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"No matter what I do, it matters how WE feel": Exploring the associations between patients' and family members' psychological distress and treatment adherence in endstage renal disease.

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Background

End-stage renal disease (ESRD) is an advance state of irreversible and progressive loss of renal function. Patients with this condition cannot survive without renal replacement therapy such as haemodialysis (HD). However, these treatments are highly demanding as they imply a strict regime of attendance to dialysis sessions and the management of several health behaviors, such as vascular access care, dietary and fluid restrictions, and poly-pharmacy protocol [1]. Adherence to these requirements is essential to avoid complications, such as cardiovascular disease and early mortality [2]. As a consequence, this condition not only affects the patients, but also the entire family who constantly needs to readapt their personal, familiar, social, and professional activities to fit dialysis requirements which can increase psychological distress and burden. However, little is known about how patients' and family members' psychological distress affects patients' clinical biomarkers of treatment adherence. Deepening this knowledge is of utmost importance to empirically sustain the development of family-based interventions to promote disease adjustment and treatment adherence (TA). This study aimed to analyse the association between patients' and family members' psychological distress and clinical biomarkers of TA among patients with ERSD undergoing HD.

Methods

An exploratory study with a convenience sample of adults undergoing HD and their respective family members was recruited from one dialysis centre. Sociodemographic and clinical characteristics were collected through a structured questionnaire. Psychological distress, namely symptoms of anxiety and depression, was assessed with the Hospital Anxiety and Depression Scale (HADS). This scale comprises 14 items divided into two different subscales: HADS-Anxiety and HADS-Depression, with seven questions each. Biomarkers were collected from the databases of the dialysis unit. Higher levels of interdialytic weight gain (IDWG), potassium and phosphorus indicate worse TA. Post-dialysis volume of fluids substitution and Kt/V are two indicators of successful dialysis. Descriptive statistics were used to characterise the sample. Mann-Whitney U test was used to compare symptoms of anxiety and depression between patients with ESRD and their family members. Cohen's r effect sizes were calculated based on the value of Z divided by the squared root of the number of observations. Spearman Rho (ρ) correlations were performed to analyse the relationship between the symptoms of anxiety and depression with the biomarkers of TA. Analyses were performed using SPSS, version 25.0.

Keywords: end-stage renal disease; psychological distress; treatment adherence

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Results

Twelve participants were included in this preliminary analysis: six patients (3 women; mean age: 65.3±13.3 years old; average time on HD: 50.7±59.2 months) and each patient family member (6 women; 3 spouses and 3 adult children; 47.3±15.6 years old). Results suggested that family members reported higher anxiety (Median = 9.50, inter-quartile range = 3.00-12.5) than patients (Median = 5.00, inter-quartile range = 2.25-8.00), but these differences did not reach statistical significance (U = 11.5, p = .31, r = .30). Similar results were found for depression, with family members also reporting more symptoms (Median = 3.00, inter-quartile range = 0.75-9.25) than patients (Median = 4.50, inter-quartile range = 0.75-7.75), although nonsignificant (U = 17.5, p = .94, r = .02). Significant strong correlations were found between patients' anxiety with volume of substitution ($\rho = .83, p = .04$) and between patients' depression with phosphorus levels ($\rho = -.85$, p = .03). The remaining results failed to reach statistical significance (p > .05) but followed a similar trend. Patients' depression showed negative moderate and strong correlations with IDWG ($\rho = -.64, p = .17$) and potassium levels ($\rho = -.62, p = .19$), and a positive moderate correlation with Kt/V values ($\rho = .53$, p = .28). Patients' anxiety showed a negative strong correlation with IDWG ($\rho = .71$, p = .11) and a positive moderate correlation with Kt/V values (p = .64, p = .17). Family members' anxiety was positively and moderately correlated with potassium levels ($\rho = .65, p = .17$) and with patients' anxiety $(\rho = .52, p = .29)$. A negative moderate correlation was also found with the patients' volume of substitution $(\rho = -.58, p = .23)$. Family members depression also showed a positive moderate correlation with patients' anxiety ($\rho = .43, p = .40$).

Conclusions

The results suggested that family members presented mild symptoms of anxiety, considering the HADS cut-off point of 8. In line with previous research, relatives also presented higher psychological distress than patients with ESRD, with a moderate effect size for anxiety (r = 30). Overall, these results seem to suggest that ESRD can be recognized as a family condition, as it affects not only the patient, but also their closest family members. In addition, patients' symptoms of anxiety and depression seem to be associated with successful dialysis, specifically with post-dialysis volume of fluids substitution, and with adherence to the restriction of aliments containing phosphorus. The remaining results were nonsignificant but reported a similar trend regarding the association of psychological distress and TA in patients with ESRD. These findings suggest that healthcare professionals should also pay close attention to adherent patients who make daily efforts to meet ESRD/HD demands. It may be that strictly following dietary and fluid restrictions increases patients' levels of distress, which can impair medium to long-term disease adjustment and TA. Some limitations should be acknowledged. Due to small sample size and lack of statistical power, the results from this preliminary study should be carefully interpreted. Future longitudinal studies with larger samples and prediction models should be developed to better comprehend these results. In conclusion, this study suggests that patients and their family members can benefit from participating in a family-based intervention aiming to promote psychological adjustment to ESRD and TA.

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