Experiences of a Community-based Lymphedema Management Program for Lymphatic Filariasis in Odisha State, India: An Analysis of Focus Group Discussions with Patients, Families, Community Members and Program Volunteers


Introduction
Globally 68 million people are infected with lymphatic filariasis (LF), a mosquito-borne disease caused by filarial worms. Disease associated with LF infection can be either acute or chronic. Chronic disease in men commonly manifests as scrotal swelling, known as hydrocele, while both men and women can develop lymphedema or elephantiasis of the limbs. India constitutes 42% of the global burden of LF.

It is well documented that chronic and acute manifestations of LF cause physical suffering, psychosocial effects on individuals, and economic burden to families. Documented psychosocial impacts include feelings of isolation and exclusion from community events, issues around gender, marriage and shame, and stigma stemming from misconceptions about lymphedema. Anti-filarial medication can help interrupt transmission of LF however morbidity management and disability prevention (MMDP) programs are required to address the needs of those experiencing symptoms of LF-related disease. The impact of MMDP programs on the health and functioning of lymphedema patients has been documented using a variety of surveys assessing quality of life, but these generic surveys can lack sensitivity to the particular effects of lymphedema in every context. This study thus adds to a previous evaluation that utilized the WHODAS tool to assess the impact on perceived disability of a community-based lymphedema management program in Odisha state, India.

Methodology
This program evaluation was conducted in Bolagarh sub-district of Khurda district in Odisha State, India, a highly endemic region for LF caused by *W. bancrofti*. The Focus group discussion method was utilized and the groups were comprised of patients (eight groups, separated by gender), their family members (eight groups), community members (four groups) and program volunteers (four groups) who had participated in a lymphedema management program for the past three years. Participants were drawn from 11 different villages and represented a convenience sample, selected and invited with the help of the Church’s Auxiliary for Social Action (CASA) to incorporate a range of perspectives and areas. Focus group discussions were conducted in Oriya, a local language, and took place in an easily accessible, central location in the community, such as a house of worship, classroom, volunteers’ home, or local business. Each focus group took approximately one hour and basic information about each participant was gathered including age, sex, occupation, and participation in mass drug administration (MDA). The patient, family member, and community member focus groups were sex segregated to encourage open discussion. Each of the focus groups were asked questions specific to their role in the disease management.
Results
Overall, 38 female patients and 36 male patients participated. A total of 74 family members of lymphedema patients as well as 28 program volunteers and 35 community members were involved in focus group discussions. Among male patients, family members and community members, the majority reported their occupation as farmers, while among females in all groups the most common reported profession was housework. 92% of patients, 73% of family members and 96% of program volunteers had participated in the most recent MDA, whereas only 31% of community members reported participation.

The focus group results showed significant social, physical, and economic difficulties as described by patients and family members, including marriageability, social stigma, and lost workdays. However, the positive impact of the lymphedema management program was also emphasized as knowledge and skills development, decreased acute episodes, and increased work productivity. Many family and community members indicated that community members were accepting of patients. Program volunteers and community members stressed the role that the program had played in educating people, though interestingly, local explanations and treatments appear to coexist with knowledge of biomedical treatments and the mosquito vector.

Discussion
The focus groups in this study demonstrated that, when exposed to education, a basic understanding of LF infection and disease can co-exist with alternative local explanations. In other studies, in India, where population was not exposed to education, results showed that only 9–20% of respondents identified mosquitoes as the vectors of infection. This acceptance of multiple explanations of disease from the patients’ standpoint by nurses is important in patients’ treatment acceptance.

The economic impacts of living with lymphedema were a major theme among patients and family members, emphasizing lost productivity and financial losses associated with lymphedema and acute episodes and costs for treatment. However, research has demonstrated the benefits of the first eight years of the global program to eliminate LF on increased work productivity amounting to $255 lifetime benefit per individual affected by lymphedema or hydrocele, even when costs associated with social stigma, family members missing work or school to care for patients, reduced quality of life, and lower productivity rates (per day at work) are excluded. Given that this study was done years after a community based program, there were positive comments about social acceptance and inclusion. However, in addition to the economic impacts, experiences of stigma discussed in these focus groups echoed themes identified by other researchers in Ghana and the Dominican Republic, including feelings of social isolation, marriage issues, teasing and fear of contamination. Finally, marriage and gender issues stemming from LF seemed to be mostly affecting women with its potential negative impact on marriageability and the implications for family life.
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