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## Lupus and Community-Based Social Work

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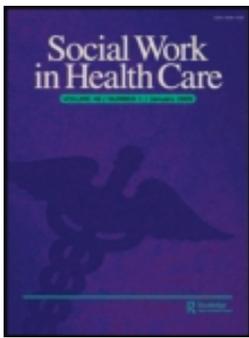
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# Lupus and Community-Based Social Work

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*Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that disproportionately strikes women of color. SLE patients frequently experience physical, emotional, and social challenges that often result in unmet biopsychosocial needs. Because of the nature of the disease and the needs of patients, agencies serving SLE patients that engage in community-based social work can positively impact their clients' lives. The S.L.E. Lupus Foundation participates in a myriad of community-based social work practices to help address the needs of their clients. These services include helping economically disadvantaged patients access appropriate services within their communities, building awareness about SLE in society, connecting with government officials at all levels, and collaborating with health care organizations to serve those affected by SLE. Specific examples of community-based activities at the S.L.E. Lupus Foundation are described in detail.*

*KEYWORDS* SLE, lupus, community social work, biopsychosocial needs

## INTRODUCTION

An estimated 1.5 million Americans suffer from systemic lupus erythematosus (SLE), a chronic autoimmune disease. Approximately 90% of SLE, or lupus, patients are women (Wallace, 2008), and SLE disproportionately affects

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Black, Hispanic, First Nation and Asian women (Alarcón et al., 2004). Black and Asian women are two to three times more likely to develop the disease, for example, than White women (S.L.E. Lupus Foundation, n.d.). People of color are more likely to develop more severe manifestations of the disease, more severe disease activity and overall damage and higher mortality rates (Moses, Wiggers, Nicholas, & Cockburn, 2005; Pons-Estel, Alarcón, Scofield, Reinlib, & Cooper, 2010).

### Chronic Illness and Biopsychosocial Needs

People with any chronic illness often deal with similar physical, emotional, and social challenges that result in common biopsychosocial needs. Biopsychosocial difficulties often center on the patient's ability to address the demands of his or her illness while simultaneously trying to achieve a fulfilling, independent life (Whittemore & Dixon, 2008).

Upon diagnosis, people with chronic illnesses frequently experience troubling emotional responses including depression, anxiety, fear, anger, and apathy (Whittemore & Dixon, 2008). While this may be the beginning of a patient's challenges, Whittemore and Dixon (2008) explain that, as disease courses change over time, biopsychosocial needs can also change over time. For example, coping strategies that may be functional for a patient at one point in his or her illness may not be sufficient at other points, and patients need to develop new ways of managing. "Ongoing resources and support appear to be critical factors in providing assistance" to patients with chronic illnesses (Whittemore & Dixon, 2008, p. 185).

Critical resources for helping patients with chronic illnesses to navigate challenges associated with disease include family, friends, support groups, and counselors. The range of help that patients receive includes physical assistance with day-to-day activities, emotional support, and companionship (Whittemore & Dixon, 2008). Therefore, Whittemore and Dixon (2008) recommend a multidisciplinary approach to addressing patients' social, emotional, physical, and vocational needs. Finally, there is some evidence to suggest that emotional states can have an impact on the physical manifestations of chronic illnesses in addition to illnesses effecting emotional distress. (Beckerman, Auerbach, & Blanco, 2011; Treharne, Kitas, Lyons, & Booth, 2005). This, then, would suggest great benefit to understanding and addressing both the physical and psychosocial needs of patients with chronic illnesses.

### Biopsychosocial Needs of Individuals With Lupus

Studies of lupus patients indicate that these individuals have similar biopsychosocial needs as people with other chronic illnesses although lupus patients have some additional needs that are unique to their condition

(Alarcón et al., 2004; Jump et al., 2005; Kozora, Ellison, Waxmonsky, Wamboldt, & Patterson, 2005). Lupus can be an invisible illness that adds another layer of complication because those afflicted with these conditions often lack obvious visible manifestations of disease. Patients may experience suspicion and withdrawal by others in addition to experiencing the physical, emotional, and other psychosocial challenges associated with their disease (Donoghue & Siegel, 2000). As a result, patients with invisible chronic illnesses can experience “shame and insecurity that can generate a vicious cycle of insecurity, depression, and social isolation” (Greenhalgh, 2009, p. 631). This can result in a lack of physical assistance with day-to-day activities and emotional support when it is most needed.

As lupus disproportionately affects people of color, some recent studies have examined the needs of minority lupus patients compared to White patients. Black and Latina patients have greater unmet physical, emotional, and socioeconomic needs than their White counterparts (Beckerman et al., 2011; Danoff-Burg & Friedberg, 2009). Additionally, Black SLE patients report more severe manifestations of lupus and more physical problems with their illness than White patients, including more difficulty managing symptoms of tiredness, not sleeping well, pain, and feeling worse after physical activity (Danoff-Burg et al., 2009; Fernández et al., 2007).

Unmet financial needs of lupus patients have been identified in several studies. These include needing help managing costs related to SLE, meeting basic living expenses, and managing employment because of problems related to lupus (Beckerman et al., 2011; Danoff-Burg & Friedberg, 2009). Lupus tends to impact people in their prime earning years, and many patients rely on public assistance. Chronic diseases with early onset have a negative impact on earnings and the ability to accrue for retirement (Yelin et al., 2007). A study of people employed at the time of lupus diagnosis found that by 5 years after diagnosis, 15% had stopped working, by 10 years, 36% had stopped working, and by 15 years, 51% had stopped working. On average, these individuals were diagnosed in their mid-thirties; therefore, almost none were employed to a typical retirement age (Yelin et al., 2007). A study of employment and work disability for people with lupus found that 33% of patients were on work disability while 47% were employed. Work disability was related to “a variety of psychosocial and disease related factors, including age, race, sex, SES [socioeconomic status], education, disease activity and duration, pain, fatigue, anxiety, and neurocognitive involvement” (Baker & Pope, 2009, p. 284).

Moses and colleagues (2005) have noted that, due to numerous unmet physical, daily living, and psychological needs, current health care services are not adequate for some people with lupus. Additionally, “referrals to organizations that provide support and information to persons with chronic illness are an important supplement to the medical treatment of SLE” (Danoff-Burg & Friedberg, 2009, p. 12).

## Community Social Work and Lupus

Community social work is macro-practice. That is, using social work skills usually associated with direct individual or group practice (e.g., engagement), community social workers seek to assist larger groups of people with some common characteristics that come together to form a community (Hardcastle, Powers, & Wenocur, 2011). Community social workers typically engage in advocacy, social action, and community organizing (Hardcastle et al., 2011; Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen, 2009). They engage directly with members of the defined community and community partners, facilitate collaboration with other organizations, disseminate public information, network, engage in social marketing, and share information with the public (Hardcastle et al., 2011; Hepworth et al., 2009). Frequently, social workers will simultaneously engage in both macro-practice and direct practice with either individual clients or smaller groups (Hardcastle et al., 2011).

Lupus, in particular, is an appropriate practice area for agencies and practitioners engaged in community social work as they have a high level of unmet psychosocial needs. Since lupus is difficult to diagnose, community-based social work activities can be used to inform the public about the disease in order to help patients identify themselves. This may be of particular assistance in communities of color with higher incidences of lupus so that psychoeducation and social support networks are prominently available. Finally, community-based social work can help engage clients and serve as a gateway to services for lupus patients with unmet physical, psychological, emotional, or socioeconomic needs. Community-based social work in the lupus community draws on the whole systems approach and the critical health approach in the prevention and management of chronic illness (Greenhalgh, 2009).

One way to better understand how community-based social work can positively impact patients with lupus is to examine an organization doing this work more closely. The S.L.E. Lupus Foundation of New York is one such organization.

### THE S.L.E. LUPUS FOUNDATION

The S.L.E. Lupus Foundation (“Foundation”) is a New York City-based organization whose mission is to provide direct services, education, public awareness, and funding for lupus research. They aim to address racial disparities through community-based outreach programs serving minority populations and effective advocacy at national, state, and local levels. The Foundation is headquartered in New York City and also has a West Coast division in Los Angeles. While the Foundation has offices in three boroughs (Bronx, Brooklyn, and Manhattan), it has a presence throughout all five

boroughs (Bronx, Brooklyn, Manhattan [Midtown and Upper Manhattan], Staten Island, and Queens). Additionally, the Foundation regularly collaborates with other lupus organizations throughout the state and nationally in order to serve clients. All services to clients are provided free-of-charge.

### Biopsychosocial Needs of the Foundation's Clients

One of the most common presenting problems for the Foundation's clients is lack of social or emotional support. New clients frequently report that family or friends do not understand the actual experiences of patients with lupus. For example, a client experiencing extreme fatigue may be told by well-meaning family to "just get out of bed" or to "try a little harder." Another problem for Foundation clients is the loss of friendships or other social connections since lupus patients may not have the energy to engage in social activities that they previously enjoyed. A study of the Foundation's membership that looked at the unique psychosocial challenges of this group, found that survey respondents had the most difficulty coping with depression, followed by anxiety and socioeconomic coping and that the greater the perceived sense of control over their condition, the less likely they were to report feeling depressed and anxious (Beckerman et al., 2011).

Other problems for Foundation clients include the financial ramifications of having a chronic illness that limits an individual's ability to work. Because of temporary employment interruptions or job loss, patients seek Foundation financial assistance to help meet basic needs critical for their well-being, such as medication, rent, or utilities. Another common example of financial need is that clients may need assistance purchasing clothing due to weight fluctuations from steroid use, which can increase a patient's weight temporarily, but rapidly.

### Services Offered by the S.L.E. Lupus Foundation

Lupus has a significant impact on quality of life due to the physical and psychological aspects of the disease and the economic burden of medical costs and job reduction or loss. The S.L.E. Lupus Foundation has programs that reach thousands of people every year to address these needs. From educational workshops with renowned medical professionals to one-on-one counseling sessions with the Foundation's staff social worker. The Programs & Social Services Team is constantly assessing their members' needs to ensure they are offering services that meet clients' varied requirements.

The Foundation's Programs and Social Services Team is comprised of a National Director of Program Development, a Director of Social Services, both of whom work out of the Midtown Manhattan headquarters, and two bilingual Outreach Coordinators who staff the Lupus Cooperative of New York offices in the Bronx and Brooklyn.

The Lupus Cooperative of New York (LCNY) is a decade-old grassroots, community-based effort that helps economically disadvantaged people living with lupus access quality health care, social services, and financial resources. They also aim to facilitate timely diagnosis and treatment. The program has an integrated network of community partnerships including community health providers, social service organizations and local businesses to improve health outcomes for those living with lupus. Outreach centers located in the Bronx and Brooklyn are each staffed by a bilingual outreach coordinator. Due to financial constraints, the presence of a full time coordinator in Northern Manhattan was scaled back to a partnership with a local health center to provide essential educational, outreach, and referral services in that community. The Foundation is working to reinstate a full time presence in Northern Manhattan by the end of 2012. In patients with a chronic disease, such as lupus, social support has been shown to act “as a protective factor or buffer, making it possible for patients and their families to navigate the health and social systems, utilize them, and benefit from them” (Pons-Estel et al., 2010, p. 263). This is the focus of the LCNY, which assists low-income, disadvantaged, individuals with lupus and their families.

In addition to these outreach centers, the Director of Social Services provides additional services to clients throughout New York City, including one-on-one counseling, support groups in addition to those at LCNY, and an online monthly advice column that covers psychosocial topics such as coping with lupus, travel, and work issues.

The Programs and Social Services Team, as a whole, assists individuals with lupus through direct support services that include help resolving difficulties related to health care, housing, employment, personal finances, education and emotional issues. Specific services include bilingual and monolingual peer-guided ongoing support groups, physician and other health care referrals, one-on-one counseling, emergency grants, nutrition and exercise workshops, referrals regarding social services and benefits and assistance filling out applications, education sessions for other community-based agencies, provider education, participation in health fairs, monthly advice column, and bilingual health education materials.

### Community Social Work at the S.L.E. Lupus Foundation

Community social work at the Foundation focuses on numerous activities with the goal of reaching and connecting different segments of the lupus community and building awareness about relevant issues in the broader society. The Foundation connects with government officials at the city, state, and national levels. The Foundation engages in community-based activities in order to reach out to patients who are already diagnosed with lupus and to build awareness about lupus in order to help patients who may not yet

be diagnosed connect to appropriate services. Furthermore, the Foundation works with health care providers through several venues in order to help them better understand lupus and issues related to the illness so that they may better serve their patients. Finally, the Foundation collaborates with a host of other organizations whose services are often needed by SLE patients.

#### THE S.L.E. LUPUS FOUNDATION AND GOVERNMENTAL COMMUNITY SOCIAL WORK

At least once a year, Foundation staff meet with New York City Council members. The goal of these meetings is, at times, to secure funding, but it is also to build a broader awareness about lupus. Council Members are regularly updated on Foundation activities and issues important to lupus patients. The Foundation activities in this area are particularly important as they relate to building awareness in public servants whose constituents may be made up of cultural groups who are traditionally underserved by the medical community and who are at greater risk for developing lupus.

On a statewide level, the Foundation partners with other organizations as part of the Lupus Agencies of New York State (LANYS). LANYS works on building awareness and engaging in advocacy to assist the larger lupus community in New York State. Previous efforts at this level have included an annual exhibit on lupus at the New York State Fair, initiating legislation to designate May as Lupus Awareness Month in New York State, and advocating for policies protecting lupus patients' access to affordable drugs. LANYS is currently promoting two bills in the state legislature to help support those with lupus.

On the national level, the Foundation is part of the Lupus Research Institute (LRI) National Coalition. The Coalition is a group of lupus patient services and advocacy organizations located in major urban markets across the country. The Coalition works to ensure funds for lupus research, protect the rights of people with lupus to get and keep adequate health care insurance coverage, eliminate racial disparities, promote education and awareness of the seriousness of lupus, and empower people to effectively advocate for themselves for improved treatments and a cure.

For example, the Coalition successfully petitioned for Congressional funding for a national lupus health education program for physicians and health care providers. The Lupus Initiative, funded by the federal Offices of Minority Health, Women's Health and Surgeon General, is aimed at alleviating racial disparities by providing health care professionals with state-of-the-art training to recognize, diagnose, and treat lupus appropriately. This innovative program includes enhanced medical education curriculum and continuing medical education credits aimed at reducing the impact of health disparities in the diagnosis and care management of people with lupus.

#### COMMUNITY SOCIAL WORK AT THE S.L.E. LUPUS FOUNDATION: REACHING OUT TO PATIENTS

The Foundation recognizes the numerous unmet biopsychosocial needs of individuals with lupus, including those who may be undiagnosed (Beckerman et al., 2011; Danoff-Burg & Friedberg, 2009; Jump et al., 2005; Kozora et al., 2005). In order to reach these patients, the Foundation engages in a wide array of outreach activities that include collaborating with other health organizations, providing information at health fairs, and public awareness campaigns.

The LCNY outreach model is specifically designed to help address racial disparities and access to health care for people of color with lupus. Through LCNY, the Foundation staffs two bilingual outreach coordinators who go into neighborhoods comprised of traditionally underserved populations to help identify community members who have or may have lupus. Once contact is made with patients, other social work services that the Foundation offers are made available within the community to help address the most pressing unmet biopsychosocial needs for individuals with lupus, discussed above.

The Foundation found that it is important to reach people through conventional and unconventional methods. Their bilingual lupus education brochures are distributed in settings that attract young, women of color who are candidates for lupus. These include places such as beauty salons, places of worship, community centers, daycare centers, *bodegas*, schools, and more. More formal methods of outreach are done also, such as attending health fairs within a variety of New York City communities, as well as educating staff from other community-based agencies about lupus. This is particularly relevant if these community-based agencies are located within communities of color and underprivileged communities. With participation in health fairs, alone, the LCNY Outreach Coordinators reached over 8,500 people between January 2011 and September 2011; these numbers reinforce the need for continued participation in community-based events.

In order to expand the breadth of its outreach programs, in 2011 the Foundation launched a Corporate Outreach program. In collaboration with human resources departments, the Foundation provides presentations about lupus to groups of employees in an effort to educate employers, supervisors, and colleagues about the biopsychosocial needs of workers with lupus, and information to help people identify symptoms in themselves, colleagues, friends, and families.

#### REACHING PATIENTS THROUGH NEW MEDIA AND TECHNOLOGY

The Foundation has realized that online media is an important way to reach underserved communities beyond New York City. In 2011, the Foundation started providing webinars that can be easily accessed worldwide by telephone and/or Internet. Recent webinars have covered numerous topics and

have included *Tools for Managing Your Lupus*, *Benlysta—The FDA Approved It, But Is It Right for Me?*, and *Lupus and Pregnancy*. The talks are given by renowned rheumatologists who partner with the Foundation to provide these services to patients. Future topics will address biopsychosocial issues in addition to medical issues.

The Foundation also utilizes social networking sites like Facebook and Twitter to share information with their members and clients and to also reach a larger audience. This allows the Foundation to provide information on the latest lupus developments and on upcoming events and support groups. Furthermore, it offers a place for people to share information and learn from each other. For example, the monthly advice column written by the Director of Social Services is posted on Facebook each month in addition to the Foundation's website. It often prompts much discussion, provides the social worker with a new way to reach out to people who express a desire for services or a need, and provides an added way for patients to reach out to and support each other. A realization of the need for call-in support groups, which the social worker will pilot in 2012 and will be available to lupus patients nationally came from the Foundation's activity on Facebook.

#### REACHING PATIENTS THROUGH ORGANIZATIONAL COLLABORATION

The Foundation regularly collaborates with other health care organizations to sponsor or co-sponsor programs that are viewed as helpful to Foundation clients and family members. One such event is the annual *Get Into the Loop & Learn About Lupus—New York City Hospital Tour*. In this month-long program, physicians give a talk in a hospital in each of the five boroughs on a topic of interest to patients with lupus. Before the talk, dinner is provided to participants. The goal of the annual Hospital Tour is to further educate lupus patients about timely and relevant topics related to lupus and to facilitate mutual support among participants. The Hospital Tour also provides patients with access to doctors and other health care providers; they are able to ask them questions in a group setting and get their questions answered.

Another example of how the Foundation collaborates with other health care organizations is in the coordination of the annual program entitled *Living Life Healthy with Lupus*, which is co-sponsored with the Hospital for Special Surgery. This program seeks to help patients with SLE learn more about living a healthy lifestyle while enjoying a little pampering. Participants can register for complimentary services that include hairstyling, makeup application, and massages. Additionally, demonstrations on feel-good activities such as Tai Chi are also available. Lunchtime speakers share ideas about wellness that are specific to individuals with SLE.

In collaboration with the Long Island University (LIU) Department of Occupational Therapy, patients in Brooklyn were able to participate in a

Lupus Aquatics Program. The first lupus aquatics class was held for six weeks in the fall of 2009. These 6-week sessions used stretching, balance, and gentle aerobic activities to strengthen the whole body. Due to the success of this program, they offered a second aquatics class in the fall of 2010, an 8-week Tai-Chi aquatics class. This exercise helps to reduce muscle and joint pain and is ideal for creating improved range of motion and mobility. The lupus aquatics program is now in its third year. It is hoped that this class will continue to be offered annually and be expanded to be offered twice a year, in the spring and fall. In addition, an elective Lupus Aquatics course was developed and is available for LIU Sport Medicine and Health Care Students.

A chronic disease self-management class is offered once a year in collaboration with the Family Health Center at North General Hospital in Manhattan. This 6-week program meets 2 hours per week and covers topics such as coping with stress, fatigue, pain and isolation; exercise and nutrition; medication usage; and improving communication with family, friends, and health professionals. The objective of this program is to educate participants on the importance of managing their disease.

This year, a 10-week nutrition workshop, in collaboration with the Cornell University Cooperative Extension, was held in the Foundation's Manhattan office and in their Brooklyn location. One is planned at their Bronx site later this year, although this is where the program was first held 2 years ago. The NYC Expanded Food & Nutrition Education Program is a free program for low-income child caregivers to teach them how to make healthy food choices with a limited budget and how to pass this information along to the children they care for. Participants meet once a week for an interactive discussion about nutrition and meal preparation. The group was led by a Community Educator from Cornell. At the end of the 10 weeks, each participant was awarded a certificate, which Cornell University encourages them to put on their resumé. This addresses multiple needs of the lupus patient: proper nutrition for themselves and their families, especially designed for those on a limited income, and proficiency that can translate into a job skill.

The purpose of these inter-organizational relationships is, typically, to enlarge the scope of services that each organization provides. Within each partnership, more patients can be reached and more services can be offered.

#### REACHING OUT TO PATIENTS AND PUBLIC AWARENESS CAMPAIGNS

The Foundation always looks for opportunities and partnerships that allow them to educate the general public about lupus both locally and nationally. For the previous 3 years, during the month of October, the Foundation has been granted free space by EHE International for a 115-square foot display window in Rockefeller Plaza in order to generate awareness about lupus.

This exhibit draws attention to this often undiagnosed disease through facts and film.

In addition, the Foundation is collaborating with CBS Cares on a public service announcement (PSA) what is scheduled to launch in early 2012. CBS Cares is a campaign where talent from many CBS programs is featured in a PSA that airs on national television and is promoted on their web site.

#### COMMUNITY SOCIAL WORK AT THE S.L.E. LUPUS FOUNDATION: REACHING OUT TO HEALTH CARE PROVIDERS

The Foundation provides direct services to lupus patients, but it also participates in activities to assist the medical community that serves lupus patients. As a result, the Foundation engages in outreach to physicians that provide medical care to lupus patients and other medically oriented institutions, including hospitals and professional organizations.

The Foundation endeavors to develop relationships with individual physicians and practices that treat individuals with lupus. This typically includes rheumatologists, but also includes general practitioners and specialists who address complications of lupus. The purpose of developing these relationships is twofold. First, the Foundation seeks to compile a comprehensive list of physicians who are well versed in treating lupus patients so they can build a referral network for their clients. Additionally, the Foundation aims to be of assistance to physicians as well as patients.

The relationship that the Foundation develops with individual physicians and practices varies based on the needs and requests of each medical practice. In the simplest case, the Foundation will periodically provide materials about Foundation services to the practice, and the practice will make the materials available to patients. In other situations, Foundation staff will meet individually with physicians to help them begin to address some of the biopsychosocial needs of patients.

#### CONCLUSION

The clients served by the S.L.E. Lupus Foundation have many of the same needs as those identified in previous studies. The Foundation recognizes that needs vary due to differences in socioeconomic status, education, and the specific lupus symptoms of the patient and tailors its services to meet the various patient needs. Since communities of color are disproportionately vulnerable to lupus, the Foundation focuses many education and outreach services in underserved communities through the LCN. As noted in earlier studies on the unmet needs of patients with SLE, emotional and social support are often the most pressing needs of clients of the Foundation (Beckerman et al., 2011; Danoff-Burg & Friedberg, 2009; Donoghue & Siegel,

2000; Greenhalgh, 2009; Moses et al., 2005; Whitemore & Dixon, 2008). Through its array of individual and group services, the Foundation seeks to meet the comprehensive biopsychosocial needs of its clients.

Lupus, however, is a complex illness, which is difficult to both diagnose and treat and much effort is required to locate and then assist those with the disease. A concerted coordinated approach, therefore, is appropriate in assisting those with lupus. While physicians are best suited to treat the physical manifestations of lupus, social workers in settings such as The S.L.E. Lupus Foundation are well-suited for addressing the biopsychosocial needs of lupus patients. Based on the apparent success of organizations such as the S.L.E. Lupus Foundation, future research should investigate the impact of community-based social work and social work education on those with lupus.

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