

LANtern® (Lupus Asian Network): Evaluation of an Innovative National Program

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ABSTRACT (REVISED)

Launched in 2003 with a mission to support, empower, and enhance quality of life for Asian-Americans with SLE and their loved ones, Hospital for Special Surgery's LANtern® (Lupus Asian Network) is a national resource for its peer based telephone SupportLine and bilingual Chinese educational publications. This complex illness affects Asian-Americans 2-3x as often as whites.

We developed a telephone evaluation for the 65 SupportLine callers with lupus or family members who used the program from 2003 – 2006. The 31-item survey consisted of a Likert scale and open-ended questions to assess user demographics, program satisfaction, SLE impact, and program service recommendations. Interviews were conducted in users' preferred language, English or Chinese (Mandarin/Cantonese), by 2 volunteers not otherwise linked with the program.

We completed 24 interviews. Attrition was due to address change, lack of return calls, or refusal. Of our sample, 22 were female; 18 with SLE; 5 were parents and 1 adult child; 21 were born in other countries, with the majority from China (50%) and Hong Kong (21%). Most callers (58%) were between ages 36-55, followed by 16-35 (38%). More than half (54%) were monolingual in their native language/dialects, in contrast with a few (13%) in English only.

Fifty percent had SLE < 5 yrs and 33% had SLE >10 yrs. Fifty percent stated that SLE interfered with their everyday life most (29%) or all (21%) of the time, focusing on employment (65%), relationship with spouse/partner (46%), and social activities

(50%). Considerable anxiety about the future was expressed (63% sometimes/very often). A majority of those with lupus (59%) reported being a burden to their family sometimes/very often, while 55% reported sometimes feeling down, depressed or hopeless.

Most users (59%) learned of LANtern via Chinese media, health fairs and word of mouth; an additional 33% were referred by social service/health care agencies. Initial contact was prompted very much by a desire to learn more about the illness (54%) and to relieve psycho-social concerns (34%). A significant number (71%) indicated a better understanding about lupus and the receipt of emotional support, and 55% felt less alone, despite the contacts being brief, with 63% reporting 1-2 contacts and 25% 3-5. 67% reported that it was "very important" that the person they spoke with has a similar cultural or language background. Program satisfaction was high, with 95% reporting program satisfaction, and 96% would recommend the program to others. Additional service needs were also assessed, with recommendations consistent, culturally and linguistically, with their reported desire for peer connections, and family/group oriented activities.

Our results, though limited by a small sample size, underscore that a unique and culturally relevant service need is being met through our telephone peer counseling model for a community reporting significant impact of SLE on their lives. Additional program modalities have since been explored and enhanced for service expansion.

PROGRAM DESCRIPTION & PURPOSE

The mission of Hospital for Special Surgery's LANtern® (Lupus Asian Network) is to support, empower and enhance the quality of life of Asian Americans with lupus and their loved ones. Specifically targeting the Chinese American community, Hospital for Special Surgery's LANtern® (Lupus Asian Network) reaches its service goal through a national telephone SupportLine, staffed by trained bilingual peer volunteers with lupus themselves, educational publications (English/

Chinese) and community outreach to bridge a language and cultural divide. LANtern's Advisory Board, comprised of the SLE Lupus Foundation, Charles B. Wang Community Health Center, Chinese Community Partnership for Health at New York Downtown Hospital, Hospital for Joint Diseases, and Center for the Study of Asian American Health at NYU Langone Medical Center, has helped to guide the program's work.

GOALS OF EVALUATION

Assess SupportLine user demographics, reasons for calling, patterns of utilization, program satisfaction, and recommendations for service enhancement. In addition, we sought to assess the impact of lupus.

METHODS

A 31-item bilingual (English/Chinese) survey comprised of Likert scale and open-ended questions was developed by LANtern's staff, and reviewed by its Advisory Board. The survey was piloted and administered over the phone by two trained bilingual interviewers who were nursing students and not involved in providing client services. Attempts (at least 3) were made to contact all identified callers with lupus, or their family members during the first four years of the SupportLine's operation (2003-2006).

RESULTS

24 interviews were completed in program users' preferred language/dialect. Of the remaining 41, 18 could not be located by phone, 13 declined, 10 did not return phone messages.

Demographic Information N=24

Gender	22 (92%) Female; 2 (8%) Male
SupportLine Users	18 (75%) Persons living with lupus 6 (25%) Family members (3 daughters, 2 sons, 1 mother)
Ethnicity	23 (96%) Chinese; 1 (4%) Korean
Primary/Preferred Language	13 (54%) monolingual Chinese; 8 (33%) some English proficiency; 3 (13%) English only
Place of Birth	12 (50%) immigrated from China; 5 (21%) Hong Kong; 2 (8%) Taiwan; 2 (8%) Malaysia [Years resided in U.S.: 9 (43%) 10 or < years; 7 (33%) 11-20 years; 5 (24%) >21 or more years] 3 (13%) were U.S. born
Age	14 (58%) between 36-55 years of age 9 (38%) between 16-35 years of age 1 (4%) age 66 and over
Marital Status	13 (54%) Married; 9 (38%) Single; 1 (4%) Separated; 1 (4%) Widowed
Highest Formal Education Received	1 (4%) Elementary school; 3 (13%) Junior high school; 8 (33%) High School; 2 (8%) Associate Degree; 7 (30%) Bachelor's; 2 (8%) Master's; 1 (4%) Medical degree from China
Residency	16 (67%) New York City; 8 (33%) Regional/National
Employment & Source of Income	10 (41%) Employed full-time or part-time (8 F-time; 2 p-time); 8 (33%) Unemployed; 4 (17%) Students; 1 (4%) Homemaker; 1 (4%) Retiree
Years Since SLE Diagnosis	12 (50%) < 5 years; 4 (17%) 6-9 years; 8 (33%) > 10 years

Referral Source, Reasons for Calling & Patterns of Utilization

- 59% learned of LANtern through ethnic Chinese newspapers, community health fairs, and family/friends; 33% through referrals from health care and social services professionals, 8% through internet search
- 54% were prompted to call related to desire to learn more about their illness, treatment, and health system navigation; 34% specific psychosocial concerns
- 63% had an average of 1-2 SupportLine contacts; 25% 3-5 contacts; 12% >6

Satisfaction & Impact

- 95% reported being satisfied (54%), extremely satisfied (33%), or "somewhat satisfied" (8%) with their SupportLine experience
- Three areas of greatest reported help: emotional support (71%); understanding lupus better (71%); feeling less alone (55%)
- 50% reported "very important" that the person they spoke with had lupus, 21% felt "somewhat important" and 29% no preference
- 67% felt it was "very important" that their peer counselor had a similar cultural/language background; 17% "somewhat important"; 16% "not important at all"
- 96% would "highly recommend" the program to others

When asked what was "most helpful" about using the SupportLine, themes focused on both offered peer support and information.

"LANtern provides a lot of information about lupus, and it has information in Chinese for people who can't read English."

"I got the support and I felt very good when talking and sharing with the (peer) volunteers who also have lupus or someone who are family members of someone with lupus. It was a warm feeling."

"I like the fact that LANtern is a support program for people from same cultural background, for Asian like me. And I know there are others who are going through the same and understand my experience. I feel connected."

Regarding service improvements, focus was on extending program reach and modalities, with 79% expressing interest in social gatherings and educational forums, and 74% in a support group.

"Maybe organize more of the social gathering or support groups, so that we can learn more and talk to each other."

"Keep on calling and provide emotional support. Sometimes, even just one phone call would make the patient feel so much better."

"Provide more information and new research information about treatment of lupus would be very helpful."

"Send brochures to all the clinics/doctors' office so that patients can get more information about lupus. Some people are not aware and confused about it. The program can help patients to know what are the dos and don'ts."

Lupus Experience & Impact

- Three areas identified as being "most strongly affected by lupus" were: Employment (65%); relationship with spouse/significant other (46%); social activities (50%)
- Lupus was reported to interfere with everyday life "most" (29%) or "all" (21%) or "some" of the time (13%), with (38%) reporting "rarely"
- Feeling that living with lupus was a burden to their family occurred "very often" (21%), "sometimes" (38%), rarely (13%) and "not at all" (29%)
- Feeling down, depressed, or hopeless occurred "very often" (13%), "sometimes" (42%), "rarely" (17%), and "29% not at all"
- A significant number felt embarrassed/ashamed (29%) at least "some of the time"
- Considerable anxiety was expressed about the future, "very often" (29%), "sometimes" (34%)
- When asked what lupus symptom(s) "bother or worry you or your family the most", responses focused on joint pain (cited 9x out of 20 responses), followed by fatigue (cited 3x). Additional symptoms described included fever, rashes, trouble remembering, and organ involvement
- The great majority reported Western medicine as their primary treatment source (96%)

DISCUSSION

Lupus had a considerable impact along several dimensions of our respondents' lives, pointing the way for further needed exploration and intervention. Despite limited usage, satisfaction with the service provided was high, with a strong desire for expanded outreach,

especially for in-person contact for support and education. As a result, LANtern has since incorporated an annual gathering during the Lunar New Year, adapting the themes of renewal and connections. This has been well-attended and well-received.

CONCLUSION

The survey results, though limited by our small sample size, underscore that a culturally relevant service need is being met for a community disproportionately affected by lupus, through our program's telephone peer-based model.