



REPORT SERIES No. 2

Support groups for women with lymphatic filariasis in Haiti

Jeannine Coreil
Gladys Mayard
David Addiss

Social, Economic and Behavioural (SEB) Research



UNDP/World Bank/WHO
Special Programme for Research & Training in Tropical Diseases (TDR)

Support groups for women with lymphatic filariasis in Haiti

Jeannine Coreil, Ph.D¹, Gladys Mayard, MS², and
David Addiss, MD³

¹ Professor and Interim Chair, Department of Community and Family Health, College of Public Health, University of South Florida, Tampa, FL, USA.
E-mail: jcoreil@hsc.usf.edu

² Senior Development Scientist, Hôpital Ste Croix, Léogane, et Centre de Recherches et Services Sociaux-Humanitaires, Port-au-Prince, Haiti.

³ Medical Epidemiologist, Division of Parasitic Diseases, National Center for Infectious Diseases, Centers for Disease Control and Prevention, Atlanta, GA, USA.

This monograph constitutes the final report for TDR Project 970184 on support groups for women with lymphatic filariasis in Haiti (Principal investigator Professor Jeannine Coreil, Collaborators Gladys Mayard, David Addiss).

TDR/STR/SEB/RP/03.1

Copyright © World Health Organization on behalf of the Special Programme for Research and Training in Tropical Diseases 2003
All rights reserved.

The use of content from this health information product for all non-commercial education, training and information purposes is encouraged, including translation, quotation and reproduction, in any medium, but the content must not be changed and full acknowledgment of the source must be clearly stated. A copy of any resulting product with such content should be sent to *TDR, World Health Organization, Avenue Appia, 1211 Geneva 27, Switzerland*. TDR is a World Health Organization (WHO) executed UNDP/World Bank/World Health Organization Special Programme for Research and Training in Tropical Diseases.

This information product is not for sale. The use of any information or content whatsoever from it for publicity or advertising, or for any commercial or income-generating purpose, is strictly prohibited. No elements of this information product, in part or in whole, may be used to promote any specific individual, entity or product, in any manner whatsoever.

The designations employed and the presentation of material in this health information product, including maps and other illustrative materials, do not imply the expression of any opinion whatsoever on the part of WHO, including TDR, the authors or any parties cooperating in the production, concerning the legal status of any country, territory, city or area, or of its authorities, or concerning the delineation of frontiers and borders.

Mention or depiction of any specific product or commercial enterprise does not imply endorsement or recommendation by WHO, including TDR, the authors or any parties cooperating in the production, in preference to others of a similar nature not mentioned or depicted.

The views expressed in this health information product are those of the authors and do not necessarily reflect those of WHO, including TDR.

WHO, including TDR, and the authors of this health information product make no warranties or representations regarding the content, presentation, appearance, completeness or accuracy in any medium and shall not be held liable for any damages whatsoever as a result of its use or application. WHO, including TDR, reserves the right to make updates and changes without notice and accepts no liability for any errors or omissions in this regard. Any alteration to the original content brought about by display or access through different media is not the responsibility of WHO, including TDR, or the authors.

WHO, including TDR, and the authors accept no responsibility whatsoever for any inaccurate advice or information that is provided by sources reached via linkages or references to this health information product.

Layout: Jocelyne Bruyère

Concept and design: Lisa Schwarb

Table of contents

ABSTRACT	4
INTRODUCTION	5
OBJECTIVES AND RESEARCH QUESTIONS	7
BACKGROUND	8
METHODS	12
- Recruitment, training and organization	12
- Programme evaluation	14
RESULTS	18
- The development of lymphoedema support groups	18
- Indigenization of the support groups	21
- Benefits of support group participation	23
- Achieving sustainability	32
DISCUSSION AND CONCLUSIONS	35
- Indigenization	35
- Benefits	36
- Sustainability	37
- Applicability to other areas	40
- Conclusion	43
ACKNOWLEDGEMENTS	44
REFERENCES	45

ABSTRACT

Support groups offer a low-cost psychosocial-educational intervention for chronic disease and disability in resource-poor settings, yet such groups have received little attention in developing countries. An experimental study of support groups for women with lymphatic filariasis was conducted in Léogane, Haiti, during 1998-2001 in order to assess the applicability of the chronic disease support group model in a developing country setting. Five groups, of which two later merged, organized in urban and rural communities were evaluated over a two-year period to determine factors which influence participation and to assess the impact of the intervention on illness management and beneficial outcomes. The research design consisted of longitudinal monitoring of process variables and a case-control study of support group members and geographic controls. Process evaluation documented high levels of participa-

tion and enthusiasm among participants. The support group model became indigenized to the Haitian cultural context, as reflected in the emphasis accorded to spiritual/expressive components and training in practical skills. Analysis of survey data collected in 1999 and 2000 demonstrated that members perceived benefits from support group participation in the areas of quality of life, understanding of the disease, home care practices, and illness symptoms. Sustainability of the support group programme was demonstrated by the fashion in which the group continued to function during periods of resource scarcity, the ability of the programme to secure extended financial support for four years, and the integration of support groups into local and national filariasis control programmes. The findings offer lessons for the application of the support group model to other health problems and regions of the world.



INTRODUCTION

In the past few decades self-help organizations have become an increasingly important component of community-based resources for dealing with illness and disability in affluent industrial nations (Katz 1981; Hatch and Kickbusch, 1983; Powell, 1994, Riessman and Carroll, 1995; Kurtz, 1997). Evaluation studies report largely positive impacts of support group participation on members' ability to cope with health problems (Gottlieb, 1982; Trojan, 1989; Branckaerts & Richardson, 1992; Hitch et al., 1994; Kaye, 1995). Three types of benefit have been documented:

- impact on disease-related stress and quality of life
- impact on relationships with family and friends
- impact on patient behaviour and use of services.

Unlike the situation in industrial countries, self-help groups for chronic disease and disability in developing countries have thus far received comparatively little attention (Lavoie et al., 1995). The literature on tropical diseases research makes scant mention of the concept of social support, and self-help groups are rarely discussed.

The concept of organizing a type of "club" for women is not entirely new in Haiti. For many years "mothers' clubs" have been operating in numerous localities in Haiti; in these clubs, a small

number of women come together to undertake a group project usually of an income-generating nature. In Brazil, Dr Gerusa Dreyer has organized "hope clubs" for people with lymphatic filariasis, large festive gatherings of members and their families, which promote community awareness and understanding about the illness, and a more positive image of those afflicted (Dreyer and Addiss, 2000). However, the notion of illness-focused self-help groups is a new idea in Haiti. There is no indigenous model for the peer-led support group. Only in recent years have illness-related support groups been formed in Port-au-Prince for diabetes and acquired immunodeficiency syndrome (AIDS) patients. In affluent industrial countries, participation in support groups has been primarily a middle class phenomenon, with very limited involvement by so-called "hard to reach" populations such as ethnic minorities and low-income groups. Specialized approaches have been necessary to reach these disadvantaged populations. We anticipated facing similar challenges in this experiment with self-help groups in Léogane.

Ethnographic research conducted in Haiti in 1996 indicated that support groups could provide important benefits to individuals affected by lymphatic filariasis. Participants in focus groups organized among women enrolled

in a lymphoedema treatment programme and individuals interviewed in Léogane expressed an openness to the notion of self-help, and a strong interest in the idea of support groups for women with lymphoedema of the leg caused by lymphatic filariasis (Coreil et al., 1998). One of the important benefits of the Ste. Croix Hospital's physical therapy treatment programme for lymphoedema identified by female patients, was the opportunity to interact with other similarly-afflicted women. Also, when asked to identify the kind of educational method they would prefer from several alternatives for learning about and dealing with the disease, the women ranked support groups as one of the top two choices, along with audiocassettes.

A recommendation of the ethnographic study was the incorporation of support groups as part of the ongoing education and illness management programme for lymphoedema at Ste Croix Hospital. The anticipated benefits of support groups included:

- sharing experiences of coping with common life situations affected by the disease;
- reducing personal feelings of social isolation because one is "different";

- the opportunity to observe improvement in symptoms among other patients, reinforcing confidence in treatment efficacy;
- exchanging practical advice about home care and following the treatment regimen.

This report describes the implementation and evaluation of a self-help programme for women with lymphatic filariasis in Haiti. The programme assessed the feasibility and impact of support group participation in a low-income community in which filariasis is endemic. The results contribute to our understanding of ways in which community resources for the control of filariasis and other tropical diseases can be utilized. Like many tropical diseases, filariasis is often associated with social stigma, loss of productivity, impaired role performance, and disruption of family relationships (Hunter, 1992; Evans et al., 1993; Bandyopadhyay, 1996). The potential impact of support groups in this setting for easing the burden of disease, improving the quality of life of patients, and enhancing illness management was assessed.

OBJECTIVES AND RESEARCH QUESTIONS

Three general objectives guided the programme:

- To organize peer-led self-help groups for women with lymphatic filariasis
- To assess individual and group factors which influence participation in these groups
- To monitor and evaluate the impact and sustainability of these support groups over time.

Specific research questions addressed included the following:

- What are the determinants of women's participation in lymphoedema self-help groups?
- Does participation vary by age, severity of disease, family characteristics, contact with the formal health care

system or other individual characteristics?

- To what extent do group characteristics (location, meeting time, group size, programme content, facilitator style) influence participation and participant satisfaction?
- How do environmental conditions (socioeconomic levels, urban/rural location) affect support group outcomes?
- Does participation in support groups improve compliance and satisfaction with physical therapy treatment for lymphoedema?
- Is support group participation associated with improved illness outcomes?
- What lessons from this programme can be applied to other developing country settings?

BACKGROUND

Historical and political economic context

Lymphatic filariasis is endemic in Haiti, primarily along the coast (Raccurt 1986). The disease is caused by thread-like, parasitic filarial worms which lodge in the lymphatic system. Transmission of the parasite, *Wuchereria bancrofti*, is particularly intense near the coastal town of Léogane (population 20 000), approximately 30 km west of Port-au-Prince, where this study took place. In the Léogane area, the prevalence of microfilaraemia (tiny larval forms) is 33% (Raccurt et al., 1988), and approximately one-half of the population is infected with the parasite as detected by filarial antigen in the blood (Lammie et al., 1994). Lymphoedema (swelling of the subcutaneous tissues caused by obstruction of the lymphatic drainage system) and elephantiasis (painful, disfiguring swelling, a classic sign of late-stage disease) of the leg are found in approximately 2% of adults (Lammie et al., 1993). As in many other areas endemic for bancroftian filariasis, women are 5–10 times more likely than men to have elephantiasis of the leg (Lammie et al., 1993; Gyapong, Magnussen & Binka, 1994). It is unclear why women are more affected than men, but sex-related differences in the location of adult *W. bancrofti* in the human body and non-filarial factors that stress the lymphatic system of the lower limbs, such as pregnancy, likely play a role.

Lymphatic filariasis is a disease associated with poverty and was brought to the New World with the importation of African slaves in the colonial era. It was described in the 18th century medical literature as “Barbados leg” by physicians assigned to the British colonies, who early on noted a link between the disease, and deforestation and sugar-cane production (Laurence, 1989). In 1877, the British doctor Sir Patrick Manson, working in a remote Chinese port, discovered that lymphatic filariasis was transmitted by mosquitos that have ingested blood from infected humans, decades before vector transmission was identified for malaria and other insect-borne diseases (Dean, 2001). Conditions in the colonies were ideal for the breeding of the mosquitos that transmitted the infection. Water storage was necessary, sanitation was poor, dense human populations had settled on the plantations, and there was pollution from sugar-cane mills; the combination of these factors facilitated the propagation of the disease. Physically and nutritionally deprived, and living in rudimentary accommodation which left them exposed to flying insects, slaves were particularly vulnerable to infection, although poor white people were also susceptible. Through trade and migration, in addition to continued slave importation, the disease spread to many areas of the Americas, and gained notable

prevalence in Hispaniola and other Caribbean islands, Brazil, Suriname, Guyana and the state of South Carolina, USA.

Three centuries after its introduction to the Western hemisphere, lymphatic filariasis remains a conspicuous relic of colonialism and poverty in a few endemic areas, including Haiti, the Dominican Republic, north-east Brazil and Guyana. In Haiti, filarial infection is widely distributed, but the disease appears to be concentrated in a few areas of high prevalence, most notably along the coastal plains surrounding the cities of Léogane and Cap-Haïtien. Interestingly, these two cities were the commercial centres of Haiti in the colonial era, and at one time Léogane was the nation's capital. Both in historical times and today, sugar-cane production in these areas was a core element of the local economy. The Léogane region is particularly well-known for sugar-cane processing and the distillation of rum, which takes place in numerous small factories dispersed throughout the plain. Water storage and drainage near these distilleries, known as *gildiv*, provide a suitable environment for the breeding of mosquitos. Municipal sanitation and mosquito-control services are absent or inadequate, and most local homes lack protective barriers against mosquitos. Thus a historical–ecological perspective on the problem highlights five key conditions that appear to characterize the areas where lymphatic filariasis persists in Haiti. These are early colonial settlement, forced migration of African slaves, sus-

tained heavy sugar-cane production, dense population and deforestation, and poverty and poor living conditions (Coreil, 2000).

It should be emphasized that poverty and poor living conditions are the fundamental causes of the persistence of the disease in Haiti and other resource-poor countries. Devastated by political instability and economic hardship, the population of Haiti struggles to maintain the basic living conditions for survival. Parasitic and infectious diseases flourish in situations of extreme socioeconomic deprivation, and, as with AIDS and tuberculosis, lymphatic filariasis can be seen as a biological expression of social inequality (Farmer, 1999). Materially-disadvantaged populations have inadequate housing, greater exposure to infected mosquitos, less resistance to infection and limited access to health information and services. While the long-term solution is social and economic development, in the short term some countries, including Haiti, are undertaking ambitious disease control programmes, with the assistance of the World Health Organization (WHO) and international donors. Lymphoedema treatment programmes have been established in two Haitian communes, with plans for expansion to other areas as the Ministry of Health undertakes a national lymphatic filariasis elimination programme (see section on *Achieving sustainability*). However, all filariasis control efforts in Haiti face major hurdles stemming from limited health resources, a precarious and deteriorating infrastructure,

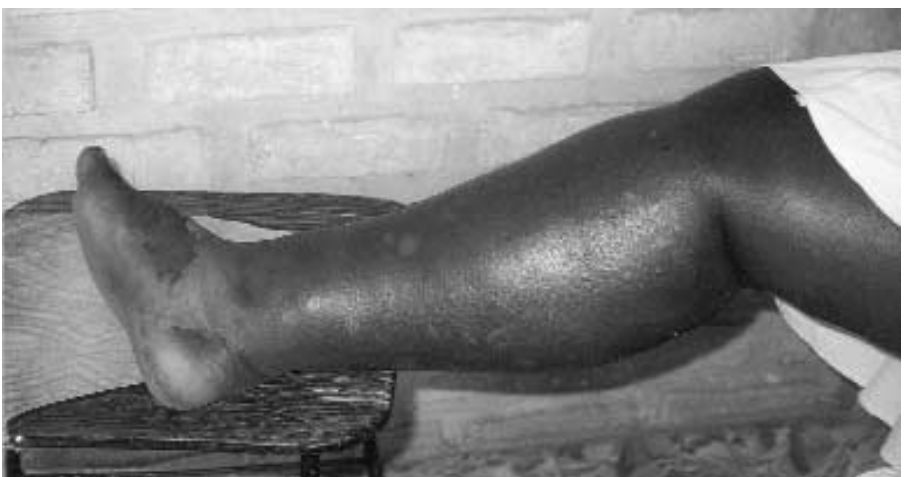
and general social welfare insecurity. The reasons why filariasis remains a serious burden in this setting thus also pose a challenge for the implementation of effective intervention programmes.

Sociocultural context

In local explanatory models of illness, elephantiasis of the leg (*gwopye*) is traditionally considered primarily a mystical or supernatural illness, caused by human malicious intent through the use of magical powders. Natural explanations are also recognized, including injury to the foot, stepping in foul water, the body getting too cold, worms, and microbes. In some instances, *gwopye* is accorded moral significance, such as being attributed to a husband's infidelities. Traditional treatment for lymphoedema included leeches, cupping and bloodletting, to "draw out the bad blood," and herbal remedies to reduce swelling. Both women and men with elephantiasis are stigmatized in the community, such stigmatization primarily taking the form of pub-

lic teasing and ridicule, the use of pejorative names and being the target of jokes. A girl's chances of marrying are impaired if she shows early signs of lymphoedema. The physical restrictions experienced by women with lymphoedema include problems with mobility, the inability to walk far or stand for long periods and difficulty finding appropriate footwear. These restrictions in turn impede social and economic activities, particularly the ability to participate in the selling of goods at the market and family rituals. Such limitations are exacerbated during times of acute episodes of bacterial adenolymphangitis (systemic bacterial infection that exacerbates lymphoedema), known as "acute attacks", when the individual is often bedridden and dependent on others' care (Dreyer et al., 1999; Dreyer et al., 2000; Gyapong et al., 1996).

At the time the support group programme was initiated, researchers at Ste. Croix Hospital had recently completed a clinical trial that attempted to compare the feasibility and efficacy of two models for lymphoedema



management. The first intervention was a simple regimen of patient self-management, developed in Brazil by Dr Gerusa Dreyer and colleagues (Dreyer et al., 2002), which included daily leg-washing, skin care (application of antiseptics, or antifungal or antibacterial creams to skin lesions), limb elevation, and foot exercises. The second intervention also included, in addition to these measures, elements of complex decongestive therapy (Foldi, 1989), specifically compressive bandaging of the affected limb, and, less sys-

tematically, massage. The clinical protocol involved regular visits to the clinic to monitor illness management. In addition, a combined patient and community education programme about the etiology, prevention and management of lymphatic filariasis was implemented in the year prior to the support group intervention. Education about filariasis for patients and their families also was offered during meetings of the hope club of Léogane, modelled on the rally-type format described earlier for Brazil.

METHODS

The research design consisted of a longitudinal study of five self-help groups for lymphatic filariasis, organized specifically for this project, but with the aim of creating groups with long-term sustainability. The groups were followed for a period of two years to assess factors which influenced the level of participation. A matched control-group design allowed the characteristics of participants and nonparticipants to be compared. Impact evaluation was assessed through participant surveys conducted after one and two years of programme operation. Process evaluation included systematic data collection on group activities, attendance patterns, and documentation of problems encountered and their resolution. Details of the research design are elaborated in subsequent sections.

Because this project introduced a new group concept into a disadvantaged population, we adapted a model used in the development of support groups for ethnic minority populations in the United States of America (USA) which applied the concept of cultural competence within an ethnographic approach to building community involvement in support group formation (Henderson et al., 1993). A basic tenet of the approach is that even marginalized populations will participate in a support group intervention when it is implemented in a manner consistent with the cultural values of the community. The model proposes a five-phase strategy:

1. targeted ethnographic survey
2. training indigenous support leaders
3. participant recruitment
4. implementation of support groups
5. feedback and evaluation.

As noted above, the targeted ethnographic survey of lymphatic filariasis was already complete at the time we began the support group programme. This report addresses implementation of phases 2-5.

RECRUITMENT, TRAINING AND ORGANIZATION

The project staff consisted of the field director, the support group coordinator, and five peer animators. The coordinator was recruited from local female candidates who had a secondary school diploma and had been recommended by hospital staff. Peer animators were recruited from the pool of female patients enrolled in the lymphoedema treatment programme. Selection of animators was based on educational background, work or related experience, staff recommendation, and

personal interview. The principal investigator and field director trained these “facilitators” in understanding the purpose of support groups, how to lead group discussions, and how to avoid common problems associated with group dynamics. The training included didactic presentations, modelling, role-playing and group discussion, with the goal of developing skills concerning moderating groups and handling potential obstacles.

Initially, five support groups were organized, two in the town of Léogane (for convenience referred to as “urban”), and three in nearby rural communities located at varying distances from town: Bineau (one km), Baussan (three km) and Croix des Pères (eight km). Early in the first year, the two urban groups were merged into a single group because members of both groups preferred meeting on the same day and to conserve resources by paying one craft teacher. Near the end of the first year, two of the rural groups merged because of small membership numbers in one of the groups. The groups began meeting once a week, and this schedule was maintained, by members’ choice, throughout the project. In the beginning, groups followed a common format, but were later allowed flexibility in determining meeting format and content.

The American Cancer Society (Hermann et al. 1995) has identified three stages of support group development – early, middle and late – with corresponding goals and tasks for the facilitators. In the early phase, members find common ground, seek information on and/or alternatives for dealing with problems. In the middle stage, members achieve mutual aid, share experiences, offer help, redefine the meaning of their experience and explore new ways of coping. In the late stage, a group may be brought to closure if it is time-limited, or it may become institutionalized. This project aimed to develop self-help groups into the early stage within the first year, and into the middle stage by the end of the second year. In the first year, facilitator tasks included establishing trust, group norms and goals, helping members share personal experiences, and providing structure through a planned agenda and continuity of activities. In year two, facilitator tasks included the development of a core group, recruitment of new members and the maintaining of momentum.

Henderson and colleagues (1993) stress the importance of labour-intensive personal contacts together with culturally-appropriate media for the successful recruitment of disadvantaged populations. Our recruitment strategy focused on face-to-face invitations of lymphoedema patients during a clinic visit, personal networks of programme staff and patients, and home visits by animators. In the first 6 months of the activity, a total of 62 women were recruited to participate in the 5 support groups.

The choice of meeting places was based on size, location and availability of suitable space. The urban groups met in a local primary school classroom. The rural groups met on the verandas or in the yards of

members or their relatives. Where support groups are a new phenomenon, it is common to have a high turnout initially, with gradual attrition of a large proportion of participants over time. Although we expected this to happen in Léogane, attendance remained very consistent during the first six months of the programme, with only five women withdrawing. Of 79 members attending at the end of year one, 17 had dropped out by the end of year two.

The format and content of meetings was initially modelled on the typical chronic illness-style support group found in many developed countries. This model usually includes the following features: introduction of participants, explanation of the purpose of the group and meeting agenda, sharing of information about treatment and/or coping with the illness, question-and-answer periods, opportunity for participants to share personal experiences, invited speaker (usually periodic, not routine), announcements and the planning of future activities, closure, refreshments, and informal socializing. The amount of time spent on any one feature will vary between meetings and over time. For example, in the early stage of group formation, it is common for participants to spend a large amount of time getting to know one another, establishing kinship connections, learning other participants' illness stories, and other tasks related to "establishing common ground." As the group develops a deeper level of comfort and trust, attention can shift to educational/informational activities or to personal sharing of difficulties and coping. In later stages, the group may decide to organize for advocacy or other social action.

It was anticipated that the standard model would need to be adapted to the local cultural context. Finding ways to make the model congruent with the Haitian milieu was an ongoing process, with continual refinements over time. During the project we periodically sought feedback from participants, facilitators, and community contacts, and solicited advice on ways to do things that were congruent with local norms.

PROGRAMME EVALUATION

The evaluation design used in this project was adapted from Schopler and Galinsky's (1993) ecological model for understanding the factors that affect support groups and for evaluating their outcomes. This model organizes the variables to be studied into four categories: environmental conditions, participant characteristics, group conditions, and outcomes. We incorporated a case-control design by matching support group participants with neighbourhood controls (women with lymphoedema who did not participate in support groups), in order to identify determinants of participation and outcomes. Outcome measures included rate of attendance, organizational functioning of group, the participant's assessment of benefits realized, physiotherapy treatment compliance, and improvement in symptoms. Data collection methods are outlined below according to process and impact evaluation.

Process evaluation

The field director documented organizational activities related to programme development, including making community contacts, disseminating information about the project, logistical arrangements, recruitment of facilitators and participants, implementation of the support groups, and resolving problems that arose. Particular attention was accorded to the documentation of decisions to modify programme activities in response to changing circumstances. The principal investigator also kept notes on project development, institutional relations (e.g. with hospital, school and other organizations providing space, etc.), staff training activities, and overall project management during supervisory visits and through telephone, fax and written communications.

The support group coordinator kept a weekly log of planning meetings with facilitators, arrangements for meeting programmes (e.g. purchase of refreshments and materials), and other coordinating responsibilities. Group animators recorded weekly logs of group activities, attendance, format and content of programmes, problems encountered, and how these were managed. A meeting assessment form was devised to aid the monitoring of meeting process and quality. Completed meeting assessment forms and weekly logs of facilitators and the group coordinator were collected on a regular basis by the field director and copies posted to the principal investigator.

At the time of the principal investigator's quarterly supervisory visits, debriefing/planning sessions were held with project staff to assess progress in meeting programme development goals. These discussions took the form of semi-structured group interviews covering the strengths and weaknesses of programme implementation to date, exploring the factors contributing to notable successes and difficulties, and making plans for the next phase of the project. The principal investigator also observed and made notes on group meetings during these visits.

Outcome evaluation

The main environmental conditions addressed in relation to outcomes were those associated with the different geographic sites where the five support groups were held. These included urban/rural area, distance from town (and the programme's institutional base), and socioeconomic differences between sites. Variables related to group conditions included composition (size, member demographics), qualities of the facilitators (age, experience, effectiveness), meeting characteristics (schedule, format, programme quality), and group dynamics (degree of rapport, level of personal sharing, adoption of a group project, socializing outside of the meeting). Data on these variables were documented in the weekly logs of facilitators and in the survey of participants, described below.

At the end of the first and second years of programme operation, semi-structured survey questionnaires were administered to all support group members and geographic controls. These included questions regarding:

- demographic information
- possessions scale
- an illness history
- knowledge and attitudes regarding *gwopye*
- quality of life measures
- home management practices
- activities of daily living, and
- assessment of support group participation.

The first six sections of the questionnaire were administered to controls. Instruments were developed by the project team and pre-tested on members and nonmembers. The possessions scale was included as a measure of economic status, and concerned six items: radio, television, storage chest, refrigerator, sofa set and bicycle or motorcycle. A test of intercorrelation among these items yielded a Chronbach's Alpha score of 0.716. Three leg measurements were also taken on all survey respondents: upper calf, lower calf, and foot circumference. A composite measure of leg size was created by adding together the latter three measurements. A team of interviewers who were not otherwise involved in the project were recruited and trained by the field director. The physiotherapy programme director trained the interviewers in leg measurement. The first survey was conducted in the summer of 1999, and included 79 members and 77 controls; the second survey was performed during the summer of 2000, and included 83 members and 101 controls.

Data analysis

Data collected for process evaluation were analysed using qualitative techniques, including critical event analysis, identification of recurrent patterns, and triangulation of sources. Critical event analysis was used to examine in depth all information related to important events in the course of programme development, in order to explain how the event influenced decisions and outcomes. Recurrent patterns were identified by careful examination of field notes, activity logs and transcripts of debriefing sessions. Attention was given to recurrent sources of tension and enthusiasm in groups.

For the case-control study, questionnaire responses were coded and entered into a database for statistical analysis using SAS software. Members were compared with controls, and differences between groups were analysed using tests of mean differences, chi-squared analysis and calculation of odds ratios. Multivariate modelling of predictors for several outcome measures was performed using logistic regression analysis.



RESULTS

THE DEVELOPMENT OF LYMPHOEDEMA SUPPORT GROUPS

The first support groups were formed during May and June of 1998. In April of that year, authors Coreil and Mayard had attended a workshop held in Ottawa, Canada, on the Special Programme for Research and Training in Tropical Diseases (TDR) Healthy Women's Counselling Guide. One of the innovative ideas taken from this meeting was the use of "listening groups" as a method of participatory education with groups of women. The method was pioneered in Nigeria with women's groups who met to listen to audiocassette tapes of a series of dramatized stories related to malaria. The groups were originally called "radio listening groups" because the tapes were designed for broadcast. In practice, most of the groups listened to the tapes from cassette players. We incorporated this method into the support group format and participants responded enthusiastically. A set of ten tapes featuring culturally appropriate characters and story lines on lymphatic filariasis had been independently developed with funding from the Office of Women's Health, United States Centers for Disease Control and Prevention. The adaptation of this method for the Haiti project represented a good example of "cross-fertilization" of innovative methods between TDR-supported projects.

These tapes, along with an instructor manual and illustrated booklets for people to take home, were the core educational tools used in the groups. The stories on the tapes were presented as dramatized vignettes with character dialogue, illustrating different aspects of filariasis transmission and treatment. The theme of each story also related to a verse from a specially-composed song – what has come to be known as "the filariasis song". The tapes repeat this memorable song about Jesula, the central character, with new verses added on each tape. Support group members enthusiastically embraced the singing of this song. The song and tapes, and educational messages about filariasis, were broadcast on the Ste. Croix Hospital radio station to the entire Léogane community. The song and stories were composed by Maude Heurtelou, a Haitian–American educational consultant to the project. The song became popular in the community, particularly among people with the illness, and their families. The support groups adopted the filariasis song as their theme song, along with other music.

Over the first few months, the support groups developed a programme of activities with a distinctly Haitian style. Social scientists refer to this process as "indigenization", the adaptation of a social institution when it is integrated into, or develops independently in a distinct cultural context (Kleinman, 1980; Atal, 1981; Etkin et al., 1990; Sahlins, 1999; Bar-on, 1999; Ho et al., 2001). A culturally meaningful meeting format evolved to include several standard features. Meetings were

opened with a prayer invocation, recited by a selected member and made relevant to a particular time and place. The prayer was followed by a religious hymn, usually something well-known to everyone, and singing of the filariasis song. Next came announcements, and sharing of personal news. Some groups then did foot exercises or leg massages. The educational portion of the meeting followed; this might consist of group discussion of particular topics, or sharing reactions to one of the dramatized sketches from the tape. Participants requested the introduction of practical skills training in crafts, so lessons on paper floral art and sewing were incorporated. Meetings were brought to a close by another personalized prayer and singing of a hymn. Refreshments were usually served after the meetings. At first, light snacks of fruit juice and crackers or biscuits were served, but in time the women expressed a strong desire for more substantial food. In response, more nutritious, meal-like refreshments were provided, including chicken, vegetables and rice.

After the first year of operation, attendance patterns were analysed. During this period (June 1998–June 1999), the drop-out rate (no attendance for 6 months) was 15% during the first 6 months, and 23% by the end of 12 months. The highest drop-out rate occurred in the group that had had consistently weak leadership and less rapport between members. An analysis of attendance trends, with drop-outs excluded, was also performed. High attenders were defined as women attending 50% or more of meetings held, and low attenders as women attending less than 50% of meetings. Results show a higher proportion of low attenders in two groups, Croix des Pères and Centre-ville, compared to the other two groups ($P < 0.03$). The low-attendance groups had a larger membership than the other two support groups, suggesting that larger group size may be related to lower-attendance patterns.

Over the first year of operation, attendance rates at all meeting sites ranged from 46–65%, with a mean attendance rate of 60.3% for 1999. In the second year, attendance rates ranged from 52–62% across sites, with a mean attendance rate of 55% for 2000. Thus attendance was fairly stable across the two years of the pilot project. A cohort of core members or “regular attenders” was identified for further analysis. This cohort included 38 members who participated in both 1999 and 2000 surveys, and had a mean annual attendance rate of above 65%. The core members made up approximately half the membership of all support groups.

Group size also appears to affect group dynamics. The large urban group, which met in a school classroom, was the first group to move in the direction of becoming a microenterprise collective, rather than a traditional support group. The members preferred to remain as a single group and not divide into smaller groups where greater rapport and personal sharing might take place. Members were very keen on learning the floral art introduced into the meeting format, and increasingly viewed the new skills as practical and potentially lucrative.

Variation in group facilitation skills between animators had to be addressed throughout the project. In some cases, the more effective leaders had limited literacy skills, which created challenges for project reporting requirements. The more competent leaders tended to be women with previous experience in church-related groups.

Over time the meeting content stabilized to include the standard set of activities described above. A key element by which members' interest in attending weekly meetings was maintained was by offering a variety of activities, instruction in practical skills, providing nourishing refreshments, and infusing the programme with significant expressive/spiritual elements. The selection of skills training to be incorporated into a group was made by the members themselves. One group chose to learn sewing, another to put together a collection of medicinal plants, a third focused on traditional handicrafts, and the large urban group selected paper floral art. Because of the strong interest members expressed in learning lucrative crafts, the second year budget was modified to provide increased funding for instruction in and materials for handicrafts. The topics covered in the educational component of the meeting programme were also selected by group members themselves, and included a comprehensive overview of filariasis and its management, male–female relationships, sexuality and contraception, family life, and other issues important to women.

Groups adopted a system by which members paid a weekly subscription to a general resource fund, to be used to help support operations after pilot project funding ended. Subscription fees were set at one Haitian gourde (about US\$ 0.06, 1999 exchange rate) per meeting.

The project encountered a number of administrative and logistical problems during both years of operation, which created instructive situations for programme evaluation. Taking into account the fact that four layers of bureaucratic structure (WHO/TDR, University of South Florida, Ste. Croix Hospital, project management) were involved, it is not surprising that a number of times there were delays in getting money to the field to purchase supplies. During these periods of several weeks, refreshments served at meetings were often meagre or not provided, and sometimes there were no supplies for the craft lessons. Records show no reduction in meeting attendance during these times.

In October 1998, Hurricane Georges swept across Haiti leaving much destruction and unsanitary conditions in its wake. Although the Léogane community was not as severely affected as other regions of the island, damages were substantial, with considerable flooding and mud covering the coastal plain. The support groups continued to meet, and such meetings served as an important venue for assisting needy families and providing meals for members. Members reported an increase in acute attacks following the storm.

Other problems related to the unstable local conditions, with telephone, fax and electronic mail services interrupted for long periods. On one occasion, communication problems between the principal investigator and field director proved to be advantageous. The principal investigator visited the study site in the belief that project staff were expecting her. They were not expecting her, the field director was away at a conference, and the principal investigator was able to observe ongoing group activities as they naturally occurred during this unplanned "surprise visit". All of the groups were scheduled to meet that week, with planned activities and programme content consistent with that which had been reported. This surprise site visit helped to verify the status of regular group meetings and the reliability of activity reports.

INDIGENIZATION OF THE SUPPORT GROUPS

Over time, the lymphoedema support groups became increasingly "Haitianized", that is, adapted to the local cultural milieu. Compared to typical support groups in North America and Europe, the Haitian women showed less interest in sharing personal stories related to the illness. Instead, enthusiasm was fuelled by opportunities to learn new things, whether about health and family life, or acquire income-generating skills. Spiritual and religious themes were expressed throughout the meetings. Some of the meeting style was undoubtedly influenced by these women's experience with church activities. Indeed, for almost all members, church groups (prayer, choir, visiting the sick, missionary work, church maintenance) were the only other type of small group meeting in which the women had ever formally participated. Thus it is not surprising that the women's previous experience with such religious groups and church congregations in general would shape the support groups. Also, there were linkages between the support group project and local churches, aside from the hospital's institutional ties to the Episcopal Church. For example, the project Christmas party of 2000 was held at a small Protestant church where one of the support group members was very active, this member having made the arrangements.

It is customary in Haiti for local organizations and groups to hold large, end-of-year parties around the Christmas holidays. In keeping with this tradition, the support groups each year organized festival-like events during the month of December. These events involved all the support groups working in unison, creating the impression of a community-wide programme. These large parties were occasions for much celebration and pride in displaying the appealing craftwork produced by the women. Community and hospital officials attended the events, providing a opportunity for enhancing the visibility of the support groups, and increasing awareness of the illness and efforts to improve the lives of people affected by it. The 1999 party was particularly festive, with large pots of food, a specially-ordered cake, music,

skits, a Master of Ceremonies, singing, speeches and a souvenir gift for members. Bright paper flowers crafted by the women themselves decorated the walls of the small church, and rows of hand-made clothing and carved gourd bowls covered display tables. A large banner proudly announcing the group's identity – "*Groupe Support*" – was stretched across the street outside.

During the autumn of 1999, the support groups began to discuss the idea of forming an association to strengthen the organizational structure of the programme, to enhance long-term sustainability and to provide a mechanism for seeking additional funding. Over a period of several weeks, discussions took place in each support group, with project management staff and with hospital administrators. The idea was enthusiastically received at all levels. By early 2000, a charter had been developed for "FADES", *Femmes en Action pour le Développement et la Santé*, (Women in Action for Development and Health). The members opted to make the association open to all women of the Léogane area, regardless of health status. FADES was officially registered with the national Ministry of Social Affairs in August 1999. Shortly afterwards, the field director began working on a proposal to seek continuation funding through FADES.

Discussions about possible association-sponsored projects also took place, with attention focused on the notion of establishing a shoe-making operation. A model shoe for large feet had been developed in 1997 by Narda Butler, a consultant to the filariasis treatment programme, with the idea of engaging patients in a microenterprise activity. The idea was rekindled in the form of a possible project for FADES. The principal investigator sought technical assistance for such a project from the Birkenstock shoe company, USA. The company was unable to respond to this request, but donated 80 pairs of sandals to the support groups.

An adverse event occurred during the autumn of 1999, when the local support group coordinator unexpectedly left the country and moved to the USA, without explanation or saying farewell to the people she had worked with closely for 18 months. Animators and members were unable to explain the sudden departure of this leader, but assumed that personal issues were involved. The gap in leadership, however, led to the formation of a strong coordinating committee composed of the four group animators, who continued to manage the project on their own. Indeed, the support groups continued to meet regularly, with minimal professional guidance, following this development. Thus a misfortune turned into a leadership development opportunity, which in the long run helped to strengthen the organizational structure of the project.

BENEFITS OF SUPPORT GROUP PARTICIPATION

The surveys administered at the end of the first and second year of the programme provided a variety of outcome measures for assessing the effects of support group participation. Results of statistical analyses will be discussed in terms of quality of life, severity of symptoms, home treatment practices, knowledge about the illness and participant evaluation of benefits and meeting activities. Members and neighbourhood controls were compared according to the above indicators for the two time periods. First the demographic characteristics of the two groups were examined, in order to identify pre-existing group differences that might have affected outcomes. Demographic data on members and controls are presented in Table 1.

No differences were found between members and controls for most demographic measures. Mean age was 40–42 years, about half were literate with a primary school education, most were married or had a partner, and the distribution of occupations was similar across the main categories of sales, farming, other work and unemployed. A few demographic differences between the groups were found. In both 1999 and 2000, there were higher proportions of non-Catholics among members than among controls. In 1999 only, members reported owning more items on the household possessions scale, more children, and more children attending school, suggesting a higher socioeconomic status for this group. Finally, a significantly higher proportion of members in both years had participated in the Ste. Croix hospital filariasis treatment programme (see Table 2).

In addition to comparisons between members and controls, additional analyses examined differential effects of the intervention on “core”, high-attendance members compared to irregular attenders and controls. Where significant intervention effects were found, we repeated the analyses controlling for whether respondents had participated in the hospital filariasis treatment programme, to determine whether support group participation had had an independent effect on outcomes. Before adding the treatment exposure variable to the multivariate models, multicollinearity tests were first performed to determine the degree of intercorrelation between support group participation and treatment programme exposure with the outcome variables. A high intercorrelation between the two predictor variables could distort the results of the regression analysis. Using the tolerance value as the diagnostic indicator, we found acceptably low levels of intercorrelation (tolerance > 0.70) in all cases, except where reported otherwise.

Table 1. Demographic data from support group surveys, 1999 and 2000

Demographic variable	1999 (<i>N</i> = 156)		2000 (<i>N</i> = 194)	
	Control (<i>N</i> = 77)	Member (<i>N</i> = 79)	Control (<i>N</i> = 101)	Member (<i>N</i> = 83)
Geographical area [% (<i>N</i>)]				
Centre-ville	67.5 (52)	59.5 (47)	42.7 (47)	35.7 (30)
Bineau	7.8 (6)	12.7 (10)	2.7 (3)	13.1 (11)
Baussan	6.5 (5)	6.3 (5)	18.2 (20)	16.7 (14)
Croix des Pères	18.2 (14)	21.5 (17)	36.4 (40)	34.5 (29)
Religion (%)				
Catholic	70.6*	53.3*	81.2*	65.1*
Non-Catholic	29.4	46.7	19.8	34.9
Occupation (%)				
Sales/farming	47.2	52.9	54.8	52.6
Other work	23.6	26.4	16.3	23.1
Unemployed	29.2	22.2	28.8	24.4
Marital status				
Have partner	65.2	80.0	62.4	67.5
No partner	34.8	20.0	37.6	32.5
Mean age (years)	40.5	40.0	41.5	41.9
Education (years of schooling)	4.7	5.5	8.3	7.7
Literacy (%)	57.4	53.1	57.4	45.8
Possessions scale	1.7**	2.6**	2.0	2.1
Children				
Mean no. alive**	2.4	3.6	NA	NA
Mean no. born	NA	NA	4.0	4.4
No. attending school	1.6***	2.9***	NA	NA
Oldest child attends school (%)	NA	NA	85.0	82.6
Youngest child attends school (%)	NA	NA	78.5	57.4
Household size				
No. living in home	4.9	5.3	NA	NA
No. sleeping in home daily				
1–2 people	NA	NA	19.4	14.1
3–5 people	NA	NA	50.9	44.7
6–7 people	NA	NA	13.9	21.2
>7 people	NA	NA	15.7	20.0

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$ Note: No. = number, *N* = population, NA = not applicable (question not posed)

Illness history and symptoms

Most respondents had been living with *gwopye* for 10–20 years. The average age of onset for the illness ranged from 22–29 years, with no statistically significant differences observed between comparison groups (Table 2).

Table 2. Illness history variables, 1999 and 2000

	1999		2000	
	Control	Member	Control	Member
Mean age of onset of illness (years)	26.2	22.0	26.8	28.7
Leg size (cm)				
Right foot	23.8	24.1	24.2	24.3
Right lower leg	24.2	25.4	24.3	25.3
Right upper leg	32.9*	34.8*	34.3	35.4
Left foot	24.2	25.5	24.4	24.1
Left lower leg	24.9	25.5	25.2	25.2
Left upper leg	34.3	35.8	34.7	34.7
Composite (sum of all measurements)	164.3	170.2	167.1	169.0
Treatment programme participation (%)	10.4****	60.8****	9.1****	54.0****
Problems living with the illness (%)				
Many	52.0**	28.4**	47.3	41.3
Some or none	47.9	71.2	52.7	58.6
How often think about illness (%)				
Rarely or never	30.3	32.0	35.4	28.7
Sometimes or often	69.7	67.9	64.5	71.3
Illness prevents from working (%) - Yes	41.6*	26.7*	52.7	58.1
Knowledge of etiology (%)				
Correct	32.5****	78.5****	31.8****	78.2****
Incorrect/don't know	67.5	21.5	68.1	21.9
Feel ashamed about the illness (%)				
Never	35.1	38.0	42.7	30.2
Rarely or sometimes	28.6	31.6	28.2	27.9
Often or always	36.4	30.4	29.1	41.9
Feelings towards others (%)				
Ashamed, embarrassed, or ill at ease	50.7*	35.4*	46.4	49.4
No problems	49.3	64.6	53.6	50.6

* P<0.05, ** P<0.01, *** P<0.001, **** P<0.0001

The various measures of leg size were similar across groups, with one small anomaly (a 2 cm difference in upper right leg circumference in 1999 only). Over the course of this project, experience gained in several clinical studies in Haiti, Brazil, and India indicated that leg size *per se* was much less important in influencing quality of life than previously thought. Much more significant was the occurrence of acute attacks of lymphangitis, severely debilitating episodes of systemic infection that exacerbate lymphoedema. These infections are caused by bacterial infection via breaks in the skin of the affected limb. The primary goal of lymphoedema management is prevention of the acute attacks through regular hygiene and skin care.

Respondents were asked to rate the frequency (never, rarely, often) at which they currently experienced acute attacks. Although when members were compared to controls no differences were observed for this variable, interesting results were found for core members. Regular attenders reported a significantly lower rate of acute attacks, in relation to the comparison group of irregular attenders and controls. While only 8.6% of core members reported having acute attacks often, 28.6% of the comparison group reported frequent attacks ($P < 0.05$). However, the effect of support group participation on frequency of attacks was highly intercorrelated with having participated in the hospital treatment programme (tolerance = 0.399), thus the observed results reflect the combined exposure to both treatment and support group intervention.

Quality of life

Quality of life was measured by several questions relating to level of difficulty experienced in living with *gwopye*. English translations of the survey items are listed below:

- Do you ever feel ashamed because you have *gwopye*?
- How do you feel towards others who do not have this illness?
- Does living with *gwopye* cause you many problems?
- What kind of problems does *gwopye* cause in your life?
- How often do you think about *gwopye*?
- Did your parents have problems when they realized you had *gwopye*?
- Does *gwopye* prevent you from working?

Improved quality of life was reported among members compared to controls in 1999 (Table 2). Members reported fewer problems living with *gwopye*, a smaller proportion said that the illness prevented them from working, and fewer individuals indicated they felt ashamed, embarrassed or ill at ease around people who did not suffer from the illness. These differences between members and controls in terms of quality of life were not found in the 2000 survey; however, comparing core members to irregular attenders and controls revealed similar patterns. Core members reported less difficulty living with *gwopye* ($P < 0.01$). The kinds of problems members reported included difficulty standing (43.7%),

problems wearing shoes (28.7%), inability to work (20.7%), and depression (12.6%). Somewhat surprisingly, only 7 out of 190 (3.6%) respondents in 2000 indicated they experienced economic problems because of their illness.

Further analyses were conducted to identify sociodemographic and other predictors of quality of life, in order to build a multivariate explanatory model of determinants of quality of life. A series of bivariate analyses were conducted on various outcomes. Those associated with a statistical probability of less than 0.05 are reported below. Difficulty living with *gwopye* was associated with age, possessions, group (member versus control) and cohort (regular attenders versus irregular attenders and controls). In both years, older women reported fewer difficulties, and in 1999 wealthier women, as measured by the possession scale, reported less difficulties. In 1999, difficulty working was associated with member status, and leg size (larger leg size being associated with more problems). In 2000, difficulty working was associated with only one variable, total number of children (fewer children associated with less reported interference with work). In 2000, feelings of shame and embarrassment were positively associated with composite leg size. Leg size, along with age, was also associated with frequency of thinking about *gwopye*. Predictors of problems experienced by parents were found in 1999 only, and were clearly age-related. Younger age and younger age of onset of illness were associated with reported problems for parents.

Multivariate analyses of predictors of quality of life

The next phase of analysis consisted of examining the combined effects of multiple predictor variables on quality-of-life outcomes. Logistic regression analyses were performed on three quality-of-life measures: difficulty living with *gwopye*, frequency with which the individual thinks about the illness, and interference with work. Outcome variables had dichotomous values, generally representing high versus moderate-to-low values. Predictor variables were selected based on significant bivariate associations with the dependent variables, and were entered into the model in descending order of statistical strength.

For difficulty living with *gwopye*, separate analyses were conducted for 1999 and 2000 datasets (Tables 3 and 4). Both analyses controlled for exposure to hospital treatment. Five variables were entered into the logistic regression model for 1999: support group membership, treatment exposure, age, leg size and possessions. When controlling for the effects of other variables, support group membership, age and leg size remained significant. For 2000, being a core member, treatment exposure, age, possessions and leg size were entered into the model; results show that age, possessions and leg size remained significant predictors. Age and leg size were stable predictors in both years, with support group membership and possessions having significance for one of the two time points.

Table 3. Multivariate predictors of difficulty living with the illness in 1999

Variable	Odds ratio	95% CI	Probability
Support group member	0.39	0.16–0.95	0.039
Treatment programme	0.76	0.30–1.89	0.551
Age	0.97	0.93–0.99	0.008
Possessions scale	0.83	0.66–1.06	0.142
Leg size	1.02	1.01–1.05	0.014

Table 4. Multivariate predictors of difficulty living with the illness in 2000

Variable	Odds ratio	95% CI	Probability
Core support group member	0.78	0.22–2.69	0.689
Treatment programme	0.48	0.16–1.44	0.190
Age	0.97	0.95–0.99	0.011
Possessions scale	0.81	0.67–0.98	0.029
Leg size	1.02	1.00–1.03	0.016

The second quality-of-life measure with multiple predictors was frequency with which one thinks about *gwopye*. In 2000, both (younger) age and (larger) leg size were associated with more frequent thinking about the illness, and both variables were significant in the logistic regression analysis (Table 5). Once again, age and leg size appear as important variables associated with quality of life.

Table 5. Multivariate predictors of frequency with which the individual thinks about their illness

Variable	Odds ratio	95% CI	Probability
Age	0.97	0.95–0.99	0.016
Leg size	1.02	1.00–1.03	0.029

Finally, bivariate predictors of whether the disease interfered with work in 1999 included support group membership, possessions, and leg size. Exposure to the hospital treatment programme was included in the regression model as a control variable. Results show that only leg size remains a significant predictor of work interference when controlling for the other variables (Table 6).

Table 6. Multivariate predictors of whether the illness interfered with work

Variable	Odds ratio	95% CI	Probability
Support group member	0.49	0.21–1.16	0.105
Treatment programme	0.89	0.37–2.14	0.790
Possessions	0.88	0.71–1.09	0.229
Leg size	1.02	1.00–1.04	0.037

Knowledge and beliefs about the illness

Demographic variables were not correlated with the individual's knowledge about lymphatic filariasis. Large differences in understanding of the vector etiology of filariasis were found between support group members and controls. Whereas only about a third (32.5%) of controls could correctly identify the cause of filariasis, more than three-quarters (78.5%) of members did so ($P < 0.0001$). To assess the effects of support group participation on understanding of etiology independent of members' having participated in the hospital treatment programme, logistic regression was performed. Both variables were entered into a model predicting knowledge of vector etiology. The results indicate that both variables had an independent and significant association with knowledge of etiology (Table 7). Support group members were more than five times more likely to know about vector transmission than controls, after adjusting for the effects of the treatment programme.

Table 7. Multivariate analysis of support group membership and hospital treatment programme exposure on knowledge of etiology

Variable	Odds ratio	95% CI	Probability
Support group member	5.29	1.90–14.7	0.001
Treatment programme	7.52	1.61–35.7	0.010

No differences were found between comparison groups in their responses to a series of questions regarding what others think about the cause of *gwopye* (e.g. mosquitos, worm bite, magical). Likewise, members and controls did not differ significantly in responses to general questions about how much the illness affects the lives of people who have the condition in the areas of work, marriage and love. When asked "What kinds of treatment are there for *gwopye*?", a significantly larger proportion of members (75.9%) compared to controls (48.2%) identified "hospital" as a therapeutic option ($P < 0.001$), but no differences were evident for other choices, including purchased medicines, home remedies and magical cures. The greater awareness regarding hospital treatment reflects the exposure of more members than controls to the Ste. Croix lymphoedema treatment programme.

Home care practices

To measure the effect on home care practices, two indicators were examined: foot washing and leg elevation. Respondents who indicated that they practised daily foot washing and elevation were compared to those who performed these practices less frequently. Demographic variables were not associated with care practices. A high proportion of women in both comparison groups (96.5% of members, 88.2% of controls) reportedly practised daily foot washing. Nevertheless, the higher rate of daily foot washing among support group members was statistically significant ($P < 0.05$). Furthermore, participation in the hospital lymphoedema treatment programme was not associated with washing. In the case of leg elevation, a somewhat lower number of women said that they performed this daily (78.2% of members and 49.1% of controls). Also, exposure to the lymphoedema treatment programme was associated with more frequent leg elevation, therefore a logistic regression was performed to determine the independent effects of support group participation on this practice. Both support group participation and lymphoedema treatment programme exposure had independent associations with daily leg elevation (Table 8). Support group members were twice as likely as controls to practise daily leg elevation, controlling for treatment programme exposure.

Table 8. Multivariate analysis of support group membership and hospital treatment programme exposure on use of daily leg elevation

Variable	Odds ratio	95% CI	Probability
Support group member	2.04	1.01–4.12	0.046
Treatment programme	5.78	2.19–15.2	0.001

Table 9. Relationship between support group participation and compliance with home care practices

Comparison group	Wash feet daily (%)	Elevate leg daily (%)
Regular attenders	100.0	84.2
Irregular attenders	93.9	73.5
Controls	88.2	49.1

$\chi^2 = 5.6$, $df = 1$, $P = 0.06$ $\chi^2 = 18.5$, $df = 1$, $P = 0.0001$

Interestingly, with these practices there appears to be a dose–response relationship among regular attenders, irregular attenders and controls (Table 9).

Member assessment of benefits

In 1999, all but two survey respondents indicated that they had experienced benefits from participating in the support groups. When asked to specify the benefits they had experienced, members cited learning new things (41.4%), floral art (24.1%), sewing (17.2%), refreshments (8.6%), encouragement (6.9%) and gifts (1.7%). Respondents were also asked to identify the aspect of the support group that they preferred. About a third of members (31.7%) responded that they liked all the group activities. Those who identified a particular component most often chose floral art instruction (31.7%) and sewing (15.9%), with less than 5% of the remaining respondents selecting topical lessons, songs, talking about the illness, encouragement, prayer, refreshments, and cooking. Only a handful of respondents identified things that they did not like about the meetings; these included too much talking, people neglecting to attend, and meeting weekly. They also noted a few problems in the groups, including low attendance, arguments, talking outside the group, and delays in getting operating funds.

A wider variety of benefits were identified by a substantial proportion of respondents in the 2000 survey. Also, a slightly higher number of respondents in the second year reported that they did not experience any benefits from support group participation (14 out of 80 respondents), although over 80% reported some benefits. The most commonly identified were gifts (51.8%), floral art instruction (50.6%), encouragement (50.6%), refreshments (48.1%), new information (43.2%), information about the illness (46.9%), topical lessons (42.2%), and sewing lessons (24.7%). Again, few women noted things that they did not like about the groups, which included people not attending meetings, too much talking, and the weekly meeting schedule. The more frequent reporting of different kinds of benefits may reflect multiple influences. By the end of the second year, members had probably been exposed to a greater variety of meeting activities, and could evaluate their benefits from experience. In addition, the responses in the first year were to an open-ended question, without specific probes. In year two, a list of categories was included for specific probing, which probably increased the number of positive responses.

Women were asked about specific kinds of support received through the group. Interestingly, types of support ranked most highly in 1999 were moral support (92.6%) and encouragement (92.6%), and the lowest were psychological support (63.2%) and material assistance (64.2%). Other types of support claimed by 80–90% of respondents included, information, support for behaviour change, greater confidence, knowledge about the illness, and lessons about life. In 2000, lower proportions of respondents identified all of the categories of support, and informational support was ranked as high as emotional support among the various categories. The types of support reported most frequently included: acquiring knowledge (55.7%) and information (45.6%), encouragement (59.5%), moral support (39.2%), material aid (33.8%),

lessons about life (24.1%), support for behaviour change (21.5%), greater confidence (21.5%), and psychological support (21.3%).

Responding to an open-ended question about other things members would like to see in the group, almost all respondents in 1999 proposed the addition of more activities such as crafts, sewing and cooking. A few mentioned expansion of the programme to include more people. In 2000, the most frequently proposed change was the provision of credit to members (41.5%), with 20–30% of respondents noting the addition of visits to other groups, provision of medicine, offering more activities, and reading classes. The idea of forming a credit association through FADES had been discussed within the groups during the second year.

Finally, it is important to note the leadership development benefits of the support group project. Administrative and leadership competencies were developed among the peer group animators, as well as among members who had opportunities to engage in public speaking and advocacy. Competition for leadership roles was marked, reflecting the high value placed on the opportunity for personal growth and achievement.

ACHIEVING SUSTAINABILITY

During the second year of the project, attention was focused on how the support group meetings could be sustained after external support had ended. At meetings, opinions were mixed about whether women would continue to participate if the groups no longer had funds to purchase refreshments, pay instructors and buy supplies. Most members surveyed (78%) doubted that interest could be maintained without outside support. Nevertheless, the groups continued to meet without operating funds for several months after grant support for field activities ended in June 2000. A visit to the support groups in January 1999 by a Presbyterian minister, the Reverend Ruth Boling of New York, eventually led to securing funding to continue the full-scale project, beginning in January 2001. A proposal to the Presbyterian Church USA, through the Creative Ministries of Presbyterian Women – Birthday Offering Fund, requested multi-year funding to expand the support group programme to the entire commune of Léogane, as well as to other endemic areas of Haiti. This project, entitled “From clinic to community: treating lymphatic filariasis and elephantiasis in Haiti”, was one of five proposals awarded funding in 2000, providing US\$ 200 000 of support.

By February 2002, the new project had achieved remarkable success in expanding the support groups to all sections of the commune. Twelve new support groups were organized, bringing the total to sixteen, with four additional groups planned to be formed. The expanded project is operating well under the direction of a management team consisting of a support group coordinator, four assistant coordinators and sixteen animators. The original project is now referred to as the “pilot project.” The field director provided training to the staff and helped organize the

new groups. The project is now more closely integrated with the hospital filariasis treatment programme, with the support group coordinator reporting to the director of lymphoedema management at Ste. Croix Hospital. The support groups continue to operate with reduced funding (about US\$ 10 per group per week, compared to US\$ 20 in the pilot project). The groups follow a similar meeting format as previously, with an emphasis on technical skills training.

The support group programme now interfaces with the hospital's filariasis morbidity control activities in several ways. Women who attend a support group but have never sought treatment at the hospital are referred to the filariasis clinic for evaluation. There they receive medical treatment as needed, instruction on home care and prevention of acute bacterial attacks, education about how to manage acute attacks, and counselling on when to seek clinical care. These new referrals are entered into the hospital's database, which is used for planning and epidemiologic assessment. At the support group meetings, members learn about the kinds of services available from the filariasis clinic. A lymphoedema technician who is part of the clinic staff serves as a liaison to the support groups, attending meetings, providing instruction, and visiting sick people at home. Support group staff and members have participated in the filariasis elimination programme by assisting with the mass distribution of antiparasitic drugs, albendazole and diethylcarbamazine (DEC). A few of the women have taken on part-time work sewing for a bednet-manufacturing project (see below). Members have provided home lodging for visiting patients from other parts of Haiti and other countries. Women who are too sick with an acute attack to attend a meeting are reported to the clinic management, which then sends out a doctor or technician to make a home visit.

An important measure of the sustainability of any new programme is the extent to which it serves as a model for programme development in other geographic areas. On this score the support group programme achieves high marks. Currently there are plans to develop comprehensive filariasis control programmes in other regions of high filariasis endemicity in Haiti. These programmes will initially focus on mass distribution of antifilarial drugs, but lymphoedema management programmes will also be established. A lymphoedema treatment clinic has already been established at Sacré Coeur Hospital in Milot, in the north of Haiti near Cap-Haitien, with support from Interchurch Medical Assistance. Two hope clubs have been established in the neighbouring commune. With recent funding from the Bill and Melinda Gates Foundation to the University of Notre Dame, plans are underway to organize coordinated training workshops in lymphoedema treatment, with the goal of establishing clinics modelled on the Ste. Croix programme. The focus will be on patient education in home management and prevention of acute attacks. Training in support group development will be included in the comprehensive training programmes to be offered, with plans to develop a support group training module for this purpose. All these activities are being undertaken in close collaboration

with the newly-organized national filariasis programme within Haiti's Ministry of Health.

An advisory committee provides supervision for the expanded support group programme. The committee includes the authors, local project staff, hospital administrators, and representatives from the Presbyterian Church. The committee meets twice a year in Léogane, each time inviting a guest that may have an interest in certain aspects of the support groups, including contacts with funding organizations. At a meeting in February 2002, the director of Self Development of People, a humanitarian arm of the Presbyterian Church, led discussions with members regarding seeking support for a microenterprise initiative. The project has rented office space in town, and may be able to start a new venture, such as a community store or boutique for selling crafts. The membership has expressed a strong interest in adding commercial activities to the group's programme, and there is support for taking this direction from the advisory committee and from hospital staff. Another malaria- and filariasis-related microenterprise project, also supported by the University of Notre Dame, is the KOLEMO initiative (*Komite de Leogann pou Moustikè*). This initiative focuses on the local manufacture of bednets for profit, and currently is in its second year of operation, with encouraging results, and has sparked greater interest in commercial ventures for the filariasis community. There is some concern, however, that a move in this direction for the support groups could lead to the loss of the original psychosocial and educational components of the programme, which have clearly produced benefits for the members.

DISCUSSION AND CONCLUSIONS

INDIGENIZATION

Adaptation of the illness-focused support group model to the Haitian context was successfully demonstrated in this project. Enthusiastic participation was sustained over two years, with consistent weekly meetings, a high level of activity at meetings, and increasing demand for expansion of the programme to new geographic areas and broader scopes of activity. Indigenization of the support groups occurred early in the development process. Unlike typical support groups in developed country settings, the Haitian groups showed only modest interest in talking about problems related to the illness. Members wanted to learn new things, acquire practical skills, and organize themselves for economic ventures. They valued opportunities to develop and display their artistic talents. Strong religious and spiritual themes were expressed in the meeting content, with elements of expressive culture incorporated into song, prayer, humour, role-playing and story-telling. Peer leaders and members alike showed great pride in the accomplishments of their groups.

The growing interest among the groups to move in the direction of organizing for microenterprise activities was probably the result of multiple influences. Firstly, a strong entrepreneurial ethos is deeply embedded in Haitian culture. History and economic necessity has engendered a keen sense for making the most of opportunity, to find ways to “do a little business” to make ends meet, to manage through part-time jobs and creative means for making extra money. This astute business sense is particularly developed among Haitian women, who traditionally handle the work of selling produce and goods in the market for the support of the family. Expanding one’s illness-support group to incorporate income-generating goals would seem to be a natural evolution in this setting. In fact, several women from the urban group have independently established flower-making businesses for weddings and other special occasions, using the skills acquired in the group. Secondly, during the duration of the project, interest in the notion of microenterprise ventures was disseminated among other groups working with various lymphoedema programmes in the community. The KOLEMO bednet cooperative began production during year two of the project, and a few of the support group members were engaged as seamstresses in this endeavour. Thirdly, the idea of forming a profitable cooperative within the membership was purposefully discussed in the support group meetings, stimulating interest in its feasibility. Finally, the impact of political and economic instability in Haiti in recent years must be taken into account, with associated dramatic increases in the cost of living for everyone. People are finding it more and more difficult to make a living and to meet the basic needs of their families. In this context, every opportunity to earn a little extra money must be exploited.

BENEFITS

Participation in the lymphoedema support groups was associated with significant benefits in the areas of knowledge about the illness, home care practices and quality of life. Compared to women who did not participate in support groups, members scored higher regarding their knowledge of the vector etiology of filariasis, and this beneficial effect was independent of participation in the hospital lymphoedema treatment programme. Recommended home care practices were more consistently followed by support group members. In the case of daily leg washing, support group members reported a higher compliance rate, and this outcome was not associated with participation in the lymphoedema treatment programme. Daily leg elevation, on the other hand, was associated with treatment programme exposure, but support group membership had an independent effect on this behaviour. Thus knowledge and self-care were positively influenced by participation in the support groups.

While knowledge and behaviour can be influenced by a variety of educational interventions, research suggests that support groups offer unique advantages for enhancing subjective perception of quality of life for people living with a chronic illness or disability. Our study supports this advantage for filariasis support groups. Across several quality-of-life measures, support group membership was associated with positive outcomes, including lower perceived difficulty living with the illness, fewer negative feelings towards others, and less interference with work. In addition to support group participation, quality of life was influenced by demographic and illness factors. In particular, age and leg size were consistently associated with quality-of-life indicators. Younger women reported more difficulty living with the illness, more time spent thinking about the illness, and more problems for their parents in dealing with their illnesses. Women with larger legs reported more problems in daily living, more time spent thinking about the illness, and greater interference with work. Less consistent demographic correlates of quality of life included relative wealth and number of children. Women who scored higher on the material style-of-life scale (possessions) reported fewer difficulties living with the illness, and women with more children reported more interference with work.

A separate longitudinal analysis of the survey data (Wolper, 2001) examined predictors of home care compliance among support group members in 2000. Interestingly, 1999 quality-of-life measures were predictive of self-care compliance in 2000, but 1999 compliance scores were not correlated with 2000 quality-of-life measures. In other words, the association between quality-of-life and compliance was unidirectional.

“Participants in the support groups with more positive attitudes regarding their quality of life were almost five times more likely to practise proper healthy compliance behaviors on a daily basis than women with more negative quality of life attitudes. Also, support group participants

with lower perceived life difficulties caused by *gwopye* were slightly less likely to practise proper daily compliance behaviors than women who reported higher perceived life difficulties” (Wolper, 2001:66-67). Similar findings were reported by Wendt (1999) for the hospital treatment group. These results underscore the importance of psychosocial interventions for sustaining long-term self-care.

The results suggest that the impact of the support group intervention was maximized for core members who attended meetings regularly during the two years. Core members reported fewer difficulties living with lymphatic filariasis in the second year. They also reported lower rates of acute attacks, although this association was strongly intercorrelated with exposure to the hospital treatment programme. The effects of sustained participation were particularly evident in self-care practices of hygiene and leg elevation, where a dose–response relationship was shown when the behaviour of regular attenders, irregular attenders and controls was compared. By the end of the second year, members were able to identify a wider variety of benefits gained from the support groups, with a higher percentages of respondents naming a broad spectrum of benefits. In both years, both informational support (learning new things) and emotional support (encouragement, moral support) were ranked high. The value participants placed on enhanced self-esteem and skills acquisition from group membership was clearly voiced by members in testimonials at support group meetings. Interviews with lymphoedema treatment staff corroborated the view that patients who belonged to a support group demonstrated increased self-confidence and optimism regarding the illness.

SUSTAINABILITY

Several issues are relevant to the sustainability of the support group programme, including the question of financially supported versus volunteer-based models of operation, the role of professional support and technical assistance, the integration of support groups into comprehensive filariasis control programmes, and the potential for new directions to redefine the purpose of the groups.

Financial support versus volunteerism

The pilot project operated with modest financial support for personnel costs, supplies, transportation and rental of the meeting place. The intention was to shift to a volunteer-based programme, which was more typical of illness support groups in other settings, at the end of grant funding. Short-term sustainability (four to six months) of the volunteer-based model was demonstrated during two periods, one during the pilot project and another during the interim period before the expanded project began. The securing of additional external financial support for the project precluded the evaluation of the sustainability of the volunteer

model. However, the long-term goal for continuation of the programme remains the attainment of self-sufficiency. This might involve the members themselves seeking limited external support for resources such as supplies and transportation through their own association, or through local institutional sponsorship. The bulk of resources could probably be provided by members themselves, including refreshments, craft supplies and volunteer instructors. Members may elect to contribute regular subscription monies to a common fund. Finding meeting space in members' homes, porches or yards should not pose a serious problem, as this was done in most of the pilot groups.

Professional support and technical assistance

In the initial phases of support group programme development, the role of professional guidance and technical assistance is vital. The local director of the Haitian programme was a professionally-trained social scientist who provided valuable leadership in programme organization and cultural adaptation of the support group model. The project invested considerable effort in training peer leaders and teaching members about the functions and goals of support groups, including how to achieve participatory management. Given the unfamiliarity of the support group concept in this setting, it was necessary to continually educate participants, animators, health care providers and the community about the nature of the programme. Over time, the peer leaders were able to assume most of the management functions of the project, and currently play important roles in the expansion project. Development of leadership and organizational skills are important goals of new and ongoing support group programmes. In our experience, effective group facilitation skills were more important for group functioning than literacy and formal education among animators.

Integration of support groups with comprehensive filariasis control programmes

Long-term sustainability of illness support groups requires some level of institutional support. For example, in the USA, the American Cancer Society provides publicity and referral information for various cancer support groups, while professional associations and hospitals sponsor other illness support groups. In the case of the Haitian lymphoedema support groups, institutional support from the local hospital, particularly its various filariasis-related programmes, provided an important social infrastructure for the programme. The support groups fit into a larger context of community-based filariasis activities, including patient outreach, ongoing elimination efforts and the development of a national filariasis control programme. The infusion of substantial external funding from the University of Notre Dame and the Bill and Melinda Gates Foundation led to the accelerated development of local and national infrastructure for both morbidity control and disease elimina-

tion. In 2000, the support groups were formally integrated into the filariasis morbidity control programme of Ste. Croix Hospital, with the support group staff reporting directly to the director of lymphoedema treatment.

The closer alignment of the support group programme with the hospital's other activities is mostly advantageous, although there are some disadvantages. The advantages include greater institutionalization of the programme, increased administrative support, higher visibility for its benefits, integration of social support with clinical care, and incorporation of support groups into plans for the national expansion of filariasis treatment in Haiti. All of these factors promote long-term programme sustainability. There are two main disadvantages. The first involves increased bureaucratization of operations, with the inherent difficulties of getting things done through an administrative hierarchy. Bureaucratization also has the potential to undermine the empowerment goals of support groups, which are to foster self-determination of women. The second disadvantage stems from the danger of becoming overwhelmed and disappearing when surrounded by large-scale, big-budget, high-profile projects concerning the same illness. Local administrative infrastructure is being strained to the maximum by huge filariasis-related undertakings. In this context, support groups may not receive the attention they need to flourish.

The advantages of institutional affiliation of the lymphoedema support groups is particularly noteworthy from the standpoint of providing integration of social support with clinical treatment. The Haitian support group intervention combined education and social support with clinical management, because a large proportion of support group members had been enrolled in the hospital treatment programme. Close linkages with clinical care are important for patient evaluation, referral of illness complications requiring medical services, and for strengthening the outreach components of morbidity control.

Potential for redefinition of purpose

As the Haitian groups move increasingly towards incorporating microenterprise activities into the programme, there is the potential for greater enrichment and strengthening of the groups. At the same time, there is the danger that economic goals could overshadow the original educational and support purposes of the programme. In areas where basic survival needs are acute, such as Haiti (as well as most areas where filariasis is endemic), this possibility should be given careful consideration. Research on globalization worldwide has shown that the values on which support groups are based have been forged in affluent countries where a postmaterialist view of the world takes for granted basic economic well-being and physical security. People who subscribe to post-materialist values are more likely to give priority to nonmaterial goals such as self-expression, belonging, and intellectual or aesthetic satis-

faction (Inglehart, 1997). Moreover, “economic advancement is associated with increased numbers of, as well as increased membership in, voluntary associations representing a wide variety of interest groups” (Kunitz, 2000:1532). Therefore, as with any evolving dynamic programme, forces which act towards redefining the purpose of support groups to meet more basic material needs can be expected in poor settings. Organizers and participants should anticipate the implications of new directions taken.

APPLICABILITY TO OTHER AREAS

The support group programme developed for Haitian women with lymphatic filariasis has applicability not only to other areas where lymphatic filariasis is endemic, but also as a general model for chronic disease self-help groups in resource-poor settings. It offers a low-cost intervention with demonstrated educational, illness management and psychosocial benefits. The financial, technological and infrastructure requirements for programme implementation are minimal. Given the magnitude of the burden of tropical diseases, support groups can provide a cost-effective adjunct to clinical care to meet patient education goals, particularly for conditions requiring a focused regimen of self-care. In addition, they can address issues of social stigma, self-esteem and quality of life much more directly. Furthermore, applicability extends beyond tropical diseases and may include chronic disease and disability generally, including mental illness, HIV/AIDS and physical impairment.

Application of the support group model to other areas and conditions requires adaptation to achieve cultural compatibility and to fit with community context (e.g. urban/rural setting), as well as tailoring to the social characteristics of members (e.g. gender, socioeconomic status, age). To aid in assessing the utility of a support group intervention for other arenas, the following general components of the Haitian model are outlined below.

Basic components of the Haitian lymphatic filariasis support group model

1. **Formative ethnographic research** to identify relevant aspects of the sociocultural context of the illness.
2. **Recruitment of key personnel:** organizer/director with social science background, local coordinator, peer animators.
3. **Intensive training of staff** in support group methods and operations.
4. **Participatory planning** of meeting format and activities, with the goal of indigenization of the model.
5. **Ongoing adjustment of programmes** to maintain interest and benefits for members.

6. **Institutional linkages** between support group programme and clinical lymphatic filariasis services.
7. **Monitoring mechanisms** to assess progress, impact and problem resolution.
6. **Attention to long-term sustainability** of programme.

Transferability of experience acquired in Haiti will require some modification in other low-income settings. While the general model as outlined above is applicable to most places, it should be noted that pilot projects by nature are often more intensive in personnel and resources than are institutionalized programmes. For example, the Haitian groups were managed by paid staff and met on a weekly basis in the pilot project, and this format has continued with the support of external funding. In other areas it may be necessary to design a management structure that relies more heavily on volunteerism and has a less frequent meeting schedule, more along the lines of illness support groups in industrial country settings. Likewise, available resources for activities and supplies will be more constrained in volunteer programmes, so that the scale of operations may need to be adjusted to fit local capacity. Programme coordination will require either recruitment of new staff or redefinition of existing community outreach personnel to include support group supervision.

The logistical demands of support group organization will vary significantly across urban, village and remote rural settlements. In cities and towns, certain aspects will be easier to accommodate, such as finding a suitable meeting place, transportation of people and supplies, and access to furnishings (e.g. tables and chairs). As with focus groups in rural areas, it is more difficult to bring people together who live far apart, and finding even the simplest meeting accommodation in poor communities can sometimes be a challenge. Institutional support for the organization of groups, particularly initially, will be essential.

Attention to the desirability of gender-specific versus mixed-gender support groups for different health problems will be needed. Because the prevalence of filariasis-related lymphoedema of the lower extremity is much higher among women in Haiti, we organized gender-specific support groups for this problem. About one year into the programme, the membership was given the opportunity to consider inviting men to join the groups, but the consensus was to maintain the groups for women only. Reasons given for this choice were that women faced different issues related to the illness, men would not share the same activity interests (e.g. craft skills), and the members felt that they would be more comfortable sharing personal stories in women-only groups. In the hope club model of filariasis community support (Dreyer and Addiss, 2000), however, both men and women with lymphoedema of the leg participate together in group activities. Much will depend on the nature of the condition in question and the degree of gender segregation in the society. For some conditions, such as malaria, tuberculosis and diabetes, gender segregation may be less important for support

group dynamics than for physically disfiguring conditions or problems related to sexuality (e.g. HIV/AIDS). Moreover, in some settings, cultural norms dictate gender segregation in all aspects of public life.

Research on stigma and tropical diseases suggests that women may experience more social disadvantages than men from physically disfiguring conditions such as lymphatic filariasis. For example, studies in Africa document that women believe strongly that onchocercal skin disease has a negative effect on their fertility (Brieger et al., 1987), and women with onchocercal skin disease married later and weaned their children sooner than women not affected by the disease (Amazigo, 1994). Women in Nigeria and other places are more frequently affected by the disease (Brieger et al., 1997), and consequently more exposed to associated stigma. Likewise, the prevalence of lymphoedema and elephantiasis of the leg from filariasis is more prevalent among women in most areas. Our earlier research in Haiti documented stigma in several areas of social life (Coreil et al., 1998). It would appear, then, that support groups may offer an important intervention in these settings for such stigmatized conditions that affect physical appearance and functional ability.

Support groups can reduce both perceived stigma and negative community attitudes toward the disease, and build social capital based on women's relationships (Kawachi & Berkman, 2000; Bourdieu, 1986). This kind of empowering intervention is particularly appropriate in areas where tropical diseases are prevalent and structural factors within society frequently make women economically dependent on men and relegate them to a lower social status (Rathgeber & Vlassoff, 1993). Furthermore, special attention to the support needs of women in relation to tropical diseases is warranted from the standpoint that gender roles tend to expose them more often to the vectors that transmit tropical diseases, and they bear harsher consequences from the burden of disease due to their caretaker responsibilities (Vlassoff & Bonilla, 1994). Gender-based support groups provide a practical strategy for advancing the integration of a gender perspective into health programme planning (Vlassoff & Morena, 2002).

Lastly, the study contributes to the anthropology of infectious diseases by expanding the focus of inquiry to a new arena of community participation in health programmes, the illness support group. It underscores the important contribution that women's groups can make in addressing their own health needs in poor areas (Farmer, 1997). Evaluation of community-based interventions has demonstrated the importance of ethnographic research for informing programme design (Inhorn & Brown, 1997); this also holds true for support group interventions. Although considerable ethnomedical research has been conducted on the vector-borne diseases (Coreil, 2003), this is the first study to apply the concept of indigenization to understand the adaptation of health-related social institutions to a local cultural context. As social scientists redirect their research lens upstream to organizational and institu-

tional processes in public health interventions (Farmer & Becerra, 2001), the concept of indigenization will be analytically useful for understanding organizational dynamics and change.

CONCLUSION

Support groups offer a low-cost, psychosocial-educational intervention for people living with chronic disease and disability. Significant benefits have been documented for illness-related support groups, but little attention has been given this type of intervention in developing countries. This report presents a case study of support groups organized for Haitian women with lymphoedema and elephantiasis caused by lymphatic filariasis. Our study documented high levels of participant acceptance and satisfaction with the support group model. The importance of indigenization of the intervention was shown in the adaptation of the model to fit the Haitian cultural context, as reflected in the emphasis on spiritual/expressive components and training in practical skills. The benefits of support group participation were evident in the areas of illness knowledge, home care practices, quality of life and illness symptoms. Lessons learned from this experiment can be applied to the incorporation of support groups into the management of other health problems in diverse cultural settings.

ACKNOWLEDGEMENTS

Our greatest thanks go to the members of the lymphoedema support groups whose dedication made the project a success. Special thanks go to the support group coordinator and animators for their hard work: Gédilia Laplante, Elizabeth Ajax, Nerla Jean-Louis, Mannie Derissaint, Denise Faustin Jean-Julien, Muracile Joseph, and Mirlande Oscar. We are grateful for the assistance provided by the Ste. Croix Hospital physiotherapy programme, particularly Jacky Louis-Charles and the lymphoedema technicians. The hospital director, Dr Jack Guy Lafontant, along with the filariasis clinical staff, Drs Marie Denise Milord, Madsen Beaudé Rochars, and Marie Carmel Michel, were extremely supportive throughout. Collateral project cooperation and logistical support were generously provided by many other members of the Léogane “filariasis community,” including Tom Streit, Pat Lammie, Victoria Yeghoyan, Joyana Wendt, Amanda Freeman and Rohini Kanniganti. Assistance with data analysis was provided by Lauren Bailey, Yolga Belizaire and Marie Denis. Birkenstock USA shoe company donated sandals to the project. Finally, we recognize the important leadership provided for gender-focused projects at TDR by Drs Carol Vlassoff, Pamela Hartigan and Patricia Hudelson, and we thank the Reverend Ruth Boling for her efforts to sustain and expand the project.

REFERENCES

- Amazigo UO (1994) Detrimental effects of onchocerciasis on marriage and breastfeeding. *Tropical and Geographical Medicine*, 46:322-325.
- Atal Y (1981) The call for indigenization. *International Social Science Journal*, 33(1):189-197.
- Bandyopadhyay L (1996) Lymphatic filariasis and the women of India. *Social Science & Medicine*, 42(10):1401-1410.
- Bar-on A (1999) Social work and the 'missionary zeal to whip the heathen along the path of righteousness'. *British Journal of Social Work*, 29:5-26.
- Bourdieu P (1986) The forms of capital. In: Richardson JG, ed. *The handbook of theory: Research for the sociology of education*, New York, Greenwood Press: 241-258.
- Branckaerts J and Richardson A (1992) Self-help groups: their impact and potential. *WHO Regional Publications: European Series*, 44:363-367.
- Brieger WR et al. (1987) Onchocerciasis and pregnancy: traditional beliefs of Yoruba women in Nigeria. *Tropical Doctor*, 17:171-174.
- Brieger WR et al. (1997) Gender and ethnic differences in onchocercal skin disease in Oyo State, Nigeria. *Tropical Medicine and International Health*, 2:529-534
- Coreil J et al. (1998) Filarial elephantiasis among Haitian women: social context and behavioral factors in treatment. *Tropical Medicine and International Health*, 3(6):467-473.
- Coreil J (2000) Local history and environment: Filariasis in Haiti. Paper presented at the Society for Applied Anthropology, San Francisco, CA, USA, March 21-25.
- Coreil J (2003) Malaria and other major insect vector diseases. In Ember C and Ember M, eds. *Encyclopedia of Medical Anthropology*, New York, Plenum. In press.
- Dean M (2001) Lymphatic filariasis: The quest to eliminate a 4000-year-old disease. Hollis NH, Hollis Publishing Company.
- Dreyer G and Addiss D (2000) Hope clubs: new strategy for lymphatic filariasis-endemic areas. *Bulletin of Tropical Medicine and International Health* (Newsletter of Royal Society of Tropical Medicine and Hygiene), 8(1):8.
- Dreyer G et al. (2000) Pathogenesis of lymphatic disease in bancroftian filariasis: a clinical perspective. *Parasitology Today*, 16:544-548.
- Dreyer G et al. (1999) Acute attacks in the extremities of persons living in an area endemic for bancroftian filariasis: differentiation of two syndromes. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 93:413-417.

- Dreyer G et al. (2002) *Basic lymphedema management: treatment and prevention of problems associated with lymphatic filariasis*. Hollis NH, Hollis Publishing Company
- Etkin N et al. (1990) The indigenization of pharmaceuticals: therapeutic transitions in rural Hausaland. *Social Science and Medicine*, 30 (8):919-928.
- Evans DB et al. (1993) Social and economic factors and the control of lymphatic filariasis: a review. *Acta Tropica*, 53:1-26.
- Farmer P (1999) *Infections and inequalities: the modern plagues*. Berkeley, University of California Press.
- Farmer P (1997) Ethnography, social analysis, and the prevention of sexually transmitted HIV infections among poor women in Haiti. In: Inhorn MC & Brown PJ, eds., *The anthropology of infectious disease: international health perspectives*. Amsterdam, Gordon & Breach, 413-438.
- Farmer P & Becerra M (2001) Biosocial research and the TDR agenda. *TDR News*, 66:5-7.
- Foldi E et al. (1989) The lymphedema chaos: a lancet. *Annals of plastic surgery*, 22:205-515.
- Gitterman A (1989) Building mutual support in groups. *Social work with groups*, 12(2):5-21.
- Gottlieb B (1982) Mutual-help groups: members' views of their benefits and roles for professionals. *Prevention in Human Services*, 1:55-67.
- Gyapong JO et al. (1996) The epidemiology of acute adenolymphangitis due to lymphatic filariasis in northern Ghana. *American Journal of Tropical Medicine and Hygiene*, 54(6): 591-595.
- Gyapong JO, Magnussen P, Binka FN (1994) Parasitological and clinical aspects of bancroftian filariasis in Kassena-Nankana District, Upper East Region, Ghana. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 88:555-557.
- Hatch S and Kickbusch I, eds. (1983) *Self-help and health in Europe*, WHO Regional Office for Europe, Copenhagen.
- Henderson JN et al. (1993) A model for Alzheimer's disease support group development in African-American and Hispanic populations. *The Gerontologist*, 33(3):409-414.
- Hermann JF et al. (1995) Guidelines for support group programs. *Cancer Practice*, 3(2):111-113.
- Hitch PJ et al. (1994) Effectiveness of self-help and support groups for cancer patients – a review. *Psychology & Health*, 9(6):437-448.
- Ho DYF et al. (2001) Indigenization and beyond: methodological relationalism in the study of personality across cultural traditions. *Journal of Personality*, 69(6):925-953.
- Hunter JM (1992) Elephantiasis: a disease of development in northeast Ghana. *Social Science & Medicine*, 35(5):627-649.

- Inglehart R (1997) *Modernization and postmodernization: cultural, economic, and political change in 43 societies*. Princeton, NJ, Princeton University Press.
- Inhorn MC & Brown PJ, eds. (1997) *The anthropology of infectious disease: international health perspectives*. Amsterdam, Gordon & Breach.
- Katz AH (1981) Self-help and mutual aid: an emerging social movement? *Annual Review of Sociology*, 7:129-155.
- Kawachi I & Berkman L (2000) Social cohesion, social capital, and health. In: Berkman LF & Kawachi I, eds. *Social Epidemiology*. New York, Oxford University Press, 174-190.
- Kaye LW (1995) Assessing the efficacy of a self-help support group program for older women. *Journal of Women and Aging*, 7(4):11-30.
- Kendall C and Zielinski E (1999) Social and cultural factors in tropical medicine: reframing our understanding of disease. In: Guerrant RL, Walker DH & Weller PF, eds. *Tropical infectious diseases: principles, pathogens and practice*, Philadelphia, Churchill Livingstone, 54-61.
- Kleinman A (1980) *Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine and psychiatry*. Berkeley, CA, University of California Press.
- Kunitz SJ (2000) Globalization, states, and the health of indigenous peoples. *American Journal of Public Health*, 90(10):1531-1539.
- Kurtz LF (1997) *Self-help and support groups: a handbook for practitioners*. Thousand Oaks, CA, Sage Publications.
- Lammie PJ et al. (1994) The age-specific prevalence of antigenemia in a *Wuchereria bancrofti*-exposed population. *American Journal of Tropical Medicine & Hygiene*, 51:348-355.
- Lammie PJ et al. (1993) Heterogeneity in filarial-specific immune responsiveness among patients with lymphatic obstruction. *Journal of Infectious Diseases*, 167:1178-1183.
- Laurence BR (1989) "Barbados leg": filariasis in Barbados, 1625-1900. *Medical History*, 33:480-488.
- Lavoie F et al. (1995) *Self-help and mutual aid groups: international and multicultural perspectives*. Binghamton, NY, The Haworth Press.
- Powell TJ (1994) *Understanding the self-help organization*. Thousand Oaks, California: Sage Publications.
- Raccurt CP (1986) La filariose lymphatique en Haïti: séquelle historique ou problème d'avenir pour la santé publique à l'échelon régional? *Bulletin de la société de pathologie exotique*, 79:745-754.
- Raccurt CP et al. (1988) Epidemiology of *Wuchereria bancrofti* in Leogane, Haiti. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 82:721-725.

Rathgeber E. & Vlassof C (1993) Gender and tropical diseases: a new research focus. *Social Science & Medicine*, 37:513-520.

Riessman F and Carroll D (1995) *Redefining self-help: policy and practice*. San Francisco, Jossey-Bass Publishers.

Sahlins M (1999) What is anthropological enlightenment? Some lessons of the twentieth century. *Annual Review of Anthropology*, 28:i-xxiii.

Schopler JH and Galinsky MJ (1993) Support groups as open systems: a model for practice and research. *Health and Social Work*, 18(3):195-207.

Shenoy RK et al. (1995) A preliminary study of filariasis related to acute lymphangitis with special reference to precipitating factors and treatment modalities. *Southeast Asian Journal of Tropical Medicine and Public Health*, 26:301-305.

Trojan A (1989) Benefits of self-help groups: a survey of 232 members from 65 disease-related groups. *Social Science & Medicine*, 29(2):225-232.

Vlassoff C & Bonilla E (1994) Gender-related differences in the impact of tropical diseases in women: what do we know? *Journal of Biosocial Science*, 26:37-53.

Vlassoff C & Moreno CG (2002) Placing gender at the center of health programming: challenges and limitations. *Social Science & Medicine*, 54:1713-1723.

Wendt JM (1999) *The impact of lymphedema and elephantiasis education in improving home treatment compliance among patients of a lymphedema treatment clinic in Leogane, Haiti: A behavioral epidemiologic analysis*. MPH thesis submitted to Emory University, May 1999.

Wolper MA (2001) *Factors associated with home treatment compliance and quality of life among women with lymphatic filariasis in Haiti by intervention status: a longitudinal analysis of secondary data*. MSPH thesis submitted to the University of South Florida, December 2001.



Mailing address:

TDR
World Health Organization
20, Avenue Appia
1211 Geneva 27
Switzerland

Street address:

TDR
Centre Casai
53, Avenue Louis-Casai
1216 Geneva
Switzerland

Tel: (+41) 22-791-3725
Fax: (+41) 22-791-4854
E-mail: tdr@who.int
Web: www.who.int/tdr