Can’t Live with You, Can’t Live without You: Negative Family Exchanges and Adaptation in End-stage Renal Disease Patients

Georgia Pomaki¹, Anita DeLongis¹, Tanya Anagnostopoulou², Jayme Heininger¹

Abstract
The present study examined associations between negative family exchanges (patient perceptions of family overprotection and negative expressiveness, and patient feelings of being a burden), and two indicators of adaptation to illness (mental health and negative affect) in patients with end-stage renal disease (ESRD). Data were collected using the perceptions of illness-related family exchanges questionnaire, the SF36 and the PANAS in a structured interview with 127 patients with ESRD in Greece. Findings indicate that patient perceptions of negative family exchanges are related to outcomes, even after controlling for demographic and clinical factors. It is important to consider caregivers in intervention programmes of ESRD patients.

Keywords
end-stage renal disease (ESRD), family burden, mental health, negative family exchanges, overprotection

According to the biopsychosocial model (Engel, 1977), disease course and resulting adaptational outcomes are influenced by complex interactions among medical, cultural and psychosocial factors. A series of studies on psychosocial factors in end stage renal disease (ESRD) has demonstrated that supportive family relationships decrease mortality, promote adherence to fluid-intake restrictions and improve psychological adjustment (Christensen and Ehlers, 2002). Much of the research to date examines social support as a protective factor in the lives of individuals with chronic conditions. However, negative aspects of social relationships have been found to have greater consequences than do positive aspects (Rook, 2001). Unfortunately, little is known about the role of negative social relationships in ESRD patients (Cukor et al., 2007). To address this gap, the present study examined the role of ESRD patients’ perceptions of negative family exchanges in adaptational outcomes and sought to understand which

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aspects of negative family exchanges are related to those outcomes.

ESRD patients face significant health challenges that are reflected in frequent and lengthy hospitalizations (1.7 hospitalizations per patient per year, for 4.8 to 11 days on average; Morduchowicz and Boner, 1996; Rayner et al., 2004). Hospitalizations can be very disruptive to an individual’s life and may lead to significant distress and uncertainty and compromised mental health (Kalantar-Zadeh et al., 2001). Poor mental health has been linked to lower quality of life, lower regimen adherence rates, decreased immune system functioning and increased morbidity and mortality in ESRD patients (Christensen and Ehlers, 2002; Kalantar-Zadeh et al., 2001; Kimmel et al., 2001). A better understanding of the factors that can undermine mental health may lead to more effective interventions.

The role of the social context in adaptation to illness

Contextual models of stress and coping (DeLongis and Holtzman, 2005; DeLongis et al., 2010) emphasize the importance of the social context in people’s ability to deal with important life stressors. Both family members and patients have to regulate their distress and cope with the burden of a chronic condition (O’Brien and DeLongis, 1997). When this process is effective, both patients and families benefit. However, research has demonstrated that family members are not always effective in supporting the chronically ill (Revenson et al., 1991).

Overprotection

Within the context of dealing with chronic illness, negative family exchanges can take different forms. Despite best intentions, family members can behave in an overprotective manner: engage in ‘speaking for’ behaviours (Croteau and Le Dorze, 2006), offer unnecessary help and limit activities (Thompson and Sobolew-Shubin, 1993a). When overprotection occurs, it can erode confidence and autonomy, lead to perceptions of loss of control and reinforce perceptions of disability in patients (Coyne and Smith, 1994; Thompson and Sobolew-Shubin, 1993a). Overprotection has been linked to depression in stroke (Thompson and Sobolew-Shubin, 1993a) and in myocardial infarction patients (Clarke et al., 1996), and to impaired physical health nine months post-myocardial infarction (Joekes et al., 2007). Based on these findings, we hypothesized that:

Hypothesis 1: Perceived family overprotection would be associated with decreased mental health and increased negative affect in patients with ESRD, after controlling for the patients’ demographic and clinical characteristics.

Negative expressiveness

Another form of negative family exchanges that can occur in families dealing with the challenges of a chronic illness is direct expression of negative feelings (Cormier-Daigle and Stewart, 1997). Patient perceived conflict with the spouse has been found to increase mortality risk by 46 per cent and has been associated with dysregulated levels of immunologic and neurohumoral markers (higher levels of IL-1 and β-endorphin) in female African American ESRD patients, but not in male patients (Kimmel et al., 2000).

In our study, we focused on the patient’s perception of the family’s direct expressiveness of negative feelings of tension, frustration and anger resulting from the experience of living with a family member with a chronic illness. It is unknown whether the expression of such negative feelings by family members is associated with mental health outcomes in ESRD patients of either gender and so, in our study, we explored whether:

Hypothesis 2: The patient’s perceptions of negative family expressiveness would be associated with decreased patient mental health and increased negative affect, after controlling for patients’ demographic and clinical factors.
**Perceived burden**

Our study also examined another aspect of negative family exchanges that is relevant to patients dealing with a chronic illness. There is theoretical and empirical evidence to suggest that feeling like a burden can influence the quality of life of chronically ill patients (McPherson et al., 2007). Equity theory posits that individuals in inequitable relationships, either receiving more than they are giving or giving more than they are receiving, feel uneasy and can become distressed (Wilson et al., 2005). Individuals with chronic illness have fewer resources to call upon, require more support and so may be unable to give an equal amount in return, leading to psychological discomfort. Research investigating burden in cancer and elderly populations has supported this claim (McPherson et al., 2007). It is unknown whether similar effects can be detected in ESRD patients, and so in the present study, we examined whether:

Hypothesis 3: Patients with ESRD who feel like they are a burden to their family would be more likely to have impaired mental health and increased negative affect.

**Hospitalizations and negative family exchanges**

In view of evidence-based interventions, it is important to identify factors that may influence the patients’ efforts to cope effectively with the challenges of the illness. Frequent or prolonged hospitalizations can impose significant stress and disruption to patients’ lives. We, thus, tested an interaction between hospitalizations and each of the three aspects of negative family exchanges. We hypothesized that:

Hypothesis 4: Patients facing challenges with disease management (i.e. longer hospitalizations) as well as with their family members (i.e. having stronger perceptions of overprotection, negative expressiveness or burden) are at greater risk for impaired mental health and increased negative affect than patients with less unfavourable perceptions of family exchanges.

We studied whether the patient’s perceptions of family overprotection, negative expressiveness and burden were associated with mental health and negative affect over and above demographic (age, gender and education), study (hospital location) and clinical factors (length of dialysis, history of transplantations and hospitalizations). We developed a new measure of negative family exchanges for the purpose of this study, as there were no existing instruments that are sensitive to the realities of and specifically designed for patients with chronic illness. We included three distinct aspects of negative family exchanges, because we wanted to cover a larger array of the patient’s experience of the family context, and because separate research literatures point to the importance of all three aspects of negative family exchanges in quality of life.

**Method**

**Participants and procedures**

Data were collected from 127 ESRD patients undergoing either haemodialysis or peritoneal dialysis in Greece at one urban and two rural region hospitals between July 2001 and January 2002. Permission was granted by hospital representatives to conduct the study, and patient consent was obtained by study interviewers who contacted potential participants during their scheduled outpatient hospital visit. Study interviewers collected all data with face-to-face interviews, consisting of structured questions. Patients were excluded from participation, if they had their first treatment session within 30 days from the beginning of the study, could not speak or understand Greek or were neither cognitively or emotionally able to participate.

The mean age of participants was 57.3 years (SD = 16, range 16–86) and 57.5 per cent were men. Half of the patients (53.4%) had elementary school education and 19.5 per cent higher
education. The majority of patients were married (76.2%). With regard to clinical characteristics, 53.5 per cent of the patients reported that they were not eligible for transplantation, 40.4 per cent were awaiting transplantation, with the rest having had a failed transplantation. The patients’ average length of dialysis was 63.2 months (SD = 63.5, range 4–294).

The response rate was 57 per cent for the first hospital location (urban) (99 patients eligible for participation, n = 56) and 43 per cent for the second (rural) hospital (70 patients were eligible for participation, n = 30). No information on response rate was available at the third (rural) hospital location (n = 41).

**Measures**

Sociodemographic factors included age, gender, education and marital status. Patients indicated how long (in months) they had been undergoing haemodialysis or peritoneal dialysis on a regular outpatient basis. Participants were not currently hospitalized, but were asked if they had been so in the past due to complications resulting from ESRD. They reported the number of days spent hospitalized during the past six months and whether they: 1 = were awaiting transplantation; 2 = had a failed transplantation; 3 = were not eligible for transplantation.

In order to assess all three aspects of negative family exchanges (overprotection, negative expressiveness, burden), we developed 11 items that comprised the perceptions of illness-related family exchanges (PIFE) questionnaire (items were translated from Greek to English and back-translated). Those items were informed by existing instruments (Coyne and Smith, 1991; Revenson et al., 1991; Thompson and Sobolew-Shubin, 1993b), by our theoretical considerations on the role of negative family exchanges in adaptation to chronic illness and by existing empirical literature. Participants provided their responses on a scale from 1 = strongly disagree to 5 = strongly agree. The items for family overprotection were: ‘Since I got sick I am not allowed to do anything’, ‘Since I got sick my family and I do not do many things together’ and ‘I have the sense that my family feels sorry for me’; for perceived family negative expressiveness were: ‘The folks at home often complain that I am not like I was before I got sick’, ‘There is more tension and unrest in our home since I got sick’, ‘My family members often yell at me when I do not follow my doctors’ orders’ and ‘The members of my family try hard to help me, but they often do not fully understand my special needs’; and for perceived family burden were: ‘I feel like I can’t contribute to my family as much as I contributed before I got sick’, ‘Since I got sick I feel I am a burden to my family’ and ‘Sometimes I feel bad that my family spends so much time and effort on me.’

In order to examine whether the assumed three PIFE factor structure is represented in our data, items were subjected to confirmatory factor analysis (EQS 6.1; Bentler, 2004). Three measurement models were tested, representing PIFE scales as a single factor, and as two and three factors. The three-factor model showed a satisfactory fit (NFI = .85, NNFI = .99, CFI = .99, RMR = .05, RMSEA = .01, $\chi^2$[41] = 41.8, p = .44) and a better fit than the two- or single-factor models (chi-square difference test for the comparison with the two-factor model: $\Delta\chi^2[2] = 7.6, p < .05$; chi-square difference test for the comparison with the single factor model: $\Delta\chi^2[3] = 35.3, p < .001$). The three subscales showed satisfactory reliability (family overprotection $\alpha = .72$, family negative expressiveness $\alpha = .62$ and family burden $\alpha = .62$). Patients also reported how many family members lived in the same household with them (M = 3.47 family members, SD = 1.64, range 1–10).

Mental health was assessed with the validated Greek version (Pappa et al., 2005) of the medical outcomes study short form-36 (Ware and Sherbourne, 1992). We used the summary mental health scale (Ware and Gandek, 1998) that consists of 14 items from four subscales (vitality, social functioning, role limitations due to emotional problems, and general mental
health; $\alpha = .86$). Negative affect was assessed as a state variable with the negative affect subscale of the positive and negative activation schedule (PANAS; Watson et al., 1988; Watson et al., 1999). Participants were asked (1 = very slightly or not at all, 5 = extremely) to what extent they experienced each of 10 negative mood adjectives (distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, afraid) at that moment in time ($\alpha = .76$).

**Results**

**Descriptive statistics and bivariate correlations**

Means from normative data for the SF-36 mental health composite ($M = 50$; Ware and Gandek, 1998) and negative affect ($M = 17.4$; Crawford and Henry, 2004) are comparable to those obtained in the present sample ($M = 52.9$ and $M = 16.9$ respectively). Perceptions of negative family exchanges were significantly correlated with each other and with the study outcomes (Table 1).

**Preliminary analysis**

Age, marital status and length of dialysis were not associated with any of the focal variables and, so, they were not included in further analyses. We also tested whether length of dialysis was non-linearly related to the study outcomes, but found no significant relationships. We compared patients recruited from each of the three hospitals on all study variables. We found that patients recruited at the first hospital were younger ($M = 52.8$, $SD = 17.6$) and had poorer mental health ($M = 47.6$, $SD = 20.4$), compared to patients at the third hospital (age: $M = 61.4$, $SD = 11.4$; mental health: $M = 63.1$, $SD = 25.5$). Patients at the second hospital had more hospitalizations ($M = 12.8$, $SD = 18.9$) than did patients at either the first ($M = 3.1$, $SD = 6.4$) or the third hospital ($M = 4$, $SD = 7.5$). Women had poorer mental health than did men ($t(122) = 3.31$, $p \leq .001$). Patients with higher education perceived their family as less overprotective than patients with elementary or high-school education ($t(108) = 2.30$, $p \leq .05$). Patients who were awaiting transplantation had better mental health ($t(110) = 2.19$, $p \leq .05$) than those who were not eligible for or had a failed transplantation. Based on these results, we included gender, education, hospital location and history of transplantations as control variables in our analysis.

**Multivariate analysis**

Mental health and negative affect were not normally distributed and were square root transformed to comply with parametric testing. Perceptions of negative family exchanges explained meaningful amounts of variance in the study outcomes, ranging from 8 per cent to 22 per cent, after controlling for the effects of demographic, study and clinical characteristics. More specifically, patients with higher reports of family overprotection, negative expressiveness and burden had poorer mental health or more negative affect (Table 2).

### Table 1. Means, standard deviations and intercorrelations (Pearson’s $r$)

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<thead>
<tr>
<th>Variables</th>
<th>M</th>
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<tr>
<td>1. Hospitalizations</td>
<td>4.8</td>
<td>9.9</td>
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<td>.21</td>
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<td>2. Family overprotection</td>
<td>3.3</td>
<td>1.2</td>
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<td>.32</td>
<td>.56</td>
<td>.36</td>
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<td>3. Family negative expressiveness</td>
<td>2.8</td>
<td>1.2</td>
<td>–</td>
<td>.38</td>
<td>.25</td>
<td>.32</td>
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<td>4. Family burden</td>
<td>3.2</td>
<td>1.2</td>
<td>–</td>
<td>.45</td>
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<td>.43</td>
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<td>5. Mental health</td>
<td>52.9</td>
<td>23.1</td>
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<td>–</td>
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<td>6. Negative affect</td>
<td>16.9</td>
<td>6.2</td>
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*p ≤ .05; **p ≤ .01; ***p ≤ .001
We predicted that perceptions of negative family exchanges would moderate the effect of history of hospitalizations on the study outcomes. There was one significant interaction between perceived family burden and negative affect, explaining 4 per cent of the variance. In order to determine the nature of the interaction, we constructed plots by computing unstandardized beta coefficients of variables at values one standard deviation above and below the mean. Simple slopes analysis (Dawson and Richter, 2006) indicated that hospitalizations had the strongest impact on negative affect when perceived family burden was high ($\beta = .40$, $p \leq .01$). The slope for low perceived family burden was not significant ($\beta = -.10$, $p > .10$). See Fig. 1.

We also tested a model whereby family overprotection, negative expressiveness and burden were included in the same step in the regression equation, after controlling for gender, education, history of transplantation, and hospital location. The results are presented in Table 2, which shows that hospitalizations had the strongest impact on negative affect when perceived family burden was high ($\beta = .40$, $p \leq .01$). The slope for low perceived family burden was not significant ($\beta = -.10$, $p > .10$). See Fig. 1.

<table>
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<th>Table 2. Multiple regressions for variables predicting mental health and negative affect</th>
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Notes: $^{***}p \leq .001$; $^{**}p \leq .01$; $^*p \leq .05$; $^p \leq .10$. $^\beta$ values from the step in which variables first appeared. $^\times$ Higher value on gender denotes women. $^\dagger$ Hospital location is coded as 1 = urban, 2 = rural A, 3 = rural B.
hospital location and hospitalizations. The three family variables together explained 22 per cent of the variance in mental health and 24 per cent of the variance in negative affect. Perceived family burden was uniquely associated with mental health ($\beta = -0.27$, $p \leq 0.05$) and negative affect ($\beta = 0.37$, $p \leq 0.01$). Family overprotection was uniquely associated with mental health ($\beta = -0.23$, $p \leq 0.05$). Negative expressiveness was not significantly associated with either outcome.

**Discussion**

The present study focused on a sample of patients with end-stage renal disease undergoing haemodialysis or peritoneal dialysis. Our findings indicate that patients’ perceptions of negative family exchanges were associated with adaptational outcomes. We found that patients who viewed their families as overprotective, negative in their emotional expression towards them or felt themselves a burden to their families were more likely to report impaired mental health and increased negative affect. Particularly, feelings of burden and overprotection had the largest and most significant contribution. These findings were independent of patients’ demographic and clinical characteristics.

A recent review on the role of psychosocial factors in the lives of ESRD patients suggested that supportive families play a protective role in quality of life and disease course (Christensen and Ehlers, 2002). Our study suggests that another side of patients’ family relationships, characterized by negative exchanges, could also play a role in adaptation to illness. Our finding that overprotection was associated with adverse mental health outcomes in ESRD agrees with prior research in other patient populations (e.g. myocardial infarction and stroke patients; Clarke et al., 1996; Thompson and Sobolew-Shubin, 1993a). Future longitudinal work is needed to disentangle the temporal link between family overprotection and mental health and further look at possible strategies that can be applied by both patients and family members to minimize overprotection. Our finding that feeling like a burden to one’s family due to the presence of a chronic illness is associated with compromised mental health outcomes corroborates prior findings in cancer and elderly populations (McPherson et al., 2007). It suggests that feelings of guilt and responsibility resulting from dependency and the need for physical assistance dictated by the presence of chronic illness should be taken into account in efforts to improve mental health in ESRD patients. Future work can focus on the impact of the patient’s perceived family burden on medical decisions and on the role that mental health plays in both burden and decision making.

Our findings agree with Fisher and Weihs’ (2000) approach to chronic disease management and imply that intervention programmes might increase their effectiveness by addressing negative family exchanges. Prior research has shown that, in the context of chronic illness, patients’ perceptions of negative family exchanges may result from a combination of insufficient caregiver support and resources, inequity in the caregiver–patient relationship and caregiver burden and resentment (Liang et al., 2001; Thompson and Sobolew-Shubin, 1993a; Thompson et al., 2002). Intervention programmes that can address those issues are in line with the present study’s findings. In addition, providing treatments and resources that allow patients to be less dependent on family care could also have a positive effect on the patient and their family. Research on severely
ill patients using home-dialysis treatment indicates that family burden and patient depression are higher under those circumstances compared to centre-based dialysis treatment (Eitel et al., 1995).

Our findings also suggest that ESRD patients who feel like they are a burden to their family are more vulnerable to the difficulties incurred by prolonged hospitalizations. In contrast, not feeling like a burden was found to act as a protective factor against the otherwise detrimental effects of lengthy hospitalizations. Such patients may have the necessary emotional resources to deal with disease complications. Future research should examine how caregivers protect patients from feeling like they are a burden.

Our study is characterized by several limitations. First, because the study design was cross-sectional, it is not possible to delineate causal direction among our variables. Rather, our study suggests that negative family exchanges are implicated in the process of adaptation to a chronic illness. Future research should examine at which stage negative family exchanges become crucial to adaptation to illness. Second, because we used a new measure to assess negative family exchanges that was specifically designed for the chronically ill and their families, more research is needed to examine the validity of this measure in similar or other patient populations and outcomes. Third, there is a need for replication of the present findings using information obtained from medical records with regards to hospitalization frequency and duration (for a discussion of accuracy of self-reported information versus medical records, see Merkin et al., 2007). Fourth, generalizability of our findings may have been compromised due to the study response rate and the lack of information about non-responders. Finally, our participants reported a history of dialysis ranging from four months to 24 years. Future work may uncover particular periods of vulnerability or opportunity to improve mental health and other outcomes in this population.

In conclusion, the present study has illustrated the importance of negative aspects of family relationships in mental health and negative affect in patients with ESRD. Our results suggest that patient perception of how the family responds to the illness is key to patient quality of life, and should be taken into account in treatment and intervention programmes.

Competing Interests

None declared.

Acknowledgements

This research was supported by a post-doctoral fellowship from the Michael Smith Foundation for Health Research to the first author and an operating grant from the Social Sciences and Humanities Research Council of Canada to the second author. We would like to thank our collaborators: D. Tsakiris, E. Vantsi and E. Dounoussi (Department of Nephrology at Veroia Hospital), N. Dombros, E. Patrikalou and K. Tassiopoulou (Department of Nephrology, AHEPA Hospital, Thessaloniki), K. Siamopoulos, J. Katopodis and D. Damigos (Department of Nephrology, Ioannina University Hospital) and A. Mastorakou, T. Leleka and N. Moutopoulou (Department of Psychology, Aristotle University of Thessaloniki).

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