

Principal Investigator	Title of Project	Department
Cindy Mendelson, PhD, RN	Living With the Wolf: Women's Self-Management of Lupus	College of Nursing

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Total Award: \$225,000

ABSTRACT

Systemic lupus erythematosus, the second most common autoimmune disease affecting women during their child bearing years, is a serious systemic autoimmune illness. The impact on the life and families of women with lupus can not be overstated. Fortunately, most women will live at least 20 years past diagnosis, however diagnosis usually occurs during the childbearing years when the multiplicity of roles and the demands on time are very high. No investigation to date has examined how women self-manage the illness trajectory of unpredictable periods of flare and remission. Consequently, the purpose of this longitudinal study is to increase our understanding of the self-management experiences and sources of support used by women with lupus. The specific aims of this study are to: a.) Identify and describe the day-to-day selfmanagement experiences of women living with lupus; b.) Identify and describe how lupus impacts upon the multiplicity of women's roles; and, c.) Describe the sources of emotional and physical support available to women with lupus.

This groundbreaking study will be conducted using ethnographic methods. Data will be gathered through 4 sequential interviews with 20 women over a 15 month time period. Since lupus disproportionately affects women of color, recruitment activities will be targeted towards Hispanic women. To determine the impact of the illness on the family and their perceived role as a source of support, supplemental interviews with friends and/or family of the participants will be conducted. To better understand the day-to-day activities and symptom fluctuation, symptom journals will be maintained by the primary participants. To further understand the nature of support, the activity on an internet listserv for people with lupus will be observed. These data sources provide both a wide view of life with lupus and insight into the details of living day-to-day in the presence of chronicity.

The multiple sources of data collected over the period of the grant will provide an abundance of information from varying perspectives about the illness experience which will allow for an in-depth exploration of the complexity of managing chronic illness. An iterative process of data analysis, based in successive readings of and reflection upon the data, will assist in the process of crystallization of insight and meaning.

An understanding of the day to day self-management experiences of women with lupus is the first necessary step to enhancing the ability of health care workers to successfully intervene to positively impact quality of life, physical functioning, and promote economic independence for these women and their families. The findings from this study will provide the first comprehensive glimpse into women's views of illness over time and into the processes that they use to manage and interpret their illness over an extended period of time.