

Social Support and Psychological Distress in Women with Systemic Lupus Erythematosus

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Statement of the Research Problem

Persons diagnosed with systemic lupus erythematosus (SLE) face many illness-related physical stressors and experience psychological distress as a result of chronic illness. Systemic lupus erythematosus is a chronic inflammatory connective tissue disease of unknown etiology affecting the skin, joints, kidneys, nervous system, serous membranes, and other organs of the body. The disease follows an unpredictable course of exacerbates (flares) and remissions, with either phase fluctuating in length (Regan-Gavin, 1988).

Systemic Lupus Erythematosus affects one out of 2000 Americans. It is diagnosed in women nine times more frequently than in men. It is primarily a disease of young women and often occurs during the childbearing years (Klippel, 1997). SLE is more common in African Americans, Asians, and people of Latin descent (Kuper & Failla, 1994).

Persons with a chronic illness, such as systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA), face a variety of illness-related physical stressors for which social support from family, friends, and professionals may be helpful (Melamed & Brenner, 1990). In the RA and SLE research literature the following illness-related physical stressors have been found to be associated with psychological distress: physical pain (Brown, Wallston, & Nicassio, 1989; Weinberger, Tierney, Booher & Hiner, 1990); decreased muscle and joint mobility or functional disability (Affleck, Pfeiffer, Tennen & Fifield, 1988; Doeglas, Suurmeijer, Krol, Sanderman, Rijswijk & Leeuwen, 1994; Goodenow, Reisine & Grady, 1990; Patrick, Morgan, & Charlton, 1986); and disease activity or severity (Affleck et al., 1988; Fitzpatrick, Newman, Archer & Shipley, 1991).

Research suggests that people with a long-term illness have a greater incidence of psychological distress than those who are well (Brown, Wallston & Nicassio, 1989; Fitzpatrick, Newman, Archer & Shipley, 1991; Goodenow, Resinine & Grady, 1990). The evidence that social support may have positive effects upon both physical health and psychological distress or well-being is quite extensive. (See, for example, Cohen and

Syme, 1985).

A long debate remains unresolved as to whether social support has direct effects upon health outcomes or only operates to buffer individuals against hazards, difficulties, or stress. The presence or absence of the direct (main) and/or buffering effects of social support could have important practice implications.

Various researchers (George, 1989; Krause, 1986; Mitchell, Billings & Moos, 1982; Vaux, 1988) have found evidence that not all stressors are buffered by social support. Identifying the illness-related physical stressors and low levels of social support would help in screening for at-risk individuals who might most need and most benefit from effective social work interventions (Blaney, Goodkin, Morgan, Feaster, Million, Szapoznik & Eisdorfer, 1991). Although all individuals might benefit from enhanced social support, the issue of an individual's relative need and relative benefit with respect to psychological distress remain prominent for investigation.

The contribution of this study will be to examine: (1) the direct or main effects of illness-related physical stressors (disease activity, pain, and functional disability) and social support (satisfaction with social support and social network) on psychological distress in women with SLE; and (2) the buffering or interaction effects of social support (satisfaction and social network) with illness-related physical stressors (disease activity, pain, and functional disability) on psychological distress in women with SLE.

Research Questions

There are three primary research questions that will be addressed using two waves of data separated by one year. The questions will be addressed at Wave 1, Wave 2, and Wave 2 psychological distress predicted from Wave 1 psychological distress and other predictors (Wave 2 residual).

Research questions this study seeks to answer:

1. After controlling for the effects of age and disease duration, is illness-related physical stress related to psychological distress?
2. After controlling for the effects of age and disease duration, is social support related to psychological distress over and above the relationship between illness-related physical stress and psychological distress?
3. After controlling for the effects of age and disease duration, is there an interaction effect of illness-related physical stressors and social support on psychological distress?

Methodology

This study used non-experimental cross-sectional and longitudinal research designs with data collection at two points of time separated by one year. After giving their informed consent, the 93 women who had been previously diagnosed with SLE from a Lupus Clinic in Cleveland, Ohio, individually completed an interview-assisted survey. The survey assessed the participants' perceptions of the physical and psychological impact of their illness as well as their satisfaction with social support and number of social resources. Clinical data were abstracted from medical records or recorded by the physician during clinical visits.

A brief description of the research measures will only be presented; however, the dissertation describes the data collection measures in detail. The Health Assessment Questionnaire (HAQ) was used to measure the participants' perceptions of their functional disability and perceptions of their pain or discomfort in the past week. (Ramey, Raynauld & Fries, 1992). Disease activity was measured by the Lupus Activity Criteria Count (LACC), which consists of seven laboratory and clinical criteria indicative of disease activity at time of examination (Urowitz, Gladman, Tozman & Goldsmith, 1989). The Social Support Questionnaire (SSQ) was utilized to measure two aspects of social support: (1) the perceived number of individuals available to provide social support; and (2) the degree to which they are satisfied with social support available (Sarason, Levine, Bashan & Sarason, 1983). A subscale of the Psychological Adjustment to Illness Scale (PAIS) was used to assess the amount of psychological distress experienced within the past 30 days. (Derogatis, 1986).

Statistical Analysis

A series of multiple regressions were performed where the interaction terms between illness-related physical stress and social support were entered in the last block, after the control variables of age and disease duration in Block 1 and the main effects of illness-related physical stress in Block 2 and social support in Block 3. The dependent variable for each analysis was psychological distress. Cross-sectional analyses were completed for Wave 1 and Wave 2 performing regressions for each of the three illness-related physical stressors. Longitudinal analysis was completed performing regressions in predicting a change in psychological distress from Wave 1 to Wave 2 by first regressing Wave 2 psychological distress in Wave 1 psychological distress and then using the residual psychological distress as the dependent variable. The control variables of age and disease duration then became the second block, etc.

Because interaction terms were being tested in the regression model, the relevant variables were centered (i.e., put in deviation score form), and the crossproduct of the centered scores of the two variables was computed and used as the interaction term.

This approach minimizes the multicollinearity between the interaction and main effect terms (Aiken & West, 1991; Cronbach, 1987). To determine the significance of the interaction, the change in R^2 is examined. The final-order b and beta weights (where appropriate) are also examined for each predictor as well as the stepwise multiple R statistics.

Results

The sample had a mild to moderate level of psychological distress. This group of women would be considered as defined by clinical features to be experiencing a mild level of SLE illness. However, this group was negatively impacted by the SLE disease. The mean age of the participants was 42 (SD = 13.2). Forty-two percent were married, 37 percent were African American and 67 percent were Caucasian. The length of the duration of the disease since diagnosis of SLE ranged from less than one year to 31 years, with a mean deviation of 7.5 years (SD = 7.33). Age and disease duration were included as control variables. No other demographic variables, such as race, marital status, SES, was found to be related to psychological distress, so the results were not included in the present study.

Cross-sectional Analysis: The only interaction that was a significant predictor of psychological distress over and above the control variables was functional disability and satisfaction with social support. The multiple R was .58 ($F = 6.15$; $df = 7.85$; $p < .01$), indicating that the total variance accounted for was 34%. The interaction block accounted for an additional 8% of the variance of psychological distress ($p < .01$) over and above what was accounted for by all the control variables. It is of interest to note that after controlling for the effects of age, disease duration, and functional disability, social support accounted for an additional 10% of the variance ($p < .01$). Continuing to examine preceding blocks, functional disability accounted for an additional 6% of the variance, after controlling for age and disease duration ($p < .05$).

Functional disability and satisfaction with social support ($b = 4.22$; $p < .01$) were significant. The interaction effects were grafted in the ANOVA model fashion to enhance interpretation, following the model given by Brown et al., (1989). Functional disability and satisfaction with social support were dichotomized at the median and the means of psychological distress for each group were then plotted. This method of plotting was selected over the plus and minus one standard deviation model suggested by the Aiken and West (1991) due to the small distribution and variance of the scores in the present sample.

The graft demonstrated that while those individuals with high functional disability tended to generally have higher psychological distress regardless of satisfaction with social support, those with low functional disability and high satisfaction with social

support had markedly lower psychological distress scores. It appears that satisfaction with social support may have a "special buffering" effect for those women with low functional disability. Interestingly, the moderating effects of satisfaction with social support on psychological distress is greater when women have low functional disability versus high functional disability.

Regarding the other two illness-related physical stressors, disease activity and pain, it was not determined that social support had a buffering or moderating effect on psychological distress. However, examination of the final-order statistics at Wave 1 and Wave 2 reveals that satisfaction with social support did have main effects in predicting lower psychological distress, with a significant beta weight of $-.27$ ($p < .01$) in each case. Pain and functional disability had main effects in predicting higher psychological distress, with significant beta weights of $.20$ ($p < .05$) and $.25$ ($p < .01$) at Wave 1 and $.41$ ($p < .01$) and $.34$ ($p < .01$) at Wave 2, respectively. These results indicate that regardless of level of pain or disability, individuals with greater satisfaction with social support have lower psychological distress. Age had significant beta weight ($b = -.30$; $p < .01$) indicating younger women had greater psychological distress.

Longitudinal Analysis

Contrary to the cross-sectional analysis, the interaction of functional disability by satisfaction with social support was not a significant predictor of psychological distress over time. There were no other interaction effects and no main effects of social support and illness-related physical stressors (with the exception of disease activity, $b = .16$; $p < .05$). Psychological distress at Wave 1 is the best predictor of psychological distress a year later ($b = .63$; $p < .01$) in each case. The results indicate a strong effect of psychological distress over time, accounting for near 53% of significance variance ($p < .01$) of the total variance in each case. The multiple R was $.76$ ($F = 15.70$; $df = 8, 84$; $p < .01$), indicating that the total variance accounted for was 58%.

Utility for Social Work Practice

The major finding of this study was that satisfaction with social support available was important in relation to participant's psychological distress. Based on the findings of this study, the at-risk individuals that would need to be targeted for intervention are those individuals who experience low levels of functional disability and are dissatisfied with social support available. All women with low or high functional disability and low satisfaction with social support would benefit from social support intervention, but the fact that this is especially true for those women with low functional disability is an interesting finding of this study. The implications for social workers is that they should

not overlook chronically ill women with low functional disability, because these may be the best candidates for successful social support intervention.

Since high levels of illness-related physical stressors were directly related to high psychological distress, psycho-educational programs that focus on pain and disability management rather than social support intervention would be fruitful intervention. Illness-related physical stressors that were measured by participants' perceptions could be the target for intervention.

The younger women in the study were also found to have greater psychological distress. Therefore, age-related assessment focusing on the point that the individuals' illnesses have an impact on their life-cycles would be crucial to consider for intervention.

In serving women with SLE, the social worker needs to be aware that individuals experiencing psychological distress may have received less social support, which in turn, may have led to increased psychological distress, and so forth. Because social support issues and psychological distress could exist in a cycle, other interventions addressing psychological distress, such as cognitive therapy for depression and anxiety, could be employed. This suggestion for practice is further supported by the empirical evidence that cognitive therapy strategies can be effective in the treatment of psychological distress with individuals who have low perception of social support as well as in correcting social support related distortions (Pierce, Sarason, & Sarason, 1996; Robinson, Berman & Neimeyer, 1990).

The results of this study indicate that satisfaction with social support available has: (1) direct or main effects on psychological distress in women with SLE; and (2) differential effects on psychological distress in women with SLE depending on the illness-related physical stressors. Social support interventions designed to foster social relationships may be important in promoting better adjustment for women with SLE.

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