

LANtern® (Lupus Asian Network) 红斑狼疮之曙光

An innovative approach to empower women with lupus and their families

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HSS

SUMMARY OF NEEDS ASSESSMENT

- ▶ Conducted in 2000 to identify psychosocial, cultural and coping concerns of Asian Americans with lupus.
- ▶ Methodology:
 - Literature reviews and questionnaires
 - Interviews with key informants: patients and health professionals
- ▶ Major findings:
 - Psychosocial concerns (ie. isolation, lack of information) may impact coping strategies
 - Need for Asians with lupus to connect with someone of same ethnicity/language
 - Need for physicians' openness to complementary modalities
- ▶ Recommendation: A culturally specific, targeted approach to increasing awareness, support, and education about lupus for both patients, medical community, and the public is needed.

IMPLEMENTING THE PROGRAM:

LANtern (Lupus Asian Network) Mission

The mission of LANtern (Lupus Asian Network) is to support, empower, and enhance the quality of life of Asian-Americans with lupus and their families by creating networks of hope and understanding.

LANtern Goals

- ▶ Provide culturally sensitive and language appropriate peer health education to Asian-Americans and their families
- ▶ Empower Asian-American volunteers with lupus by training them as peer health educators and counselors
- ▶ Enhance access, communication, and understanding among relevant health providers, patients, and community resources to improve knowledge and support regarding the impact of lupus in Asian-American communities



PEER HEALTH EDUCATOR MODEL

LANtern Training

Training curriculum adapted from LupusLine Leader's Manual (Hospital for Special Surgery: 1993). Modified training emphasizes: cultural competency, guest lecturer participation, shortened & simplified language

6-week training curriculum consists of 2-hour sessions:

- ▶ Session 1: Overview of Lupus
- ▶ Session 2: Eastern & Western Approaches to Treating Lupus
- ▶ Session 3: Mental Health & Asians: Coping with Lupus
- ▶ Session 4 & 5: Peer Health Educator Skills: Cross-cultural communication issues
- ▶ Session 6: Accessing Resources

Challenges to recruitment, retention and peer health education roles

- Limited availability & varying commitment level to training & volunteer program
- Participation limited due to need for bilingual proficiency
- Importance of privacy & self-disclosure issues
- Unfamiliarity with volunteer process affects record keeping and ongoing supervision
- Tendency to give advice
- Unfamiliarity with extended counseling relationship
- Discomfort in confronting emotional concerns
- Different expectation levels on the part of caller and volunteer

LANtern Support Line

- ▶ National toll-free number 866-505-2253, Launched in April 2003
- ▶ Volunteers are available to speak to callers in Cantonese and Mandarin
- ▶ 498 Client contacts made
- ▶ Language breakdown: 44% Cantonese, 25% Mandarin, 30% English
- ▶ Category of callers: 34% Lupus patients, 33% family member/friend of person with lupus, 16% unsure if they or family member has lupus, 17% unknown
- ▶ Geographic origin: 65% Local (Tri-state area), 16% National, 4% International



LANtern Advisory Board



National Conferences



Educational presentations



Community events

LANtern ADVISORY BOARD

- ▶ Our first Advisory Board meeting was Dec. 2001. Members include physicians, peer consumers, and representatives from the following organizations:
 - S.L.E. Lupus Foundation, Inc.
 - Charles B. Wang Community Health Center
 - New York Downtown Chinese Community Partnership for Health
 - Hospital for Joint Diseases
 - The Center for the Study of Asian American Health at NYU School of Medicine.
- ▶ Quarterly meetings, chaired by the Program Coordinator, provide strategic direction and help to inform priorities for the program, including:
 - developing culturally appropriate print materials
 - working with CBOs to give educational presentations
 - enabling on-site presence at a city hospital
 - gaining access to community health fairs
 - elucidating differences in outreach strategies to ethnic media

CLIENTS SERVED

- ▶ Since 2003, program has made over 2000 client contacts through our support line, presentations, and community events.
- ▶ Over 3200 award-winning "What Chinese-Americans & Their Families Should Know About Lupus" bilingual booklets have been distributed by request.
- ▶ LANtern has participated in 28 local & national professional conferences.
- ▶ Over 20 presentations have been made to medical staff and health professionals.
- ▶ Coverage in ethnic print media, local TV station NY1

LESSONS LEARNED:

- ▶ Importance of reaching out to family members/friends, who are looking to learn more about lupus and to find ways to support their loved one with lupus.
- ▶ Misconceptions about lupus are pervasive as reflected by the general lack of knowledge and education about lupus in the Asian community.
- ▶ A modified screening process must take into account language fluency and confidentiality with clients who are reluctant to communicate
- ▶ Clients are primarily concerned with changes in appearance due to treatment, medications & side-effects, learning how to cope, nutrition/diet, sense of isolation and fear of the future.
- ▶ Education of health professionals on the diagnostic criteria, symptomatology, prevalence, and impact of lupus on the Asian community is essential.

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