a healthy group. This can be explained by highly perceived task difficulty by the caregiver, shortage of medical treatment/nursing services and transportation [32], plus the mandatory sticking to dietary restrictions and lifestyle behaviors affecting the family and social life flow. Also, nephrology team rely on the parents on the daily management of the patient at home, plus having to travel for long distance to attend the weekly clinic visits and dialysis sessions and having to cover some costs of unanticipated management obligations [33].

This is similar to a study that found that 69.4% of caregiver mothers reported feeling pain in the body among which 2.10% had moderate level of burden, whereas a high prevalence of moderate to severe depression and anxiety were reported in (18.4%) and anxiety (47%) of the caregivers respectively [34].

Furthermore, mothers were found to be immersed in various psychological pressures in the journey of their children's treatment with theme expression like suffering "bewilderment between hope and despair," "endless concerns," "agony and sorrow," and "a sense of being ignored." [35].

These findings were similar to results reported by various previous studies in which caregivers of patients with ESRD and chronic kidney disease exhibited mild to moderate and severe psychological burden in (49.1% and 33.3%, respectively) with highly significant rate of occurrence of depression among the caregivers especially among females [24], other studies found declining physical health, and experience impaired psychosocial functioning and relationships [27, 36]. Also, a study confirmed that caregivers experience hassles about living with continuous uncertainty, stress, fatigue, disrupted peer relationships, plus external pressures related to seeking treatment like management of the medical regimen, seeking information, transportation, accommodation and finances, complying to the child's liquid and diet restrictions, and adjusting home duties to medical care [37]. It has been also reported that there is an increased risk for anxiety and depression in caregivers of children with CKD [38, 39].

A study in Peru presented depression in 54.54% of caregivers of children with nephrotic syndrome with difficulty in maintaining daily functioning among which 9.09% had moderately severe depression, 18.18% had moderate and 27.27% displayed mild depression [40]. Another study showed that 43.82% of caregivers of children on hemodialysis suffered from depression with a significant relation between depression and perceived burden and depression among patients with ESRD and their caregivers [41] as well as anxiety, depression, poor sleep, and psychological burden [42]. A Taiwanese study showed that a significant proportion of caregivers had probable depression, and compared to mothers of healthy children, depression was fivefold more common and the quality of life was significantly lower in the mothers of these patients [43].

An Australian study working with parents of children receiving PD explained how parents face status stress through their struggling to accept their child's diagnosis and undergoing traumatizing invasive interventions, feeling guilty when their child has treatment related complications, having conflicts with the spouse and other siblings due to neglecting their needs and through feeling fully dependent on support from health professionals and in need to follow other parents' advice [44].

Despite the fact that there is an absence of studies on families of young children with ESRD, more than a dozen studies have focused on older children with chronic kidney disease. Eleven reviewed between 1980 and 2008 showed increased parental burden caused by caretaking duties, high levels of perceived stress, sense of social isolation, depression and anxiety and uncertainty about the future. Such adjustment difficulties also appeared to be more prevalent among parents with a lower socio-economic status [45].

Risk factors of depression in caregivers of children with CKD

The current study found that the main predictors for depression in caregivers of children with CKD are Zarit Burden Interview and Social Readjustment Stress Scale, which agrees with a study that the mean Zarit scores are positively correlated with depression and anxiety parameters [24]. However, other findings showed that children's number of medicines and injections, a diagnosis of ADHD in addition to the primary medical condition, frequent primary health care centers and ER visits, and lower child self-efficacy were predictors of increased caregiver burden [46].

Conclusions

The study concluded that the rate of occurrence of depression and psychological burden is indeed higher in caregivers of children with chronic kidney disease therefore; this population needs to be assessed thoroughly for depression and burden. Supportive interventions should be provided to improve their wellbeing as well as their patient's wellbeing during the long journey of chronic kidney disease.

Limitation of the study

In addition to the small sample size, further questionnaires assessing quality of life, socioeconomic status, and psychiatric effects in caregivers are recommended to be used in future studies to deeply tackle the psychological and social stress and its impact on patients and their families.

Abbreviations

CKD: Chronic kidney disease; ESRD: End stage renal disease; QoL: Quality of Life; BDI: Beck Depression Inventory; ZBI: Zarit Burden Interview; SRRS: The Social Readjustment Stress Scale; SPSS: Statistical Package for the Social Sciences

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Authors' contributions

D.A.M.: contribution in research idea selection, paper writing, and revising the references. A.S: contribution in sample idea selection, sampling planning, supervising the field work. Y.H.A.: recruiting and interviewing the patients, applying the questionnaires and sample collection. Y.E.: contribution in paper writing, revising methodology, and paper submission. All authors have read and approved the manuscript.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Subjects were enrolled in the study after explaining the purpose and procedure of the study and obtaining a written informed consent ensuring their confidentiality. The study was conducted in accordance with the guidelines of Research and Ethics Committee of the Institute of Psychiatry, Ain Shams University. The Committee's reference number is not available.

Consent for publication

Consent for publication was obtained.

Competing interests

All authors declare that they have no competing interests.

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References

- Watson AR, Hayes NH, Vondrak K et al (2013) Factors influencing choice of renal replacement therapy in European Paediatric Nephrology Units. Pediatr Nephrol 28:2361–2368
- Bikbov B, Purcell CA, Levey AS et al (2020) Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet 395(10225):709–733
- Watson AR (2014) Psychosocial support for children and families requiring renal replacement therapy. Pediatr Nephrol 29:1169–1174
- Glazebrook C, Hollis C, Heussler H et al (2003) Detecting emotional and behavioural problems in pediatric clinics. Child Care Health Dev 29:141–149
- Kierans C, Padilla-Altamira C, Garcia-Garcia G et al (2013) When health systems are barriers to health care: challenges faced by uninsured Mexican kidney patients. PLoS One 8(1):e54380

- Crews D, Bello AK, Saadi G (2019) World Kidney Day Editorial burden, access, and disparities in kidney disease. Braz J Nephrol: 'orgao oficial de Sociedades Brasileira e Latino-Americana de Nefrologia 41(1):1–9. https:// doi.org/10.1590/2175-8239-JBN-2018-0224
- Tang ST, Chang WC, Chen JS et al (2012) Course and predictors of depressive symptoms among family caregivers of terminally ill cancer patients until their death. Psychooncology 22(6):1312–1318
- Saeed Z, Ahmad AM, Shakoor A et al (2012) Depression in patients on hemodialysis and their caregivers. Saudi J Kidney Dis Transpl 23:946–952
- Eirini G and Georgia G. Caregivers of patients on hemodialysis, caregiving and home care, Mukadder Mollaoglu, IntechOpen (Submitted August 7th 2017 Reviewed November 13th 2017 Published December 20th 2017). https://doi. org/10.5772/intechopen.72400. Available from: https://www.intechopen.com/ books/caregiving-and-home-care/caregivers-of-patients-on-haemodialysis.
- Gerogianni G, Polikandrioti M, Babatsikou F et al (2019) Anxiety-Depression of Dialysis Patients and Their Caregivers. Medicina Kaunas 55(5):168
- Flanagin EP, Chivate Y, Weiner DE (2020) Home dialysis in the United States: a roadmap for increasing peritoneal dialysis utilization. Am J Kidney Dis 75(3):413–416
- Affinito J, Paterson W (2017) Recognizing burden in unpaid caregivers of ESRD patients. University of New Jersey, Wayne, New Jersey, USA. NKF, spring clinical meetings abstracts
- Kiliś-Pstrusińska K, Medyńska A, Adamczyk P et al (2014) Disease-related social situation in family of children with chronic kidney disease-parents' assessment: A multicentre study. Ann Agric Environ Med 21(4):876–881
- First MB, Spitzer RL, Gibbon M, Williams JBW (1996) Structured clinical interview for DSM-IV axis I disorders, clinician version (SCID-CV). American Psychiatric Press, Washington, DC
- El Missiry A, Sorour A, Sadek A et al (2004) Homicide and psychiatric illness: an Egyptianstudy [MD thesis]. Faculty of Medicine, Ain ShamsUniversity, Cairo
- Beck AT (1961) An inventory for measuring depression. Archives of General Psychiatry 4(6):561
- Zarit SH, Reever KE, Bach-Peterson J (1980) Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist 20:649–655
- Seng B, Luo N, Ng W et al (2010) Validity and reliability of zarit burden Interview in assessing caregiving burden. Ann Acad Med Singapore 39(10): 758–763
- Holmes TH, Rahe RH (1967) The Social Readjustment Rating Scale. JPCRAT 11(2):213–218
- Okasha A, Sadek A, Lotaief F (1981) The Social Readjustment Rating Questionnaire: A study of Egyptians. Egypt. Psychiat 4:273–283.23
- 21. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp; 2011
- Rioux JP, Narayanan R, Chan CT (2012) Caregiver burden among nocturnal home haemodialysis patients. Hemodial Int 16:214–219
- Oyegbile OY, Brysiewicz P (2017) Exploring caregiver burden experienced by family caregivers of patients with End-Stage Renal Disease in Nigeria. Int J Afr Nurs Sci 7:136–143
- Adejumo OA, Iyawe IO, Akinbodewa AA et al (2019) Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. Ghana Med J 53(3):190–196
- Deater-Deckard K, Panneton R (2017) Parental stress and early child development: adaptive and maladaptive outcomes. Springer International Publishing, Cham
- 26. Grapsa E, Pantelias K, Ntenta E et al (2014) Caregivers' experience in patients with chronic diseases. Social Work in Health Care 53(7):670–678
- 27. Given BA, Given CW, Kozachik S (2001) Family support in advanced cancer. CA-CANCER J CLIN 51(4):213–231
- Belasco A, Barbosa D, Bettencourt AR et al (2006) Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. Am J Kidney Dis. 48:955–963
- Harding R, Higginson IJ (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. J Palliat Med 17(1):63–74
- Toledano-Toledano F, Domínguez-Guedea MT (2019) Psychosocial factors related with caregiver burden among families of children with chronic conditions. BioPsychoSoc Med 13:6
- Calderón C (2013) Redistribute care: the challenge of public policies. ECLAC, Santiago. Chile
- Macedo EC, da Silva LR, Paiva MS et al (2015) Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. Rev Lat Am Enfermagem 23:769–777

- 33. Alnazly E (2020) Predictors of the burden on family carers of patients on haemodialysis in Jordan. EMHJ 26(5):565–572
- Bignal ORN, Goldstein SL (2015) Childhood CKD affects the entire family.
 Am J Kidney Dis 65(3):367–368
- Lima AGT, Sales CC, Serafim WF (2019) Burden, depression and anxiety in primary caregivers of children and adolescents in renal replacement therapy. J Bras Nefrol 41(3):356–363
- Pourghaznein T, Heydari A, Manzari Z, ValizadehZare N (2018 Jul-Aug)
 Immersion in an ocean of psychological tension: the voices of mothers with children undergoing hemodialysis. Iran J Nurs Midwifery Res. 23(4):253–260
- 37. Wilson-Genderson M, Pruchno RA, Cartwright FP (2009) Effects of caregiver burden and satisfaction on affect of older end-stage renal disease patients and their spouses. Psychol Aging 24:955e67
- Tong A, Lowe A, Sainsbury P et al (2008) Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. Pediatrics. 121(2):349–360
- Chen CK, Tsai YC, Hsu HJ et al (2010) Depression and suicide risk in hemodialysis patients with chronic renal failure. Psychosomatics 51: 528e528 e6
- Lanatta V, Quiñones C, Paredes J, Sarabia S et al (2019) Alta frecuencia de sintomatología depresiva en cuidadores de pacientes pediátricos en diálisis peritoneal y hemodiálisis en un hospital público de Lima. Rev Neuropsiguiatr 82(3):202–208
- Arechabala MC, Catoni MI, Palma E et al (2011) Depression and selfperceived burden of care by hemodialysis patients and their caregivers. Rev Panam Salud Publica 30:74e9
- Çoban GI, Kaşikçi M, Gençdoğan B (2009) Fatigue and depression in patients with end stage renal disease and their caregivers. Turkiye Klinikleri J Nephrol. 4:47.
- 43. Tsa T-C, Liu S-I, Tsai J-D et al (2006) Psychosocial effects on caregivers for children on chronic peritoneal dialysis. Kidney Int 70(11):1983–1987
- Tong A, Lowe A, Sainsbury P et al (2010) Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. Child Care Health Dev 36(4):549–557
- 45. Aldridge MD (2008) How do families adjust to having a child with chronic kidney failure? A systematic review. Nephrol Nurs J 35:157–162
- 46. Javalkar K, Rak E, Phillips A et al (2017) Predictors of caregiver burden among mothers of children with chronic conditions. Children (Basel) 4(5):39

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