Purpose in life and caregiver burden in kidney failure: Preliminary results from a hierarchical multiple regression analysis

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Introduction:

Hemodialysis (HD) is the most common renal therapy for kidney failure; however, it is highly demanding due to inflexible treatment schedules, complex medical recommendations (e.g., dietary and fluid restrictions), and serious complications (e.g., cardiovascular and/or pulmonary disease, electrolyte imbalances, fatigue), all of which increase patients' dependence on family caregivers [1]. Therefore, caring for a family member on HD has been described as one of the most burdensome experiences, marked by adjustment struggles, social isolation, and psychological distress [2,3].

According to Pearlin's Stress Process Model [4], caregiver burden can be affected by caregiving stressors (e.g., caregiving daily demands) and caregiver's background/context (e.g., gender, kinship with the patient); nonetheless, resources like social support and/or coping, can buffer the impacts of caregiver stress and improve well-being [4,5]. Previous research has evidenced that purpose in life can help promote dementia caregivers' ability to regulate negative emotions, persevere despite obstacles, and increase engagement in self-care activities [6,7]. However, purpose in life as a psychological resource remains largely unexplored in the caregiving literature and, to the best of our knowledge, has not yet been examined in the context of HD caregiving demands.

This study aimed to explore the role of purpose in life in the caregiver burden of family members of patients undergoing HD, after accounting for social support and coping.

Methods:

A cross-sectional study was conducted with a convenience sample of family caregivers of patients undergoing HD. Participants completed an online assessment protocol with validated self-report measures to assess caregiver burden, social support, coping, and purpose in life (Table 1). A hierarchical multiple regression (HMR) analysis was performed to explore the role of purpose in life as a potential predictor of caregiver burden, after controlling for social support and coping. The set of predictors was entered in a sequence of two blocks; Block 1 contained social support and coping dimensions and Block 2 included purpose in life. To ascertain whether the HMR could be used and guarantee the validity of the results, some first-line tests were performed [12] (Supplementary Data 1). All statistics were computed using SPSS 28.0. Statistical significance was set at $p < 0.05$.

Results:

The sample consisted of 77 family caregivers with a mean age of 60.4 years old (SD=13.3). Most were female (76.6%), married to the cared-for person (51.9%), and caring for less than four years (58.4%); 41.6% reported high levels of caregiver burden (Table 2). Pearson's R coefficients (Table 3) showed significant associations between caregiver burden and social support (r=-0.249, p=0.029), purpose in life (r=-0.584, p<0.001) and the following coping dimensions: positive reframing (r=-0.317, p=0.005), acceptance (r=-0.289, p=0.011), self-blame (r=0.235, p=0.040), and denial (r=0.316, p=0.005). Regarding the HMR analysis (Table 4), Model 1 with social support and the aforementioned coping dimensions predicted approximately 28.4% of the variance of caregiver burden (R^2=0.284, $F_{(5,71)}$=5.63, p<0.001). After the inclusion of purpose in life, Model 2 explained an additional 14.4% (ΔR^2=0.144) predicting approximately 42.8% of the variance of caregiver burden (R^2=0.428, $F_{(6,70)}$=8.73, p<0.001). Purpose in life was the significant predictor with the highest contribution (β=-0.493, p<0.001).

Table 1 - Self-report measures used to assess caregiver burden, social support, coping, and purpose in life.

Variables	Self-report measures	Brief description
Caregiver Burden	Zarit Burden Interview [8]	Scale composed of 22 items, considered a reference measure to assess caregiver burden. Each item is rated on a 5-point Likert scale (1 = never; 5 = almost always). The global score ranges from 22 to 110; higher scores correspond to higher levels of burden. Three benchmarks allow a better interpretation of caregiver burden levels: (i) scores below 46 = no burden; (ii) scores between 46-56 = mild burden; and (iii) scores above 56 = intense burden. In this study sample, this scale presented good psychometric qualities (α=0.89).
Social support	Medical Outcomes Study-Social Support Survey [9]	Questionnaire with 19 items that assesses the perception of social support rated on a 5-point Likert scale (1 = never; 5 = always). The scoring range is from 0 to 100, with a higher score indicating better perceived social support. In this study sample, this questionnaire showed excellent psychometric qualities (α=0.96).
Coping	Brief Cope [10]	Instrument composed of 28 items that evaluates the strategies that each individual adopts to deal with different life situations. Each item is rated on a 4-point Likert scale (0 = I never do that; 3 = I almost always do that) distributed over 14 subscales: use of instrumental support, use of emotional support, self-distraction, active coping, substance use, behavioral disengagement, venting, planning, humor, religion, positive reframing, self-blame, acceptance, and denial. There is no total score, since only a profile of the individual should be presented. In this study sample, this instrument has good psychometric qualities (α=0.78).
Purpose in life	Purpose in Life Test Revised [11]	A 20-item questionnaire that aims to assess the goals and ambitions that support a sense and purpose of personal life. Respondents rate each item on a 7-point Likert scale that is specifically designed for that item. The minimum score is 20 (lowest purpose) and the maximum is 140 (highest purpose). In this study sample, this questionnaire revealed good psychometric qualities (α=0.84).

Table 2 - Sociodemographic and caregiving characteristics of the study sample

Characteristics	Family caregivers (n = 77)
Gender	
Female, n (%)	59 (76.6)
Age (years old), M ± SD	60.4 ± 13.3
Kinship with the patients, n (%)	
Spouse (legally or otherwise)	40 (51.9)
Other (siblings and adult children)	37 (48.1)
Caregiving (years), M ± SD	
< 4	45 (58.4)
> 4	32 (41.6)
Classification of caregiver burden, n (%)	
No burden (<46)	22 (28.6)
Mild burden (46 – 56)	23 (29.9)
Intense burden (> 56)	32 (41.6)

Notes: M=mean; SD=standard deviation.

Table 3 - Pearson's R coefficients (and p-values) for the associations of caregiver burden (dependent variable) with social support, coping dimensions (positive reframing, self-blame, acceptance, and denial), and purpose in life (potential predictors).

	Caregiver burden
Social Support	-0.249* (0.029)
Positive reframing	-0.317* (0.005)
Self-blame	0.235* (0.040)
Acceptance	-0.289* (0.011)
Denial	0.316* (0.005)
Purpose in life	-0.584* (0.001)

Notes: * $p<0.05$. The remaining coping dimensions (self-distraction, active coping, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, planning, humor, and religion), did not present statistically significant associations with caregiver burden and, therefore, were excluded from the HMR analysis. To consult all Pearson's R coefficients and p-values, see Supplementary Data 2.

Table 4 - Results from the HMR analysis.

		B	β	p-value
Model 1	Social support	-0.179	-0.226*	0.040
	Positive reframing	-4.634	-0.237	0.061
	Self-blame	8.144	0.211*	0.044
	Acceptance	-3.395	-0.142	0.263
	Denial	5.595	0.196	0.077
	R^2	0.284		
	$R^2_{adjusted}$	0.233		
	F	5.63		
	p value	<0.001		
Model 1	Social support	-0.001	-0.002	0.988
	Positive reframing	-1.959	-0.100	0.394
	Self-blame	6.713	0.174	0.065
	Acceptance	-0.266	-0.011	0.925
	Denial	5.791	0.202*	0.043
	Purpose in life	-0.463	-0.493*	<0.001
	R^2	0.428		
	$R^2_{adjusted}$	0.379		
	ΔR^2	0.144		
	F	8.73		
	p value	<0.001		

Notes: * $p < 0.05$. β=beta coefficient; B=unstandardized coefficient; ΔR^2=the change in R^2 values from Model 1 to Model 2.

Discussion:

The results showed that the perception of purpose in life among family caregivers of patients on HD seems to have a protective role against burden, even after accounting for social support and several coping dimensions. This finding has crucial implications for the development of psychological interventions aimed at facilitating caregivers' adjustment to dialysis care demands, suggesting that purpose in life is a key target. Future studies are needed to better comprehend the benefits of integrating meaning-making strategies into these interventions, in order to maximize caregivers' understanding of their life priorities, pursuits, personal, family, and social roles, beyond (and including) caregiving demands [6,7]. This study also expands Pearlin's Stress Process Model [4,5] of caregiving by identifying purpose in life as an important psychological resource in the context of hemodialysis caregiving.

Limitations

This is a cross-sectional study with a small preliminary sample and, therefore, causal associations and interpretations should be made with caution.

Ethics committee and informed consent:

The current research was approved by an independent ethics committee (UICISA:E_669_05-2020) and subjects gave their informed consent before they were enrolled in the study.

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