

Research Article

Prevalence of depression, psychological distress and burnout syndrome in primary caregivers for patients with chronic kidney disease under substitutive therapy in Mexico

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ABSTRACT

Introduction: Chronic kidney disease is a serious condition demanding effort from patient, health professionals, and Primary Caregiver (PC). Our aim was to get knowledge about psychosocial status of PCs in charge of patients with chronic kidney disease (CKD) under substitutive therapy.

Materials and Methods: Analytic cross-sectional study of PC in charge of a patient with CKD under substitutive therapy. Goldberg health, Zarit, and Beck questionnaires were applied. Statistics were run in SPSS V22.0.

Results: 201 PCs were interviewed, with an average age of

46.21±14.23 years. 88.1% were women. As per Goldberg’s psychological distress scale, 51% of caregivers required psychological support. Based on Zarit scale, 17% suffered light burnout, and 38% suffered intense burnout. With Beck scale, 12% showed data of moderate depression, 3% suffered serious depression and two PCs had extreme depression.

Conclusions: ESRD patients shown biopsychosocial affection potentially affecting their health status and maybe having an impact on family nucleus and patient dynamics.

Keywords: *Caregivers, End-Stage Renal Disease, Burnout*

Introduction

The instauration of a chronic or terminal disease poses a severe problem for patient and patient’s family [1-3]. Upon a chronic disease, everything is mixed up in patient’s and family’s lives (4). Under these conditions, a family crisis might arise due to the initial disorder that takes place, with an impact of each family members [1,4].

Chronic kidney disease (CKD) is a severe illness demanding an intense patient’s effort, care and attention from professional

health service suppliers (formal care system: hemodialysis units or peritoneal dialysis clinics), besides informal care at home, usually under the responsibility of some member of the family, which will become the patient’s primary caregiver [5-7].

World Health Organization (WHO) defines PC as “the person, within patient’s environment, voluntarily assuming the role of responsible for the patient. Broadly, this individual is willing to make decisions for the patient and to cover patient’s basic needs, either directly or indirectly, without receiving financial retribution or previous training” [8].

Care of a person with a chronic-degenerative illness demands the exercise of cognitive, affective and behavioral functions to carry out a substantial number of tasks frequently surpassing actual caregiver's possibilities. Although affection, love and even responsibility are motivations for providing care, it is also widely proven that giving care to a chronically ill person is a stressing experience, resulting in alterations of primary caregiver's physical and emotional health [9,10].

Our country shows a high incidence of chronic kidney disease [11]. This has resulted in an increase of the number of patients requiring substitutive therapy and, hence, primary caregivers. PCs are seldom looked upon as persons who also require attention and care. Therefore, it is important to identify their emotional and overburden conditions. Studies on primary caregivers are widely known for patients with cancer, neuropsychiatric or degenerative alterations [12-15]. However, we know less about physical and emotional conditions of PCs for patients with CKD [16]. Hence, we set ourselves as a goal to get knowledge of sociodemographic and biopsychosocial features of primary caregivers for patients with chronic kidney disease. Getting to know and acknowledge primary caregivers as a key piece in the health-patient-primary caregiver triad, we will be enabled to set up strategies that will help us to improve the life quality and control morbidities suffered by this population because of facing the need to give care to a chronic kidney disease patient.

Material and methods

Research type and design

This is an analytic, observational, cross-sectional and prospective study. Goldberg questionnaires were applied for caregiver's psychosocial scale, Zarit questionnaires for burden scale and Beck for depression and anxiety. All instruments were applied by persons qualified in psychology (BSc or MSc).

Population and sample size

About one thousand patients admitted to the hospital with a diagnosis of advanced chronic kidney disease (stage 5 CKD based on the KDIGO) and with renal replacement therapy (ESRD, defined) that receive medical attention every month at the external consultation of the Nephrology Service of "Dr. Eduardo Liceaga General Hospital" in Mexico City. Two hundred out of them are first-time patients, while 800 are subsequent patients. Each of these patients are usually accompanied by a relative. Considering this, and according to reports, prevalence of depression, burnout and emotional distress in primary caregivers fluctuates between 15% and 33% [17]. A sample was calculated by EPIDAT 3.1® statistic package based on a population proportion, considering as population size the 800 persons attending subsequent consultation at the Hospital and an expected proportion of events of interest (burnout, depression, emotional distress) of 20%, with a confidence level of 95% and a p value of less than 0.05. A minimum sample size was estimated as 189 subjects plus 10% of potential losses. Finally, a total of 201 surveys were applied. Participants were randomly taken at waiting rooms of Nephrology external consultation when they met the inclusion criterion of giving care to a patient

with chronic kidney disease in substitutive therapy. Those who agreed on participating in the study signed an Informed Consent Letter stating privacy and accepting publication in accordance to the Helsinki Declaration ethical principles. This research project was approved by the Hospital's Committee on Ethics and Research, under approval number DI/16/105-B/03/049.

Outcome variables

For this research, we defined *psychological distress* as the level of perceived stress, discouragement, discomfort and uneasiness related to self-perception of thoughts, feelings and behaviors, which can be shown through different symptomatology such as alterations of sleep, psychosomatic affections, fear feelings, fear, despair and addictions that can be a health problem [18]. For evaluating psychological distress, Goldberg's General Health Questionnaire (GHQ-28) was applied, validated in Spanish [19,20].

We regard *caregiver burnout* as the negative feelings and pressure experience resulting from giving care to a person with a chronic disease [21]. To define it, Zarit's Primary Caregiver Burnout Scale was applied, validated in Spanish [22]. For depression, DSM-5 definition was used, and Beck's Depression Scale was applied, validated for Mexican population [23-25].

Statistics

To ascertain the impact of variables in different scales, a T Student test was applied when there were 2 variables, and a variance analysis (ANOVA) when there were three or more variables. Critical value of $p < 0.05$ was regarded as statistically significant.

Results

201 primary caregivers were surveyed, 177 (88%) women, with a mean age of 46.21 ± 14.23 years, average schooling of 8 ± 4.14 years. 53% were married. 57% of caregivers were housewives, and 14% employees. 78% were Catholic, 8% nonbelievers, and 8% non-Catholic Christians. As to health self-perception, 62% defined their health as fair, and 33% as good. Feeding was reported as fair by 69%, and as good by 24% of participants. Only 17% of them reported receiving some kind of financial support from a government public program (Table 1).

As per Goldberg Psychological Distress Scale, 51% ($n=102$) of caregivers required psychological support. Based on Zarit Scale, 17% ($n=34$) showed slight burnout, and 38% ($n=76$) intense burnout. Whereas with Beck Scale, 12% ($n=24$) of PCs showed moderate depression data, 3% ($n=5$) showed serious depression, and there were two cases with extreme depression.

Regarding psychological distress, a significant difference was observed between male and female caregivers, while no statistically significant difference was shown for other tests. (Figure 1a). No statistically significant differences were observed regarding biopsychosocial effects related to age range or family relationship (Figures 1B and 1C). On the other hand, no apparent increase in biopsychosocial distress was observed as related to time elapsed since subject began acting as a primary caregiver (Figure 1D): psychosocial affection percentages were

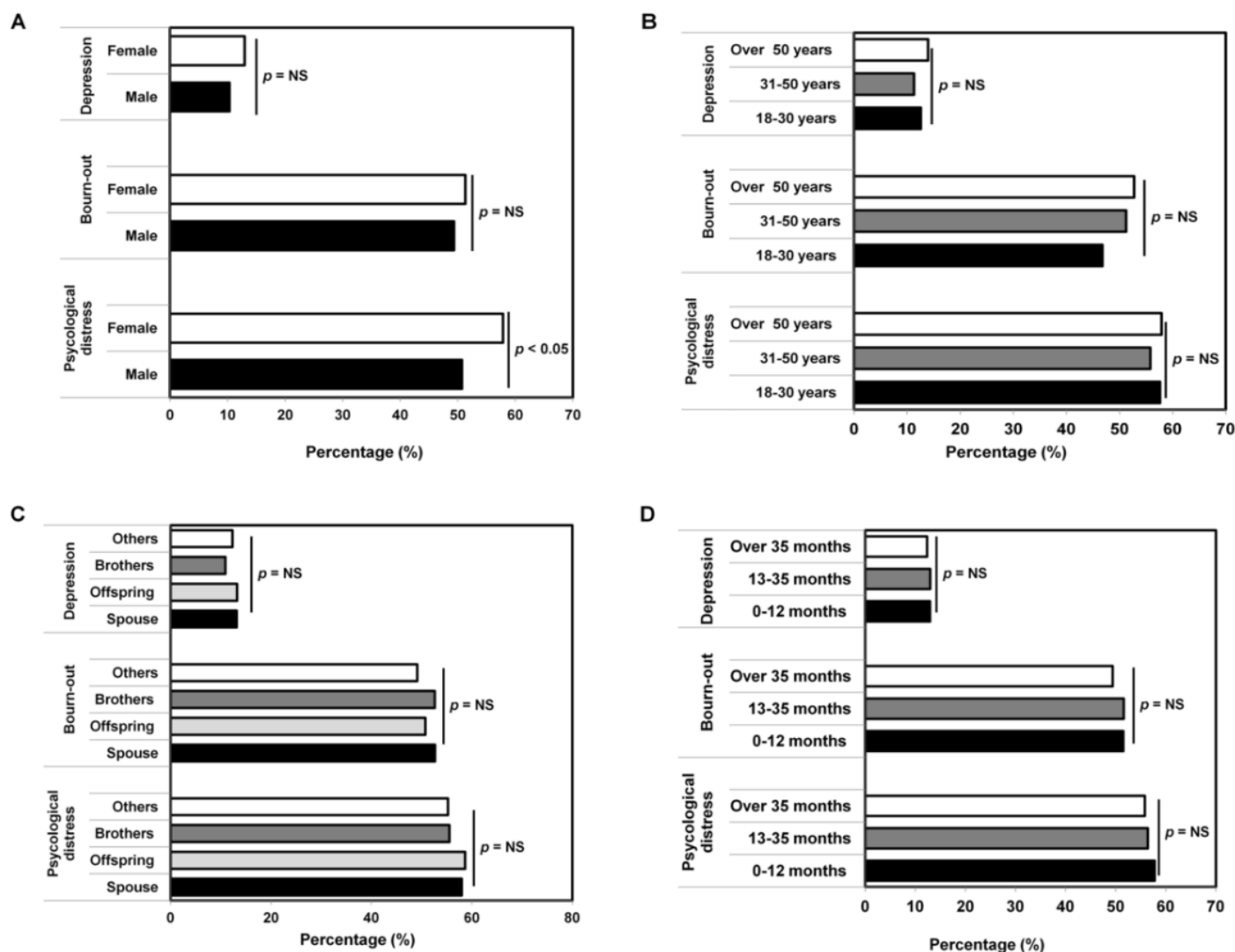


Figure 1. Biosocial Impact on Primary Caregivers. (A) Results of applying scales according to caregiver's gender. The only statistically significant difference observed was a higher psychological distress in women than in men ($p < 0.05$). (B) No difference related to age range was observed in depression, burnout and psychological distress. (C) Regarding filiation, there was no difference when caregiver had a special kind of emotional relation with patient. (D) Evolution time as a caregiver did not show any statistically significant difference.

similar for persons with 12, 13-35 or over 35 months of being primary caregivers.

Discussion

A family member's chronic illness and its economic and psychosocial consequences involve the entire family and affect their lifestyle. Family caregivers of patients with a chronic illness experience a vast range of physical and emotional distresses and psychological symptoms, including depression, anxiety, anger, despair, and feelings of guilt and shame [26,27]. ESRD leads to significant changes in the lives of patients and their families. The need for frequent hemodialysis or peritoneal dialysis and its associated health problems reduce patients' energy and negatively affect their ability to work and to perform routine daily activities [28-30].

Our results show a high prevalence of psychological fatigue, overburden and depression among caregivers for patients with CKD under substitutive therapy in our country. As expected, eighty percent of caregivers are women, half of them married, middle aged, housekeeping, with low schooling -basic level-with health, eating and sleep perceived as medium, and 8 out of 10 do not have a financial support.

Studies showed that family caregivers have an exclusive role in caring for these patients and therefore are under considerable physical and psychological pressure [31-33]. In a recent study, Abbasi et al. investigated the burden on caregivers of hemodialysis patients and reported that 74.2% of them experienced severe burden [34]. Over time, as patients worsen, their caregivers' burden also increases and they experience

Table 1. Socio-demographic Features of Primary Caregivers

Variable	Total Population N =201 (%)
Gender	
Male/Female	24 (11.9)/177(88.1)
Age, years	46.21 ± 14.23
Schooling, years	8 ± 4.14
Marital Status	
Single	39 (19.4)
Married	106 (52.7)
Widowed	12 (6.0)
Free union	33 (16.4)
Divorced	11 (5.5)
Job	
Laborer	10 (5.0)
Farmer	3 (1.5)
Housewife	115 (57.2)
Employed	29 (14.4)
Unemployed	5 (2.5)
Other	39 (19.4)
Religion	
Catholic	157 (78.1)
Non-Catholic Christian	17 (8.5)
Jehovah Witness	3 (1.5)
Evangelic	2 (1.0)
Non-believer	17 (8.4)
Other	5 (2.5)
Health Condition	
Good	66 (32.8)
Fair	124 (61.7)
Deficient	11 (5.5)
Food Intake	
Good	48 (23.9)
Fair	139 (69.1)
Deficient	14 (7.0)
Financial Support	
Yes / No	34(16.9)/167(83.1)
Relative's Substitutive Therapy	
Hemodialysis	79
Peritoneal Dialysis	21

more physical and psychological problems, social isolation, and disruption in family relationships, which might finally lead to shortcomings or discontinuing the patient care [35]. Therefore, these family caregivers are at risk of disease and are sometimes referred to as hidden patients [36].

Psychology and Social Work support is supplied at the Nephrology Service of General Hospital to relatives of recent diagnostic patients or those entering substitutive therapy, so that they have the required help to respond to their patients' needs. However, there is no structured program aimed at preventing or reducing biopsychosocial distress of primary caregivers.

Besides knowledge and skills on coping strategies, caregivers of hemodialysis patients need counseling, empathy, and psychological support to cope with their caregiving roles

[37,38]. Isenberg et al. [39] and Khanjari et al. [40] showed that group discussions and sharing experiences among caregivers are effective in providing ways to give and receive empathy and psychological support. Confirming the findings of previous studies, the present study also showed that these strategies, along with educating the caregivers on problem-focused coping strategies, were significantly effective in reducing the burden on caregivers of hemodialysis patients.

Interesting data were those reported by Romero et al., who researched on life quality of caregivers for patients with chronic kidney disease; such caregivers are led, through emotional overburden and chronic stress, to emotional fatigue, loss of emotional resources, development of negative attitudes towards the person receiving care, insensitivity, reduction or loss of self-realization, devaluation of their own work, and decrease or loss of self-esteem [41].

Velázquez et al reported burnout, anxiety and depression in informal caregivers for patients with chronic renal insufficiency. They found that 91.6% of caregivers suffered conditions such as musculoskeletal diseases, psychic disorders and headaches, blood hypertension and cardiovascular problems, and 100% of caregivers showed anxiety and depression, out of which 58.3% showed high levels of anxiety and 41.6% had medium levels. These data became highly relevant when considering that 95.8% of caregivers devoted full time to the task, which is correlated with researches reporting more anxiety and depression upon longer time devoted to patient's care, and the lack of another activity besides caregiving [42].

These data become more relevant when looking at those reported by Saeed et al. [43] who reported very high percentages of depression in patients with chronic kidney disease under hemodialysis, and their caregivers. They found that 75% of patients with kidney disease suffered moderate to severe depression (7.8% with minimum depression and 38.9% with severe depression), while 33.4% of caregivers also suffered depression (35.0% minimum depression and 5.6% severe depression).

In view of this clinical situation, some groups have started the development of actions focused on primary caregivers, with several strategies that have proven effective in reducing psychosocial burden on persons responsible for patients with kidney diseases [44-47].

Conclusion

In conclusion, ESRD is a catastrophic event deeply altering familiar and social dynamics. Most researches report that primary caregivers are, as a vast majority, relatives of patients. These patients' relatives suffer an insufficient social support, and that both patients and caregivers acknowledge some degree of physical or emotional burden that could physically and mentally affect them, which could necessarily evolve towards a more problematic family situation where not only one sick

person should be considered in the family, but maybe two: patient and caregiver. Our results show the need of giving support to primary caregivers for patients with chronic kidney disease, through multi-discipline strategies and support groups. They spent hours at waiting rooms for hemodialysis, doctor consultation or laboratory analysis. Some amusing activities such as board games, sewing workshops or a walking library to help them improving their cultural level could be some approaches, besides the classes they already receive.

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Conflicts of interest

The authors do not have any conflict of interest for the development and publication of this project.

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