Published in final edited form as:

Curr Rheumatol Rev. 2016 ; 12(3): 232–238.

The Relationship Between Social Support, Social Constraint, and Psychological Adjustment for Patients with Rare Autoimmune Disease

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Abstract

Our goals were to describe the balance of social support to negative social interactions (i.e. social constraint) for autoimmune disease patients and determine whether support and constraint from spouses and non-spousal family and friends interact to influence patients' psychological adjustment. Using cross-sectional survey data from 109 married vasculitis and lupus patients, we found that patients reported that spouses and family/friends provided more social support than social constraint. In regression models, constraint from spouses ($\beta = -0.45$, $p<0.01$) and family/friends ($\beta = -0.89$, $p<0.001$) were associated with worse patient psychological adjustment. A significant 3-way interaction revealed that patients with low spousal support had worse psychological adjustment as the levels of family and friend support increased. In contrast, patients with high levels of spousal support reported better psychological adjustment as family and friend support increased. Future longitudinal studies may help to elucidate the complex interplay between constraint and support from spouses, family, and friends.

Keywords

Social support; social constraint; psychological adjustment; vasculitis; lupus

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CONFLICT OF INTEREST

The authors confirms that this article content has no conflict of interest.

1. INTRODUCTION

The emotional and physical health of patients living with a chronic disease is influenced by the people around them, including their spouses, family, and friends. Social support is the term most often used to describe the processes by which a patient's social network members provide emotional, instrumental, informational, and appraisal resources during a patient’s time of need [1, 2]. Although less studied, social constraints, or interactions with social network members that cause individuals to feel unsupported, may be as or more influential for patients’ well-being [3–5].

Individuals with chronic diseases are likely to experience anxiety and depression [6]. Cognitive processing theories emphasize how emotional distress associated with negative psychological states, such as anxiety and depression, impedes individuals’ mental processes (i.e., confronting, contemplating, and reevaluation) to cope with illness [7]. A supportive social environment has been demonstrated to enhance cognitive processing by allowing individuals to communicate and contemplate their experiences, thoughts, and emotions [7]. Thus, support from social network members can help chronic disease patients create or maintain a positive self-concept and worldview, which can ultimately lead to better psychological adjustment.

Spouses are a key source of social support for chronic disease patients. Social support from spouses may affect both psychological and physical outcomes through a number of biological, psychological, and behavioral pathways [8]. For example, married patients have consistently demonstrated less depression [9], more effective illness coping strategies [10], better adherence to treatment regimens [11], more motivation, fewer risky behaviors, and more stress resistance than unmarried individuals [12]. For patients living with rheumatic conditions like arthritis, social support from spouses is associated with less disease activity, greater life satisfaction [12], and better psychological adjustment [10].

Support from family and friends also has been associated with greater psychological adjustment, including more life satisfaction, more positive moods, and less depression in healthy adults [9, 13–15]. For rheumatoid arthritis patients, support and help from close friends and family is related to less depression [16]. Moreover, friend support has been associated with better adherence to blood glucose testing for diabetes patients [17].

In addition to being sources of support, spouses are also sources of unsupportive interactions (or social constraints) for patients. Sometimes spouses make supportive attempts that are not desired or well-matched with patients’ needs; doing so can increase patients’ anxiety and ultimately may worsen psychological adjustment [3, 18] and negatively impact disease outcomes, such as pain [12]. In addition, social constraints from spouses may increase patient anxiety and depressive symptoms [10, 15, 16, 19] and lower patient adherence to self-care activities [20].

Family (other than spouses) and friends are less studied sources of social constraints for patients. For the general population, negative exchanges with family and friends are likely to increase stress [21] and depressive symptoms [9]. Previous research has found that negative interactions with friends were associated with an increase in depressive symptoms for HIV patients [19] and a decline in psychological health and poor metabolic control for adolescents with diabetes [22].

In the few studies that have compared the relative influence of different social network members on patients' psychological adjustment, the results have been mixed. In one study of HIV patients by Scrimshaw (2003), social constraints from non-spouse family members were a stronger predictor of depressive symptoms than social constraints from spouses or friends. In contrast, Walen and Lachman (2000) reported that support and constraints from spouses had a stronger effect on psychological well-being than support and constraints from friends and other family members; however, only friend support was significantly associated with subjective health. Other researchers have shown that social support from spouses, family, and friends exert a similar influence on depressive symptoms [9]. Holt-Lunstad and colleagues (2008) found that the effect of family/friend support varies based on spousal relationship quality. A supportive network of family and friends did not buffer the negative health effects of a low-quality marriage [23]. Gender may also moderate the relationship between support, constraint, and psychological outcomes, since women are more likely to report low quality relationships [13] and report more negativity in their relationships than men [24, 25].

Outside of the cancer sphere, few studies have examined how support and constraints from spouses, family, and friends interact to influence patient psychological adjustment. Both vasculitis and lupus are autoimmune conditions associated with unpredictable periods of relapse and remission resulting in spouses unexpectedly having to perform intense caregiving duties. Thus, the nature of spouse constraints may vary substantially between vasculitis/lupus patients and cancer patients. Our goal was to build upon previous research to describe the balance of social support to social constraint for vasculitis and lupus patients and determine whether support and constraint from spouses and non-spousal family and friends interact to influence patients' psychological adjustment. In line with Lepore's (2001) model, we expected social constraints from all sources (spouses, family/friends) to be associated with worse psychological adjustment [7]. Although findings on the relative effects of spouses and family/friends is mixed, we hypothesized that the effects of spousal support and constraint on patient psychological adjustment would not vary by levels of family and friend support; or, in other words, the interaction terms between spouse support and family/friend support and spouse constraint and family/friend constraint would be statistically insignificant.

2. MATERIALS AND METHODS

All data reported in this article are from the Partners Adjusting to Illness with Relationship Support (PAIRS) Study, a longitudinal, observational study of married couples in which one partner has antineutrophil cytoplasmic anitbodies-associated small vessel vasculitis (ANCA-SVV) or lupus. In the PAIRS study, patients and their spouses completed a baseline and 12-month follow-up mailed questionnaire at home. In this article we use cross-sectional data from the 109 patients who completed the 1-hour, self-administered, follow-up questionnaire. The PAIRS study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

2.1. Participants

We recruited patients by mailing recruitment letters to physician-diagnosed vasculitis and lupus patients who were part of the Glomerular Disease Collaborative Network (GDCN) registry and posting a variety of general recruitment announcements in patient newsletters, websites, conferences, and support group meetings. In total, 282 patients expressed interest in the study and completed a phone screening to determine eligibility. Patients were excluded if they did not have a self-reported diagnosis of vasculitis or lupus for at least six months (n= 3), were currently on dialysis (n= 1), had a kidney transplant (n= 4), or were not legally married (n= 18). Patients were also excluded if they or their partners were less than 18 years of age, could not read, speak, and write in English, or had a significant uncorrected hearing problem (n= 3). Lastly, couples who did not agree to travel to one of the study's interview offices to complete the interview portion of the study (n=52) or were uninterested in participating after learning more about the study (n=5) were excluded. The remaining couples (n=196) were mailed study consent and HIPAA forms.

Of the 196 eligible and interested couples, 140 (71%) provided consent and completed the baseline assessment and 109 (56%) completed the 1-year follow-up questionnaires. Reasons for loss-to-follow-up included patient too sick or patient/spouse death (n=5) or no desire to continue with the study (n=26).

2.2. Measures

Psychological adjustment. Patients' psychological adjustment was measured using a composite of five indicators: 1 & 2) positive and negative affect; measured with the Positive and Negative Affect Scale (PANAS; alpha=0.91; positive affect and 0.87 negative affect) [26]; 3) depressive symptoms; measured with the Center for Epidemiologic Studies Depression Scale (CES-D; alpha= .90) [27–29]; 4) satisfaction with life; measured with the Satisfaction with Life Scale (SWLS; alpha= .89) [30]; and 5) dispositional optimism; measured with the Life Orientation Test (LOT) [31]. In a factor analysis, all five indicators loaded strongly onto one factor, just as in a previous study of rheumatoid arthritis patients [32]. Thus, we calculated the mean of the five psychological adjustment indicators as our final measure; higher scores indicated better adjustment. Cronbach's alpha of this final composite measure was 0.82.

Social support and social constraints. Illness-specific social support and social constraints from spouses were assessed with three subscales from the Partner Responses to Cancer Inventory (PRCI) [10], modified to pertain to vasculitis and lupus. The PRCI asks patients to report how often during the past month their spouses acted in particular ways, using a four-point Likert scale (1= "never responded this way" to 4= "often responded this way"). We used the emotional/instrumental support and cognitive information/guidance subscales to assess spousal support and the criticism/withdrawal subscale to assess spouse constraints. These three subscales have demonstrated good internal consistency reliability and construct validity in previous studies with couples encountering various types of cancer [10]. The emotional/instrumental support subscale (8 items) assessed patients' perceptions of tangible support from spouses; e.g., how often spouses said they would be available for assistance when patients needed them. The cognitive information/guidance (9 items) subscale assessed spouses' efforts to help patients solve problems related to their illness; e.g., helping patients analyze a problem in order to understand it better. The criticism/withdrawal subscale (14 items) assessed patients' perceptions of spouses' negative behaviors; e.g., criticizing patients' coping behavior or avoiding patients when they were not feeling well.

We used the same three PRCI subscales to assess illness-specific social support and social constraints provided by other family members and friends, by replacing references to the "spouse" with references to "family and friends (other than your spouse)".

We used a principal component analysis (PCA) with oblique rotation to verify the factor structure of the PRCI in our sample. Our results indicated the same component structure for both the spouse and friend/family PRCI scales: positive/supportive behaviors (social support), consisting of items from the emotional/instrumental and cognitive information/ guidance scales, and negative/unsupportive behaviors (social constraints), consisting of items from the criticism/withdrawal scale. After removing underperforming items (see supplementary materials), the final social support scale consisted of 13 items and had good internal consistency (α=0.90 for spouse items; α=0.91 for family and friends items) and the social constraints scale consisted of 14 items (α=0.91 for spouse items; α=0.88 for family and friends items).

Sociodemographic and clinical characteristics. Patients reported their age in years, gender, race (dichotomized to white versus non-white), years of education (1 to 17+), and the number of months/years they had been diagnosed with vasculitis or lupus. To assess patients' level of disease activity, we faxed a form to all patients' physicians, asking them to rate the patient's current condition (based on the patient's last visit) using a 10-point scale (1= "remission" to 10= "most active disease").

2.3. Data Analysis

We used SAS Version 9.3 to conduct all analyses. First, we calculated means and standard deviations to describe patients' social characteristics. Then we inspected Pearson correlation coefficients to examine unadjusted relationships between support and constraints from spouses and family/friends and patient psychological adjustment. To examine the relative associations of spouse and family/friend support and constraint with psychological adjustment, we ran a series of regression models; age, race, sex, education, disease duration, and disease activity were included as control variables and listwise deletion was used for cases with missing data in all models.

In Model 1, patient psychological adjustment was the dependent variable and spouse support and constraints were the primary independent variables. Model 2 also had patient psychological adjustment as the dependent variable, but family/friend support and constraints were the primary independent variables. In Model 3, we assessed the relative influence of spouses versus family and friends by including all four variables (spouse support, spouse constraints, family/friend support, family/friend constraints) as predictors of patient psychological adjustment. We included a three-way interaction term to explore support interactions (spouse support X family/friend support X patient gender) in Model 3 and included a three-way interaction term (spouse constraint X family/friend constraint X patient gender) to explore constraint interactions in Model 4. For Models 3 and 4, we conducted F-tests with 3 degrees of freedom to determine whether the addition of interaction terms significantly improved the models.

3. RESULTS

Patients' sociodemographic characteristics are presented in Table 1. Spouses ($t_{(106)}$ =15.42, p<.0001) and family/friends ($t_{(107)}$ =15.66, p<.0001) were more likely to provide patients with social support than social constraints. However, spouses provided more support ($t_{(106)}$ =6.89, p<.0001) and more constraints ($t_{(106)}$ =3.16, p=.002) than family and friends.

As shown in Table 2, social support from spouses (r=.19, p=.04), but not family and friends (r=.01, p=.94), was associated with better patient psychological adjustment. In contrast, social constraints from both spouses and family/friends were significantly associated with worse psychological adjustment (r=−.35, p<.001 and r=−.31, p<.001, respectively). Additionally, there was a negative correlation (r=−.41, p<.001) between spouse support and spouse constraints. Gender (r=.21, p<.05) was significantly associated with family/friend support. Age (r=.26, p<.01) was significantly associated with spouse support. Race was not associated with any patient psychological adjustment. Yet, there was a negative correlation (r=−.19, p<.05) between education and spouse support. A higher level of disease activity was associated with more constraints from both spouses (r=.25, p=.01) and family/friends (r=.24, p=.02). Longer disease duration (r= .27, p<.01) was significantly associated with spouse constraints.

3.1. Regression Results

In Model 1 (Table 3), in which spouse support and constraints were the independent variables, spouse constraints were associated with worse patient psychological adjustment. Similarly, in Model 2, more constraints from family and friends were associated with worse patient psychological adjustment. In Model 3 (Table 4), the three-way interaction between spouse support, family and friend support, and patient gender was significant (p=0.01). Patients with low spousal support demonstrated worse psychological adjustment as the levels of family and friend support increased. In contrast, patients with high levels of spousal support reported better psychological adjustment as family and friend support increased. Male patients with supportive spouses showed a more marked improvement in psychological adjustment when support from family and friends increased. In Model 4, the three-way interaction between spouse constraint, family/friend constraint, and gender was insignificant.

As shown in Tables 3 and 4, the overall F-tests for each model were significant. The addition of the three interaction terms to Model 3 did not significantly improve the model ($F_{(3)}$ = 2.43, p=0.07). Similarly, the addition of the three interaction terms to Model 4 did not significantly improve the model ($F_{(3)}$ = 0.44, p=0.72).

4. DISCUSSION

This study adds to previous studies by examining the relative effects of social support and social constraints from spouses versus family and friends on psychological adjustment in married individuals living with rare autoimmune conditions. Our hypothesis that social constraints would be associated with worse psychological adjustment was supported. However, contrary to our hypothesis, there was a significant interaction between support from spouses and family/friends such that the effect of family/friend support varied based on levels of spousal support and patient gender.

Consistent with previous research [3, 4, 5, 15, 19], constraint from social network members was a more powerful predictor of patient adjustment than support, even though constraints occurred less frequently than support. Although there has been a limited body of work that explores the relative effects of constraint from social network members, Scrimshaw (2003) found that criticism and withdrawal from family, but not from spouses, predicted depressive symptoms for HIV patients. In models that included both spouse constraints and family/friend constraints, we found that social constraint from family/friends was more strongly associated with psychological adjustment than constraint from spouses. Because spouses are likely the patient's main caregiver and may have to engage in a number of daily caregiving tasks, patients may be more likely to expect negative interactions with the spouse than with their family/friends. Because social constraints from family/friends are less expected, they may be particularly detrimental to patient psychological adjustment. Future qualitative work that examines patient reactions to constraint from family and friends is warranted to better understand why constraints from family and friends exhibit such a strong relationship with psychological adjustment in this population.

Correlations revealed that patients perceived more social constraints from both spouses and family/friends when they had higher levels of disease activity. In autoimmune conditions, such as vasculitis and lupus, disease flare-ups are unpredictable and can be quite severe, sometimes requiring hospitalization. Thus, more active disease may stress patients' relationships with social network members, who may then be more likely to engage in negative social behaviors.

In Model 3, we found a complex relationship between social support and patient psychological adjustment in our sample. Family/friend support was helpful only for those patients who report high levels of spousal support. Because available support tends to be activated when people need it most [33], it is possible that patients who are healthier report less support from network members, presumably because they are functioning at a high level and have fewer needs. This could explain why patients who reported low levels of both spouse and family/friend support also reported better psychological adjustment. Along these lines, if family and friends are offering unwanted support to healthier patients, then this may have made patients in our sample anxious and negatively impacted their psychological adjustment. On the other hand, patients who were receiving higher levels of support from their spouses may have been less healthy. These patients may have desired support from additional sources, possibly explaining why support from family and friends increased psychological adjustment for patients who reported greater support from their spouses.

As shown by the significant spouse support X family/friend support X gender interaction term in Model 3, when compared with women, men with supportive spouses showed a more marked improvement in psychological adjustment when support from family and friends increased. Male patients also reported less family/friend support than female patients. These findings are consistent with previous studies which documented that spouses are the primary source of support for men [34]. Because male patients are less likely to seek support from family and friends [34], support from these sources may be particularly helpful in regards to psychological adjustment, especially if the patient is experiencing active symptoms of the disease.

4.1. Limitations

This study has several limitations. First, because we recruited via general announcements, we were unable to calculate a response rate and cannot estimate the effects of a potential selection bias. Also, patients in our sample may have had greater marital quality and been healthier than the general population of lupus and vasculitis patients (i.e., they were able to travel for interviews); thus, these results may not generalize to the larger patient population. In particular, selection bias may be causing the positive relationship between well-being and support, and the effect of support on patient psychological adjustment may be smaller in the larger population. The lack of diversity in our sample further limits our ability to generalize the study results. Second, we cannot determine whether the relationships between support, constraint, and patient psychological adjustment are causal due to the cross-sectional nature of the study. Third, we adapted the social support and constraint measures from a scale that had been used with cancer patients. Although our factor analyses and Cronbach alphas indicated sound psychometric properties for the adapted scales, further psychometric testing with larger samples should be conducted to establish the validity and reliability of these measures in this population. Additionally, our support and constraints measures combined friends and family, we were unable to determine whether friends or family were more influential. However, family was more likely to be a source of negativity than friends in a previous study [19]. Additionally, the PCRI measures assessed received support rather than perceived support, which have different theoretical relationships to patient outcomes. Last, we did not include a measure of satisfaction with received support; therefore, we could not control for this variable in our regression models.

CONCLUSION

Despite our study’s limitations, our results suggest that family and friends may be overlooked sources of influence for patients living with rare illnesses like vasculitis and lupus. Given the robust nature of the family and friend constraints variable, clinicians and health educators should provide patients with resources that address how to cope with negative social interactions in the context of chronic disease. Interpersonally-focused interventions that encourage helpful interactions with patients’ social network members may be especially important for diseases like lupus and vasculitis in which the psychosocial aspects of disease are often neglected [35, 36, 37]. Information about how to help patients, spouses, and family/friends communicate during periods of high disease activity may be particularly helpful for vasculitis and lupus patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Declared none.

This project was supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (P60-AR49465-05) and the Renal Epidemiology Predoctoral Traineeship at the University of North Carolina Kidney Center.

Biography

Delesha M. Carpenter

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Table 1

Participant characteristics.

Characteristics	**N**	**Mean (SD) or %**
Socio-demographic		
Age	109	52.4 (14.6)
Male	109	39.5%
White	109	86.2%
Education (in years)	109	14.9 (2.1)
Years Married	109	25.9 (16.3)
Disease		
% Vasculitis	109	69.7%
Years with disease	108	8.6 (7.8)
Disease activity	97	2.3 (1.5)
Social		
Spouse support	107	3.0 (0.6)
Family/Friend support	108	2.6 (0.7)
Spouse constraints	108	1.6 (0.6)
Family/Friend constraints	108	1.4 (0.4)

Table 2

Pearson correlation coefficients between patient psychological adjustment and predictor variables.

Variable	1	2	3	4	5
1. Psychological Adjustment	–	.19[*]	−.35[‡]	.01	−.31[‡]
2. Spouse support		–	.41[‡]	.47[‡]	.03
3. Spouse constraints			–	.01	.44[‡]
4. Family/friend support				–	.02
5. Family/friend constraints					–

[*] p<.05

[†] p<.01

[‡] p<.001.

Table 3

The main effects of spouse and family/friend support and constraints on psychological adjustment (n=95).

	Model 1 Spouse Only		**Model 2 Family/friend Only**	
Variable	***B***	**SE B**	***B***	**SE B**
Spouse support	.07	.15	–	–
Spouse constraints	−.45[**]	.17	–	–
Family/friend support	–	–	.13	.12
Family/friend constraints	–	–	−.89[***]	.18
Adjusted R^2	**.10**		**.23**	
F-test	**$F_{(94)} = 2.25$**[*]		**$F_{(94)} = 4.45$**[***]	

[*] p<.05,

[**] p<.01,

[***] p<.001,

Note: Not shown in this table are covariates (age, race [ref=white], education, disease activity, disease duration); none of which evidenced significant relationships with the outcome variable.

Table 4

The interaction effects of spouse and family/friend support and constraints on patient psychological adjustment (n=95).

Variable	Model 3 Support Interaction		Model 4 Constraint Interaction	
	B	**SE B**	**B**	**SE B**
Spouse support	.00	.51	.15	.17
Spouse constraints	.06	.19	.74	.77
Family/friend support	.09	.46	.09	.15
Family/friend constraints	−.87***	.20	−1.31	.74
Spouse support X male gender	−.55	.42	–	–
Family/friend support X male gender	−.83*	.40	–	–
Spouse support X Fam./fr support male X gender	.27*	.10	–	–
Spouse constraints X male gender	–	–	−.45	.51
Fam/fr constraints X male gender	–	–	.28	.51
Spouse constraints X Fam./fr constraints X male gender	–	–	–.02	.16
Adjusted R^2	**.28**		**.22**	
F-test	**$F_{(94)} = 3.78$*** **		**$F_{(94)} = 3.11$*** **	

*p<.05,

**p<.01,

***p<.001,

Note: Not shown in this table are covariates (age, race [ref:white], education, disease activity, disease duration); none of which evidenced significant relationships with the outcome variable.