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Social support predicts survival in dialysis patients

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Abstract

Background. Social support is a consistent predictor of survival, as evidenced in empirical studies in patients with cancer or cardiovascular disease. In the area of renal diseases, this topic has not yet been studied extensively. This study, therefore, aimed to investigate the association between social support and survival for patients on dialysis.

Methods. Between December 1998 and January 2002, 528 incident haemodialysis (HD) and peritoneal dialysis (PD) patients from multiple centres in The Netherlands were consecutively recruited as part of the NECOSAD-2 study. Patients completed the Social Support List (SSL) at 3 months after the start of dialysis. The SSL measured two aspects of social support: interaction and discrepancy. Cox regression analysis was used to estimate all-cause mortality risk from baseline till censor date on 1 January 2005.

Results. Perceiving a discrepancy between expected and received social support was associated with increased mortality: social companionship (RR_{adj}: 1.06, 95% CI: 1.00–1.13), daily emotional support (RR_{adj}: 1.10, 95% CI: 1.02–1.18), and total support (RR_{adj}: 1.02, 95% CI: 1.00–1.04). This association was similar for PD and HD patients. Social support (interaction) was not associated with survival, neither in the whole sample nor when stratified by therapy modality.

Conclusions. These results point to the importance of psychosocial risk factors for mortality in patients on dialysis. More efforts are needed to improve support for these patients.

Keywords: dialysis; ESRD; mortality; social support

Introduction

Mortality in dialysis patients is positively associated with age, comorbidity, inflammation and a number of other factors related to atherosclerosis [1–3]. As these factors are often non-modifiable, research is also focusing on potential modifiable psychosocial factors such as social support as possible mediator for survival amongst dialysis patients. Having access to social support, be it from the spouse, family members, friends, colleagues or the community, has been consistently linked to better health outcomes for patients with various chronic illnesses [4–6].

Compared with chronic illnesses like cancer or cardiovascular disease, there is a paucity of research addressing the association between social support and mortality rates in dialysis patients. A literature search in this area identified three relevant studies, which all described an increased risk of mortality with lower levels of social support [7–9]. These associations could be mediated by better dietary [10] and treatment [9,11] compliance, and the promotion of a sense of well-being [7]. Interpretation of the results should be made with caution as these studies are limited by small sample size, focus mainly on haemodialysis (HD) or use prevalent instead of incident patients.

Understanding how having social support at the start of dialysis treatment is associated with survival and well-being may have important clinical benefits for this patient population as it can inform clinical practice for the promotion or improvement of patients' support networks. Using a large sample from the Netherlands Co-operative Study on the Adequacy of Dialysis (NECOSAD-2) [12,13], our study examined the effect of social support at the commencement of dialysis on survival rates amongst patients on dialysis.

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Subjects and method

Patients

Incident dialysis patients with informed consent were consecutively recruited between December 1998 and January 2002 from multiple centres as part of the NECOSAD-2 study. Eligibility included being over 18 years of age, having had no previous history of renal replacement therapy, and surviving the initial 3 months of dialysis. This study was approved by all local medical ethics committees.

Measurements

Data on demographics, underlying cause of kidney failure, body mass index (BMI), serum albumin level, residual renal function and comorbidity were collected at baseline. The primary cause of kidney disease was classified using the European Renal Association-European Dialysis and Transplantation Association codes. Residual renal function parameters included the residual glomerular filtration rate (rGFR) (calculated as the mean renal clearance of urine and creatinine corrected for body surface), and the Kt/V_{urea}/week (calculated as renal urea clearance corrected for the urea distribution volume according to Watson *et al.* [14]). Patients' comorbidities were classified using the 3-point Davies score [15] which was determined by the number and type of comorbid conditions present. Nutritional status was measured with the 7-point Subjective Global Assessment (SGA) scale [16]. Functional status of the patients was assessed by dialysis staff using the Karnofsky scale [17]. Two items from the Kidney Disease and Quality of Life Short Form (KDQOL-SF) were used as depression indicators: 'Have you felt so down in the dumps that nothing can cheer you up?' and 'Have you felt downhearted and blue?' [18]. Patients rated these two items on a 6-point scale (1 = all the time; 6 = never). A score of ≤3 for any one of the two items was considered an indication of depression.

Social support was assessed using the self-administered Social Support List (SSL) [19], a validated instrument that has been used with kidney transplant patients [20] and other population samples [21,22]. Patients were given the SSL during their baseline visit at 3 months from start of dialysis, with instructions to return the filled questionnaire via pre-paid post within a week. Thirty-four items from the SSL were used as a measure of two aspects of social support: 'Interaction' (SSL-I) measures the frequency of social support that the patient receives; and 'Discrepancy' (SSL-D) is the perceived difference in social support between that which is desired and what is received by the patient. Both SSL-I and SSL-D assess three types of social support (Appendix 1): 'social companionship' measures the frequency of social activities such as telephone calls, visits and invitations from friends that patients received; 'Daily emotional support'

pertains to shows of affection received; and 'Emotional support with problems' refers to acts of motivation, encouragement, comfort, advice giving and/or problem solving received. Patients rated items from the three subscales using a 4-point scale (1 = seldom/never; 4 = very often) on the frequency in which they received social support (interaction). The sum of the items in each subscale forms the subscale score. A total support score is obtained by summing the three subscale scores. High scores indicate that patients report receiving good social support. For the discrepancy score, patients rated their perceived discrepancy between the desired and received level of social support on a 4-point scale (1 = 'I miss it; would like more'; 4 = 'Happens too often; wish it was less'). Item-scores were recoded to calculate the discrepancy in patients' desired and actual level of support received. Higher discrepancy scores suggest lower level of perceived support. The SSL has good reliability, ranging from 0.81 to 0.91 for the different aspects of social support in both the interaction and discrepancy subscales [19]; in our study, the Cronbach α for the various aspects of social support in both subscales were between 0.82 and 0.94.

Statistical analyses

Cox proportional hazard models were used to determine the associations between social support and mortality, with adjustments for demographics, comorbidity, serum albumin (as an indicator for chronic inflammation or malnutrition), functional ability, depressive symptoms and treatment modality. Patients were followed till death or censor. Reasons for censoring included loss to follow-up, transplantation or end of follow-up on 1 January 2005. Significance levels were determined at $P \leq 0.05$.

Results

Of the 606 eligible patients, 528 (87%) returned the SSL as per instructions. Reasons for non-response were poor health or being not fluent in Dutch. Patients were followed up for an average of 910.8 days (±563.4 days). Mean sample age was 58.8 years (±14.3), with 59% male and 68% married or living together (Table 1). Females, elderly (≥65 years), and HD patients perceived having slightly better emotional support with problems (5% higher score, i.e., 0.2SD), but no differences on other social support dimensions were observed. Baseline covariates such as age, treatment modality, education level, employment, primary cause of kidney disease, comorbidity, SGA scores, serum albumin, Karnofsky scores, and depression indicators were significantly associated with mortality in univariate analyses.

A total of 189 patients died during follow-up. The main cause of death was due to cardiovascular reasons (23.6%).

Table 1. Baseline characteristics and relative risk for mortality

Risk factors	Total group[a] (n = 528)	RR[b] (crude)	95% CI
Male (%)	59.1	1.176	0.877–1.577
Age	58.8 ± 14.3	1.052	1.039–1.065
Dialysis modality (%)			
HD	65.0	1.836	1.317–2.559
Ethnicity (%)			
Caucasian	93.8	1.496	0.737–3.038
Education (%)			
Low	57.4	1.523	1.120–2.072
Marital status (%)			
Married	67.6	0.720	0.698–1.282
Employed (%)			
No	76.7	3.605	2.090–6.217
Primary cause of renal failure (%)			
Diabetes mellitus	13.8	1.000	–
Glomerulonephritis	12.9	0.189	0.095–0.378
Renal vascular disease	18.9	0.895	0.595–1.345
Others	54.4	0.453	0.312–0.658
Davies comorbidity score (%)			
Low	43.0	1.000	–
Medium	47.9	4.251	2.881–6.273
High	9.1	6.690	4.109–10.892
SGA score (%)[c]			
5 or less	21.2	2.425	1.781–3.301
BMI	24.9 ± 4.4	0.990	0.956–1.026
Serum albumin (g/l)	35.9 ± 5.0	0.956	0.930–0.984
Kt/V_{urea}/week	3.1 ± 1.0	1.056	0.926–1.204
rGFR (ml/min/1.73 m^2)	4.0 ± 2.9	0.957	0.901–1.016
Karnofsky index	80.2 ± 14.6	0.960	0.952–0.968
Indication of depression (%)	14.6	2.248	1.600–3.160

[a]Values presented are: mean ± SD or percentage.
[b]RR per unit increase for continuous variable.
[c]High SGA score indicates better nutritional status (6–7: well nourished, ≤5: malnourished).

The social support interaction subscales were positively associated with each other, and negatively associated with the social support discrepancy subscales (Table 2). No correlations were found between the social support variables and clinical variables such as BMI, serum albumin, and Kt/V. Indication of depression was negatively correlated with social companionship (interaction) and daily emotional support (interaction), and positively associated with all three of the social support discrepancy variables.

Table 3 shows the hazard estimates between social support and mortality for the whole sample. The adjusted hazard ratios suggest there were no significant associations between any of the three aspects of social support (interactions) and survival.

The association between discrepancy in social support and mortality suggests that patients who perceived receiving insufficient social support have an increased mortality risk (Table 3). A 1-point adjusted increase in the discrepancy score for social companionship, daily emotional support and total support was associated with a 6%, 10% and 2% increase in mortality risk, respectively. The risk associated with discrepancy in emotional support with problems was reduced to non-significance following adjustments.

The effect of social support on mortality was similar in HD when compared with peritoneal dialysis (PD) patients. However, due to the smaller sample in each category following stratification, the confidence intervals (CI) in both subgroups were slightly wider (data not shown). Only daily emotional support (discrepancy) remained significant for HD patients after adjustments.

Discussion

Our study, using a large sample of incident dialysis patients, suggests that higher discrepancy between received and expected level of types of social support such as social companionship, daily emotional support and total support, was associated with higher mortality. These risks remained even after controlling for possible confounders such as age, gender, education level, marital status, comorbidity, serum albumin level, depression indicators, functional ability and treatment modality.

Social support affects health through behavioural, physiological and psychological mechanisms [23]. Provision of social support can be through emotional means, tangible efforts, information sharing or advice giving.

The disease characteristics of end-stage renal disease (ESRD) and its treatments are functionally debilitating, affecting social relationships and activities of daily living [24]. Discrepancy in social support expectations between patients and their family and friends results if patients hope to minimize lifestyle changes within the restrictions of dialysis whilst their support network might be unaware or unsure of how to cope with the patients' treatment and dietary needs [25]. Our results suggest an increased mortality risk amongst patients who perceive that they have insufficient supportive interactions. Our results are consistent with that of Christensen et al. [7] who reported that higher perceived family support was associated with lower mortality in HD patients.

That social companionship is important to our sample is consistent with previous research of dialysis patients using different cohorts, or in patients with other chronic illnesses [9,26,27]. Feeling socially isolated can induce stress and anxiety, which in turn can produce physiological changes, such as a compromised immune system [28], which if prolonged, could lead to higher morbidity and mortality [29].

Perceiving inadequacy in daily emotional support or shows of affection was associated with higher mortality in our sample. This finding again suggests that in view of the tremendous changes brought on by dialysis, patients might develop feelings of guilt and of being a burden to family and loved ones [24]. This in turn could increase patients' need for shows of affection and acceptance from their support network.

Both receiving and perceiving having inadequate emotional support with problems were not associated with mortality in our study. Although receiving

Table 2. Pearson correlations between social support variables, depression indicator and clinical variables

	SC-I	ES-I	DS-I	TS-I	SC-D	ES-D	DS-D	TS-D	DEP	Age	KI	rGFR	BMI	ALB
ES-I	0.67													
DS-I	0.69	0.74												
TS-I	0.86	0.94	0.87											
SC-D	−0.64	−0.38	−0.48	−0.53										
ES-D	−0.54	−0.56	−0.57	−0.62	0.71									
DS-D	−0.54	−0.51	−0.63	−0.61	0.70	0.83								
TS-D	−0.62	−0.54	−0.61	−0.64	0.86	0.95	0.91							
DEP	−0.20	NS	−0.15	NS	0.38	0.24	0.30	0.32						
Age	NS	NS	NS	NS	NS	NS	NS	NS	0.12					
KI	0.11	NS	NS	NS	−0.19	NS	NS	−0.10	−0.29	−0.31				
rGFR	NS	−0.11	NS	NS	NS	NS	NS	NS	NS	NS	0.23			
BMI	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS		
ALB	NS	NS	NS	NS	NS	NS	NS	NS	NS	−0.27	0.18	0.17	NS	
Kt/V	NS	NS	NS	NS	NS	NS	NS	NS	NS	0.19	NS	0.33	−0.14	NS

SC-I, social companionship-interactions; ES-I, emotional support with problem-interaction; DS-I, daily emotional support-interactions; TS-I, total support-interactions; SC-D, social companionship-discrepancies; ES-D, emotional support with problem-discrepancie; DS-D, daily emotional support-discrepancies; TS-D, total support-discrepancies; DEP, indicator of depression; KI, Karnofsky Index; rGFR, residual renal function; BMI, body mass index; ALB, serum albumin; Kt/V, renal urea clearance;
All correlations shown were $P < 0.05$; NS, non-significant.

Table 3. RR of aspects of social support on all-cause mortality from baseline to end of follow-up

Type of social support	Mean ± SD	Risk estimate			
		Crude		Adjusted[a]	
		RR[b]	95% CI	RR[b]	95% CI
Interaction					
Social companionship (range: 5–20)	11.74 ± 3.23	0.949*	0.906–0.994	0.972	0.924–1.023
Daily emotional support (range: 4–16)	10.30 ± 2.65	0.988	0.935–1.044	0.984	0.926–1.047
Emotional support with problems (range: 8–32)	19.74 ± 5.42	1.016	0.988–1.044	1.005	0.976–1.036
Total support (range: 17–68)	41.78 ± 10.19	0.988	0.984–1.013	0.998	0.982–1.014
Discrepancy (*Perceiving that not enough social support is received*)					
Social companionship (range: 5–15)	7.26 ± 2.50	1.113*	1.055–1.174	1.068*	1.004–1.135
Daily emotional support (range: 4–12)	5.55 ± 2.06	1.093*	1.023–1.168	1.098*	1.020–1.183
Emotional support with problems (range: 8–24)	10.98 ± 4.04	1.042*	1.007–1.078	1.033	0.997–1.071
Total support (range: 17–51)	23.79 ± 7.89	1.028*	1.010–1.045	1.022*	1.003–1.042

*$P < 0.05$.
[a]Adjusted for age, gender, education, marital status, Davies comorbidity score, serum albumin, functional ability, depression symptoms and treatment modality.
[b]RR per unit increase.

encouragement and advice from one's social support network can facilitate lifestyle change, it can also interfere. It interferes when the instances of support were deemed non-supportive by the patient despite the provider's best intentions, and could signify the failure of the provider to understand the patient's needs [30]. Patients might consider encouragement and advice giving as undesired criticism or control by their loved ones [31]. Viewed in this context, our patients might consider that being told to persevere in their illness, advice giving, or being given a nudge in the right direction, as being unhelpful or even a source of conflict.

We found no significant differences between HD and PD patients in the frequency of supportive interactions received and mortality. However, HD patients perceived receiving less sufficiency of daily emotional support compared with PD patients. This is of interest as it could be again related to the point discussed above regarding feelings of guilt and burden associated with dialysis. Compared with PD, patients on HD might require more help with transportation, financial support and home management [32].

This study does have limitations. Social support needs can be dynamic [33]. We measured social support once at baseline whilst the follow-up period could be up to 6 years. Thus, our data might reflect the needs of patients at the early stages of dialysis and may not be representative over time.

Previous research suggests that depression is significantly associated with mortality in dialysis patients [34,35]. Depression was also found to be associated

with lower levels of perceived social support in HD patients [36]. In our study, depression indicators were significantly associated with mortality, and were included in our model for adjustment. However, the association between social support and mortality remained similar when we excluded depression indicators from the model (results not shown). This suggests that possible depression is not an important factor in our study.

Understanding that patients on dialysis require different types of social support has important clinical implications. Clinical care providers could tailor intervention programmes to improve social support based on patients' needs, such as recommendations to appropriate programmes like self-help groups [37] or psycho-educational programmes [38–41] designed to promote self-efficacy in coping with dialysis. Besides providing relevant medical information regarding lifestyle changes due to dialysis, clinical care providers should also highlight to patients and family/caregivers the relational dynamics involved in lifestyle changes [31]. Patients and their family/caregivers could be made aware of potential conflicts that could arise when communicating encouragement and support for lifestyle change.

ESRD patients undergoing dialysis could require different types of social support depending on their social environment and the severity of the illness. Future studies could provide a longitudinal assessment with several points of data collection to chart for possible changes in social support needs since the start of dialysis and its association with survival.

In conclusion, this study suggests that patients' perception regarding the adequacy of their social support is an independent predictor of mortality. Different aspects of social support have varying levels of importance to the patients. To improve the long-term outcome of dialysis patients, efforts to prepare patients psychologically for the demands of dialysis treatment should be an integral part of their clinical care.

Conflict of interest statement. None declared.

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Appendix 1. Items in the Social Support List (SSL) subscales

Scale	Item (Does it ever happen to you that people*….)
Social companionship	– ask you to join in?
	– just call you up or just chat to you?
	– drop in for a (pleasant) visit?
	– go shopping, to the movies or sports matches, or just go out for a day with you?
	– invite you to a party or to dinner?
Daily emotional support	– are affectionate towards you?
	– cuddle/hug you?
	– lend you a friendly ear?
	– show that they are fond of you?
Emotional support with problems	– stand by you?
	– perk you up or cheer you up?
	– give you a nudge in the right direction
	– give you good advice
	– tell you to persevere?
	– comfort you?
	– help you to clarify your problems?
	– reassure you?

*'people' refers to all the people the patient associates with, such as family, friends, acquaintances, neighbours, colleagues, etc.