

A pilot study to address the mental health of persons living with lymphatic filariasis in Léogâne, Haiti: Implementing a chronic disease self-management program using a stepped-wedge cluster design

Shanze Sadiq^{a,†}, Karen E. S. Hamre^{b,†}, Samhita Kumar^{a,*}, Sarah Bazur-Leidy^a, Luccène Désir^b, M. Martha Désir^c, Murielle C. Gilbert^d, V. Madsen Beau de Rochars^{b,e}, Marc-Aurèle Telfort^d, Gregory S. Noland^b and Eve Byrd^a

^aMental Health Program, The Carter Center, Atlanta, GA, 30307, USA; ^bHispaniola Initiative, The Carter Center, Atlanta, GA, 30307, USA;

^cNotre Dame Haiti Program, University of Notre Dame, Port-au-Prince, Haiti; ^dNational Program to Eliminate Lymphatic Filariasis, Ministry of Public Health and Population, Port-au-Prince, Haiti; ^eDepartment of Health Services Research, Management and Policy, University of Florida, Gainesville, FL, 32610, USA

*Corresponding author: Tel: +1 404-420-5173; E-mail: samhita.kumar@cartercenter.org

[†]The authors wish it to be known that, in their opinion, the first two authors should be regarded as joint first authors.

Received 31 May 2023; revised 7 August 2023; editorial decision 9 January 2024; accepted 9 January 2024

Background: Neglected tropical diseases (NTDs) inflict significant comorbid disability on the most vulnerable communities; yet interventions targeting the mental health of affected communities are lacking. A pilot study to assess the effectiveness of a chronic disease self-management program (CDSMP) was introduced to lymphatic filariasis peer support groups in Léogâne, Haiti.

Methods: Using a closed-cohort stepped-wedge cluster trial design, Hope Clubs were assigned into Arm 1 (n=118 members) and Arm 2 (n=92). Household surveys, measuring self-rated health, depression, disease self-efficacy, perceived social support, and quality of life, were conducted at baseline (before CDSMP); midpoint (after Arm 1/before Arm 2 completed CDSMP); and endpoint (after CDSMP). Non-Hope Club member patients (n=74) were evaluated at baseline for comparison.

Results: Fifty percent of Hope Club members (Arm 1: 48.3%, Arm 2: 52.2%) screened positive for depression at baseline, compared with 36.5% of non-Hope Club members. No statistically significant differences were found in outcome measures between intervention observation periods. At endpoint, depressive illness reduced to 28.7% (Arm 1) and 27.6% (Arm 2).

Conclusions: The intervention was feasible to integrate into Hope Clubs, showed overall positive effects and reduced depressive symptoms. More studies are needed to evaluate the efficacy of implementing CDSMP in the NTD context.

Contexte: Les maladies tropicales négligées (MTN) infligent d'importantes incapacités comorbides aux communautés les plus vulnérables; pourtant, les interventions ciblant la santé mentale des communautés affectées font défaut. Une étude pilote visant à évaluer l'efficacité d'un programme d'autogestion des maladies chroniques (CDSMP) a été introduite dans des groupes de soutien par les pairs pour la filariose lymphatique à Léogâne, en Haïti.

Méthodes: Dans le cadre d'un essai en grappe à cohorte fermée, les clubs Hope ont été répartis entre le bras 1 (n=118 membres) et le bras 2 (n=92). Des enquêtes auprès des ménages, mesurant l'auto-évaluation de la santé, la dépression, l'auto-efficacité face à la maladie, le soutien social perçu et la qualité de vie, ont été menées au départ (avant le CDSMP), à mi-parcours (après que le bras 1 / avant que le bras 2 ait terminé le CDSMP) et à la fin (après le CDSMP). Les patients non membres du Hope Club (n=74) ont été évalués au début de l'étude à des fins de comparaison.

Résultats: Cinquante pourcent des membres du Hope Club (bras 1 : 48,3%, bras 2 : 52,2%) ont été dépistés positifs pour la dépression au début de l'étude, contre 36,5% des non-membres du Hope Club. Aucune différence statistiquement significative n'a été constatée dans les mesures des résultats entre les périodes d'observation de l'intervention. À la fin de l'étude, la maladie dépressive était réduite à 28,7% (bras 1) et 27,6% (bras 2).

Conclusions: L'intervention a pu être intégrée dans les clubs Hope, elle a montré des effets globalement positifs et a permis de réduire les symptômes dépressifs. D'autres études sont nécessaires pour évaluer l'efficacité de la mise en œuvre du CDSMP dans le contexte des MTD.

Antecedentes: Las enfermedades tropicales desatendidas (ETDs) infligen una importante discapacidad comórbida a las comunidades más vulnerables; sin embargo, faltan intervenciones dirigidas a la salud mental de las comunidades afectadas. Se introdujo un estudio piloto para evaluar la eficacia de un programa de autogestión de enfermedades crónicas (CDSMP, por sus siglas en inglés) en grupos de apoyo entre pares de filariasis linfática en Léogâne, Haití.

Métodos: Utilizando un diseño de ensayo por conglomerados de cohortes cerradas escalonadas, los Clubes Esperanza fueron asignados al Grupo 1 (n=118 miembros) y al Grupo 2 (n=92). Se realizaron encuestas en los hogares para medir la autoevaluación de la salud, la depresión, la autoeficacia frente a la enfermedad, el apoyo social percibido y la calidad de vida en la línea de base (antes del CDSMP), en el punto medio (después de que el Grupo 1/antes de que el Grupo 2 completara el CDSMP) y en el punto final (después del CDSMP). Los pacientes que no pertenecían al Club Esperanza (n=74) fueron evaluados al inicio del estudio a modo de comparación.

Resultados: El 50% de los miembros del Club Esperanza (Grupo 1: 48,3%, Grupo 2: 52,2%) dieron positivo en depresión al inicio del estudio, en comparación con el 36,5% de los no miembros del Club Esperanza. No se encontraron diferencias estadísticamente significativas en las medidas de resultado entre los periodos de observación de la intervención. Al final, la enfermedad depresiva se redujo al 28,7% (Grupo 1) y al 27,6% (Grupo 2).

Conclusiones: La intervención fue factible de integrar en los Clubes Esperanza, mostró efectos positivos generales y redujo los síntomas depresivos. Se necesitan más estudios para evaluar la eficacia de la aplicación del CDSMP en el contexto de las ETD.

Keywords: chronic disease self-management, depression, lymphatic filariasis, mental health, neglected tropical diseases.

Introduction

Neglected tropical diseases (NTDs) include 20 conditions caused by several pathogens found primarily in tropical environments in low- and middle-income countries.¹ NTDs affect nearly 1 billion people globally, and can lead to physical and mental impairments and disability, affecting social, economic and overall well-being.^{1,2}

Lymphatic filariasis (LF), a mosquito-borne NTD caused by parasitic worms, can manifest in the enlargement of limbs, genitals and/or breasts, leading to significant disfigurement called elephantiasis. An estimated 51.4 million people were infected globally in 2018 among approximately 859 million living in one of 72 remaining LF-endemic countries.³ Many LF patients experience stigma and social disconnectedness, impeding their ability to work, pursue education and engage in their communities.^{2,4,5} In a study assessing prevalence and severity of depression among individuals with physical disfigurement due to LF, 20% of respondents met the criteria for depression.⁶ Psychosocial comorbidities of NTDs can compound disability significantly, with one study demonstrating a twofold increase in disability burden since 2010 among filariasis patients with depressive illness.^{7,8} Accordingly, the WHO proposed a holistic response to LF management in the 2021–2030 roadmap for NTDs, including accessible and inclusive

care to reduce stigma and improve the mental well-being of LF patients.³ Further, the WHO recommends that individuals with LF have access to psychological and social support as a component of morbidity management and disability prevention (MMDP) strategies.⁹

Haiti is one of four LF-endemic countries in the Americas. The strategy to eliminate LF as a public health problem outlined in the WHO's Global Program to Eliminate Lymphatic Filariasis involves baseline mapping to identify districts that are endemic and in need of annual mass drug administration (MDA). The MDA campaigns are continued until the levels of infection are reduced below a level at which transmission is unlikely to be sustainable, after which post-treatment surveillance (PTS) activities are conducted to monitor for recrudescence. In Haiti, 88% of the country was considered endemic during baseline mapping conducted in 2001.¹⁰ Due to its widespread geographic distribution, Haiti's National Program to Eliminate Lymphatic Filariasis made a programmatic decision to scale-up MDA to all 140 districts; 122 (87.14%) are currently in PTS.¹¹ Yet, as is true elsewhere, the scale-up of MMDP activities in Haiti has been difficult. At study initiation, Hôpital Ste. Croix (HSC) in Léogâne had the only LF clinic in Haiti providing sustained comprehensive morbidity support services. These include: (1) provision of the WHO Basic Package of Care (hygiene, skin care, treatment and

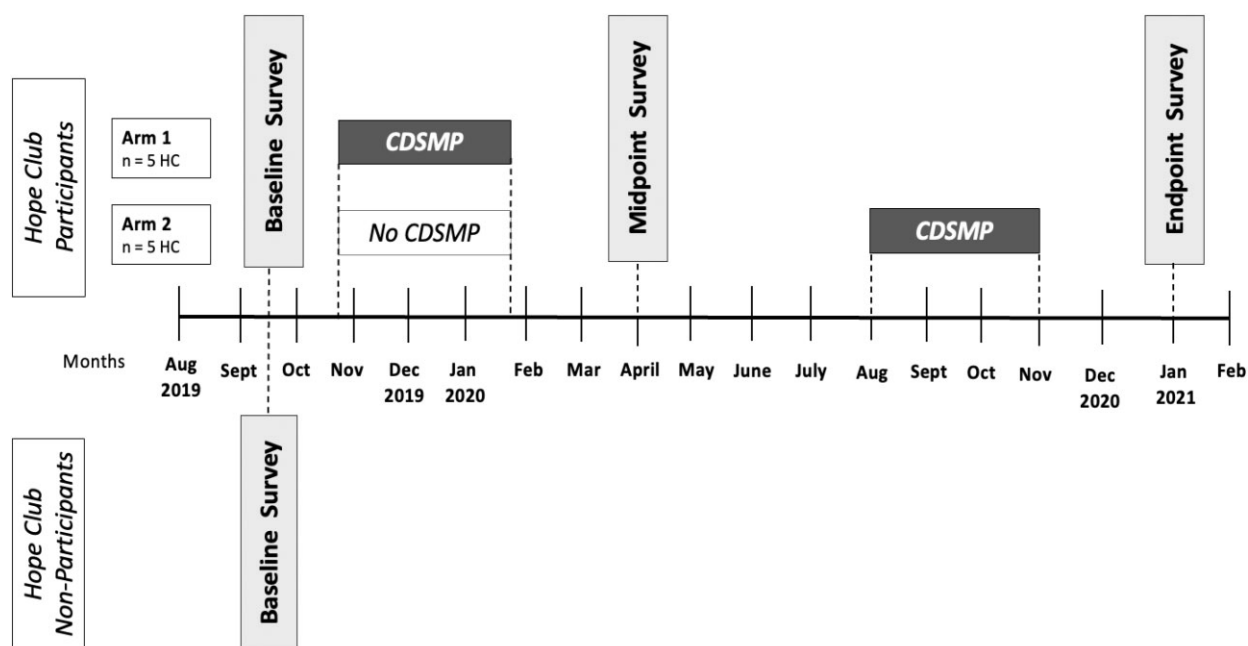


Figure 1. Timeline of study activities. CDSMP, Chronic Disease Self-Management Program; HC, Hope Clubs.

prevention of acute adenolymphangitis, and education); (2) hydrocelectomy procedures; (3) lymphatic massage and compression therapy; (4) individual and community-based psychosocial services; and (5) income-earning opportunities through vocational training. In 1998, five peer-led support groups called 'Hope Clubs' were organized at HSC for women with LF.¹² Women are 5–10 times more likely than men to have elephantiasis of the leg.¹³ Hope Clubs met weekly in the community and were led by animatrices, who are LF patients themselves trained in risk reduction, hygiene and basic lymphedema care. Their aim is to provide education about the etiology of LF, self-care motivation and opportunities to enhance self-esteem and disease management. A formal curriculum was instituted when the clubs were established, however, no formal evidence-based group facilitation or health management curriculum was in place in recent years prior to this study. Men were first invited to join Hope Clubs in 2012. At study onset, 10 Hope Clubs existed that met monthly across Léogâne district.

While the relationship between mental health and NTDs has been documented,¹⁴ interventions to address chronic disability caused by NTDs and co-occurring symptoms of mental illness are limited.^{15,16} Other chronic diseases studies provide evidence for improving overall health outcomes and quality of life (QoL) by addressing patients' mental health.^{16,17} This study evaluated the applicability of a Chronic Disease Self-Management Program (CDSMP) as a potential tool to address the mental health and QoL of persons living with NTDs.

CDSMP, developed by researchers at the Stanford Center for Research in Patient Education (renamed Self-Management Resource Center [SMRC]), trains persons living with chronic diseases to facilitate group education and skills-building sessions. The program helps people with chronic conditions gain self-confidence and other necessary skills, including health

literacy, to achieve positive outcomes from their disease self-management. CDSMP's curriculum covers a range of topics on health-related self-management behaviors such as addressing the psychological effects of chronic disease; symptom management; and effective communication. The model has significantly and cost-effectively decreased symptoms of depression and improved participants' QoL for multiple conditions including arthritis, diabetes, chronic pain, HIV and cancer.¹⁹ While SMRC has previously partnered with the Pan American Health Organization to successfully implement CDSMP in the region, to the best of our knowledge, this is its first use for NTDs.

The primary aim of the study was to assess whether the introduction of a CDSMP into existing Hope Clubs in Léogâne, Haiti, results in improvements in depressive symptoms, self-rated health (SRH), chronic disease self-efficacy, social support and QoL among LF patients who participate in Hope Clubs. A secondary aim was to estimate the prevalence of depressive symptoms among LF patients, by Hope Club participation status.

Methods

Study design, participants and location

A closed-cohort stepped-wedge cluster trial was designed where existing Hope Clubs in Léogâne were separated into two arms: Arm 1 consisted the five odd-numbered Hope Clubs, while Arm 2 comprised the five even-numbered Hope Clubs (Figure 1). All Hope Club members, 133 in Arm 1 and 106 in Arm 2, were eligible to participate. An additional 155 non-Hope Club member LF patients in Léogâne, identified using HSC's LF roster, were recruited to participate in a cross-sectional survey to compare with baseline assessments of Hope Club members (Figure 2).

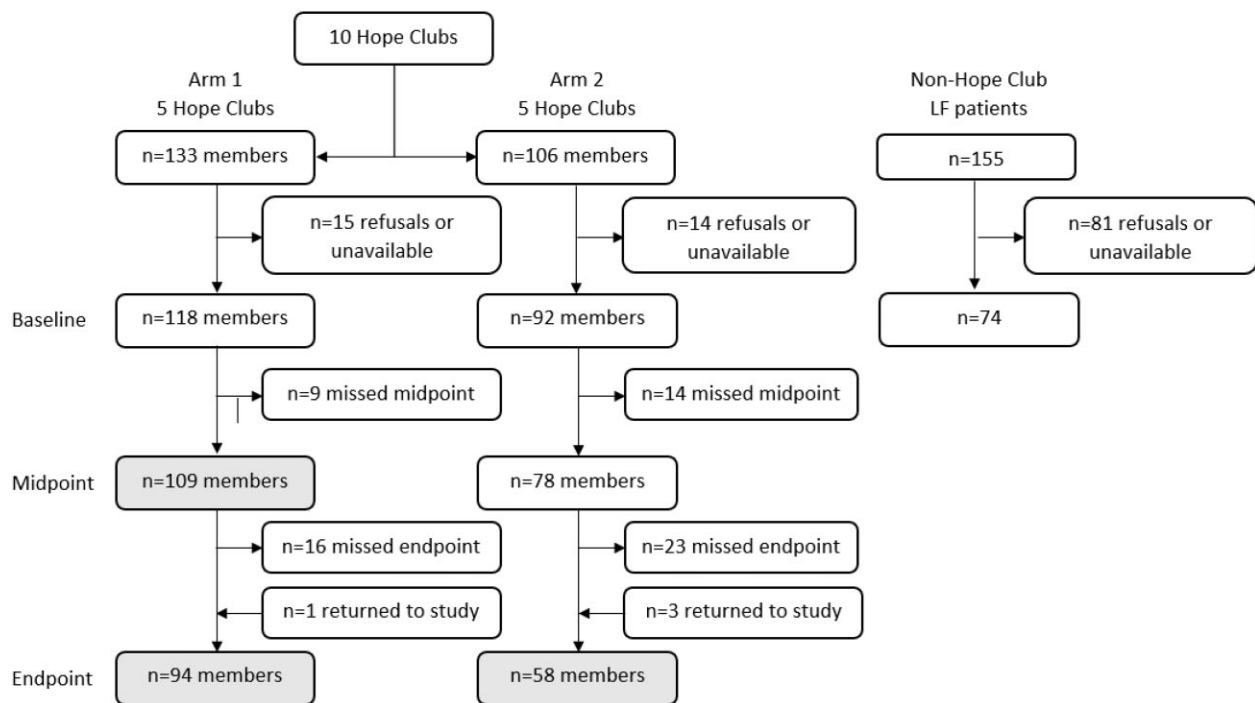


Figure 2. Numbers of lymphatic filariasis patients in Léogâne, Haiti, with data collected, by Hope Club member status, arm and time point, during preintervention (white) and postintervention (gray) observation periods in the closed cohort stepped-wedge cluster trial.

Intervention and training

CDSMP is delivered in a small group workshop format by two facilitators, both of whom have chronic conditions. Workshops consist of six participative classes held for 2.5 h each, where participants are guided to tailor the workshop content to their individual needs. CDSMP workshop materials were contextualized to the Haitian context and to LF care in collaboration with SMRC prior to delivery (Supplementary Table S1). Example session topics included: dealing with difficult emotions, balance management and fall prevention, pain and fatigue management, communication skills and making informed treatment decisions. CDSMP was incorporated into existing Hope Clubs that met twice a month over the course of 3 mo to complete the six workshop sessions.

CDSMP workshops were conducted by animatrices, who facilitate the Hope Clubs. Two Haitian nurses received CDSMP training at SMRC in California then trained the animatrices. Ongoing unrest in Haiti led to a 3-mo delay in initiating CDSMP after the training, so SMRC provided an online refresher training 1 wk prior to the start of the intervention.

Study timeline and measures

Figure 1 illustrates the timeline of study activities. A baseline assessment was conducted at Hope Club member households in September–October 2019. Arm 1 Hope Clubs received the CDSMP first from November 2019–January 2020, while Arm 2 Hope Clubs served as wait-listed controls. Each of the five Hope Clubs in Arm 1 received the intervention separately, meeting independently every other week for 12 wk to complete the six CDSMP sessions.

After completion of CDSMP in Arm 1, a reassessment of both arms was conducted at households at study midpoint in April 2020. After a delay due to the onset of the coronavirus disease 2019 (COVID-19) pandemic, CDSMP was introduced into Arm 2 Hope Clubs from August to November 2020. To accommodate social distancing measures, Hope Clubs were reduced in size. A final reassessment of both arms was conducted at households at study endpoint in January 2021. This design allowed for all Hope Club members to receive the CDSMP, in addition to evaluating whether it influenced depressive symptoms, SRH, chronic disease self-efficacy, social support and QoL in persons living with LF. The household surveys collected data on basic demographics and outcome measures using five tools, asked in the following order:

Self-Rated Health (SRH)

A globally utilized and validated, one-item measure that asks, ‘In general, would you say your health is...’, with five response options ranging from Excellent (1) to Poor (5).²⁰ A higher score indicates a poorer self-perception of health.

Zanmi Lasante Depression Symptom Inventory (ZLDSI)

A 13-item screening instrument to measure symptoms of depressive illness developed by Partners in Health/Zanmi Lasante in the wake of the 2010 earthquake in Haiti.²¹ The tool measures a respondent’s mood and vegetative symptoms for the past 15 d and is scored from 0 to 39. A score of ≥ 13 indicates likely depressive illness.

Table 1. Characteristics and scores of five scales to measure disease self-management and mental health of the study population, by Hope Club member status, at baseline

Characteristic or measure score	Non-Hope Club members (n=74)	Hope Club members—all (n=210)	p-value ^a
Gender (female), n (%)	53 (71.6)	197 (93.8)	<0.001
Age (y), mean (SD)	48.2 (15.3)	54.4 (14.0)	0.001
[min–max]	[20–85]	[24–97]	
SRH, n (%)			Overall NS
Excellent	5 (6.8)	3 (1.4)	
Very good	3 (4.1)	14 (6.7)	
Good	11 (14.9)	30 (14.3)	
Fair	40 (54.1)	114 (54.3)	
Poor	15 (20.3)	49 (23.3)	
ZLDSI, mean (SD)	10.0 (8.9)	12.9 (9.1)	0.020
Depressive illness (ZLDSI \geq 13), n (%)	27 (36.5)	105 (50.0)	0.045
SMCDS, mean (SD)	6.8 (2.1)	6.8 (2.1)	NS
MSPSS, mean (SD)			
Family	17.9 (6.3)	18.2 (6.1)	NS
Friends	15.2 (7.7)	14.2 (7.4)	NS
Significant person	22.1 (5.5)	20.7 (6.2)	NS
DLQI, n (%)			Overall NS
No effect	40 (54.1)	81 (38.6)	
Small effect	19 (25.7)	63 (30.0)	
Moderate effect	8 (10.8)	34 (16.2)	
Very large effect	5 (6.8)	24 (11.4)	
Extremely large effect	2 (2.7)	8 (3.8)	
DLQI, mean (SD)	3.6 (5.6)	5.0 (5.9)	NS

Abbreviations: DLQI, Dermatology Life Quality Index; MSPSS, Multidimensional Scale of Perceived Social Support; NS, non-significant; SMCDS, Self-Efficacy for Managing Chronic Disease 6-Item Scale; SRH, self-rated health; ZLDSI, Zanmi Lasante Depressive Symptom Inventory.

^aAnalyzed using cluster-adjusted χ^2 tests for categorical variables or *t*-tests for continuous variables. *p*<0.05 considered significant in bold.

Self-Efficacy for Managing Chronic Disease 6-Item Scale (SMCDS)

A tool that measures self-efficacy among persons with chronic diseases.¹⁹ The items measure respondents' confidence, on a scale of 0 (not at all confident) to 10 (totally confident), in their ability to perform daily activities related to managing their health, while managing symptoms such as fatigue, pain and emotional distress. The score is the mean of six items; higher scores reflect greater self-efficacy.

Multidimensional Scale of Perceived Social Support (MSPSS)

This 12-item scale is divided into three subscales to measure perceived social support from a person's family, friends and significant other (or 'special person').²² Items are rated on a Likert scale of 1 (very strongly disagree) to 7 (very strongly agree). Scores by subscale were averaged; higher scores indicate higher perceived social support.

Dermatology Life Quality Index (DLQI)

A 10-item survey that measures the impact of skin disease on the QoL during the previous week.²³ Questions concern patients'

perceptions of their disease's impact on various QoL aspects, including ability to perform daily activities, and impact on relationships and self-esteem. Each question is scored 0–3 and summed to determine the DLQI score; the higher the score, the more QoL is impaired. DLQI score categories include: no effect (0–1); small effect (2–5); moderate effect (6–10); very large effect (11–20); and extremely large effect (21–30).

Survey tools and consent forms were translated and administered in Haitian Creole. Seven unblinded locally trained surveyors collected data on tablets using ODK Collect.

The scales were selected in consultation with SMRC and members of the Project Advisory Committee (PAC), comprising people living with LF, staff at HSC, collaborators and researchers. Culturally or regionally validated tools were used where available.²¹ The PAC met throughout the study to review materials and findings, inform data collection procedures and intervention roll-out, and address challenges that arose during the study. The ZLDSI was selected as a culturally validated tool for depression in Haiti.²¹ MSPSS, SRH and SMCDS scales have been extensively used to measure the effectiveness of the CDSMP and results of their use are documented in scientific literature.^{24–26} To the best of the authors' knowledge, SRH, ZLDSI, SMCDS and MSPSS have not been previously used in the NTD space. ZLDSI and DLQI were included specifically for their use in the mental health-NTD (MH-NTD) nexus.^{21,23}

Table 2. Characteristics and scores of five scales to measure disease self-management and mental health of Hope Club members, by study arm and time point

Characteristic or measure score	Baseline ^a		Midpoint		Endpoint	
	Arm 1 (n=118)	Arm 2 (n=92)	Arm 1 (n=109)	Arm 2 (n=78)	Arm 1 (n=94)	Arm 2 (n=58)
Gender (female), n (%)	113 (95.8)	84 (91.3)	104 (95.4)	72 (92.3)	90 (95.7)	54 (93.1)
Age (y), mean (SD)	53.3 (13.9)	55.8 (14.1)	54.6 (14.0)	55.6 (14.3)	54.9 (13.9)	56.1 (16.1)
[min-max]	[26-83]	[24-97]	[27-83]	[24-92]	[27-84]	[25-99]
SRH, n (%)						
Excellent	2 (1.7)	1 (1.1)	3 (2.8)	1 (1.3)	1 (1.1)	0 (0)
Very good	11 (9.3)	3 (3.3)	2 (1.8)	2 (2.6)	3 (3.2)	2 (3.4)
Good	17 (14.4)	13 (14.1)	17 (15.6)	7 (9.0)	17 (18.1)	8 (13.8)
Fair	63 (53.4)	51 (55.4)	74 (67.9)	57 (73.1)	61 (64.9)	37 (63.8)
Poor	25 (21.2)	24 (26.1)	13 (11.9)	11 (14.1)	12 (12.8)	11 (19.0)
ZLDSI, mean (SD)	12.9 (9.5)	12.9 (8.6)	9.7 (7.6)	10.1 (7.8)	9.1 (8.6)	8.6 (7.1)
Depressive illness (ZLDSI \geq 13), n (%)	57 (48.3)	48 (52.2)	38 (34.9)	27 (34.6)	27 (28.7)	16 (27.6)
SMCDS, mean (SD)	6.6 (2.0)	7.0 (2.1)	6.9 (1.6)	6.7 (1.7)	7.1 (1.8)	7.0 (1.9)
MSPSS, mean (SD)						
Family	18.4 (6.1)	18.0 (6.1)	18.6 (5.7)	18.8 (5.6)	19.3 (5.0)	19.6 (4.6)
Friends	14.4 (7.4)	13.9 (7.6)	14.5 (7.0)	14.0 (7.2)	15.4 (6.7)	15.9 (7.2)
Significant person	21.0 (5.7)	20.4 (6.8)	20.7 (5.3)	21.2 (5.5)	21.6 (3.9)	20.9 (5.2)
DLQI, n (%)						
No effect	47 (39.8)	34 (37.0)	62 (56.9)	45 (57.7)	56 (59.6)	32 (55.2)
Small effect	35 (29.7)	28 (30.4)	30 (27.5)	13 (16.7)	24 (25.5)	12 (20.7)
Moderate effect	16 (13.6)	18 (19.6)	7 (6.4)	11 (14.1)	9 (9.6)	4 (6.9)
Very large effect	15 (12.7)	9 (9.8)	9 (8.3)	6 (7.7)	4 (4.3)	7 (12.1)
Extremely large effect	5 (4.2)	3 (3.3)	1 (0.92)	3 (3.8)	1 (1.1)	3 (5.2)
DLQI, mean (SD)	4.9 (6.0)	5.2 (5.8)	2.8 (4.6)	3.7 (5.8)	2.6 (4.2)	4.6 (7.1)

Abbreviations: DLQI, Dermatology Life Quality Index; MSPSS, Multidimensional Scale of Perceived Social Support; SMCDS, Self-Efficacy for Managing Chronic Disease 6-Item Scale; SRH, self-rated health; ZLDSI, Zanmi Lasante Depressive Symptom Inventory.

^aNo statistically significant differences were detected between study arms at baseline.

Analysis

Demographic characteristics and baseline scores of non-Hope Club participants were compared with Hope Club participants (combined Arm 1 and Arm 2); similarly, Hope Club participants assigned to Arm 1 were compared with those assigned to Arm 2. Data were analyzed using cluster-adjusted χ^2 tests for categorical variables or *t*-tests for continuous variables. To evaluate whether the CDSMP intervention had an effect on symptoms of depression, SRH, chronic disease self-efficacy, social support and QoL, the distribution of results across the preintervention control observation period (i.e. baseline Arms 1 and 2 plus midpoint Arm 2) were compared with the results across the postintervention observation period (i.e. midpoint Arm 1 and endpoint Arms 1 and 2). Data were analyzed using multilevel mixed effects regression models (linear, logistic and ordinal, as appropriate) where intervention status and time period were considered fixed effects and Hope Group clusters and individuals with repeated measurements across time periods were considered random effects. Data were analyzed using Stata version 16 (College Station, TX, USA) where $p < 0.05$ was considered statistically significant.

Results

Among the 10 Hope Clubs in Léogâne, which ranged from 18 to 30 members each, all 239 (133 in Arm 1 and 106 in Arm 2) members were eligible to participate. A total of 210 (87.9%), 118 among five Hope Clubs assigned to Arm 1 and 92 among five Hope Clubs assigned to Arm 2, consented to participate in the baseline assessment. The ages of consenting Hope Club members ranged from 24 to 97 y and 93.8% were female. An additional 74 (47.7%) of 155 non-Hope Club member LF patients from the community consented to participate in the baseline assessment (Figure 2). Non-Hope Club LF patients in the study ranged in age from 20 to 85 y and 71.6% were female. Compared with Hope Club members, non-Hope Club LF patients were statistically significantly more likely to be younger males (mean age: 48.2 vs 54.4 y, $p=0.001$; % female: 71.6% vs 93.8%, $p < 0.001$), with fewer screening positive for symptoms of depressive illness (mean ZLDSI: 10.0 vs 12.9, $p=0.020$; % ZLDSI \geq 13: 36.5% vs 50.0%, $p=0.045$) (Table 1). There were no statistically significant differences among SRH, SMCDS, MSPSS or DLQI between Hope Club and non-Hope Club participants (Table 1).

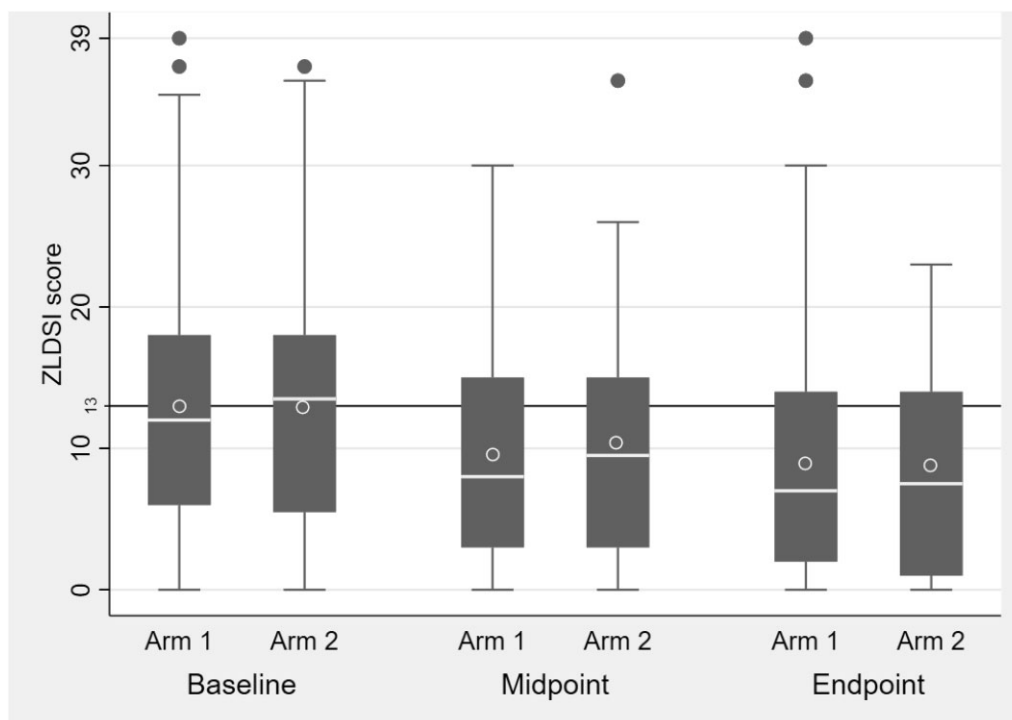


Figure 3. Distribution of Zanme Lasante Depression Symptom Inventory (ZLDSI) scores, by study arm and survey time point. Mean scores represented as hollow white circles.

Among Hope Club members at baseline, no statistically significant demographic characteristics or measurement scores were detected across study arms (Table 2). Both Arms were predominantly composed of female participants (95.8% and 91.3% in Arms 1 and 2, respectively), who ranged in age from 24 to 97 y. More than 74% of Hope Club members in each arm reported SRH as Fair (Arm 1: 53.4%, Arm 2: 55.4%) or Poor (Arm 1: 21.2%, Arm 2: 26.1%). A positive trend from Poor to Fair was observed at midpoint and endpoint in both arms, with SRH reported as Poor reduced to 12.8% and 19.0% in each Arm at endpoint, respectively. It is noteworthy that 50% of Hope Club participants (Arm 1: 48.3%, Arm 2: 52.2%) screened positive for symptoms of depressive illness. This decreased to 34.9% and 34.6% in Arms 1 and 2 at midpoint, and to 28.7% and 27.6% at endpoint, respectively. Similarly, mean ZLDSI scores in each arm reduced from baseline to midpoint to endpoint (Arm 1: 12.9, 9.7, 9.1; Arm 2: 12.9, 10.1, 8.6) (Table 2, Figure 3). While positive trends were observed descriptively by time point throughout the study, no statistically significant differences were detected in any measure by observation period (Table 3). From baseline to endpoint, a total of 58 participants (27.6%) were lost to follow-up (Figure 2).

Discussion

Overall impact

The results of this pilot support that the Chronic Disease Self-Management Program intervention is acceptable and feasible to implement within LF Hope Clubs in Haiti, and that the intervention

showed overall positive effects among participants. Symptoms of depression at baseline were high in Arms 1 and 2, supporting literature that established the link between NTDs and mental health burden.^{8,14} Levels of depression were higher among LF patients who were participating in Hope Clubs compared with non-participants. This suggests that LF patients with a greater mental health burden might be more likely to seek social support or be willing to vocalize depressive symptoms. Scores observed on the MSPSS scale also suggested that non-Hope Club members perceived more social support than Hope Club members; this supports the previous postulation as perceived social support is a widely accepted protective factor against depression.²⁷

Depressive symptoms decreased in each Arm from baseline to midpoint, and from midpoint to endpoint (Table 2). This consistent decline might suggest that, despite the intervention time point, both Arms have a similar response over time. This could be attributed to myriad factors, including cross-pollination or a Hawthorne Effect. The decrease in mean ZLDSI score in Arm 1 between midpoint and endpoint may suggest a continued effect of the intervention postimplementation, or that consistent Hope Club engagement is protective. The decrease in mean ZLDSI score from midpoint to endpoint in Arm 2 indicates that this group continued to improve after the intervention was implemented. This may suggest that the original decrease in mean ZLDSI observed in Arm 1 was attributable to the CDSMP intervention. Further, given that self-efficacy is a key CDSMP component, the decrease in depressive symptoms could be due to mediating effects of health literacy and patients' confidence in their ability to perform self-care, as observed in other studies.^{28,29}

Table 3. Effect of the chronic disease self-management program (CDSMP) on the study measures, among Hope Club members living with LF in Léogâne, Haiti

Measure	Adjusted risk or OR ^a (95% CI)	p-value
SRH	1.02 (0.48–2.1)	NS
Excellent		
Very Good		
Good		
Fair		
Poor		
ZLDSI	0.52 (0.07–3.7)	NS
Depressive illness (ZLDSI _≥ 13)	1.0 (0.39–2.6)	NS
SMCDS	0.71 (0.89–2.3)	NS
MSPSS		
Family	0.74 (0.21–2.6)	NS
Friends	1.8 (0.32–10.2)	NS
Significant person	0.42 (0.12–1.5)	NS
DLQI	0.96 (0.45–2.0)	NS
No effect		
Small effect		
Moderate effect		
Very large effect		
Extremely large effect		
DLQI	0.78 (0.20–3.0)	NS

Abbreviations: DLQI, Dermatology Life Quality Index; LF, lymphatic filariasis; MSPSS, Multidimensional Scale of Perceived Social Support; NS, non-significant; OR, odds ratio; SMCDS, Self-Efficacy for Managing Chronic Disease 6-Item Scale; SRH, self-rated health; ZLDSI, Zanmi Lasante Depressive Symptom Inventory.

^aAnalyzed using multilevel mixed effect linear (continuous), logistic (dichotomous) or ordinal (categorical) regression models.

While mean SMCDS scores increased slightly in both Arms after the CDSMP was introduced, the change was not statistically significant.

Comparing these results with existing literature should be done with caution, as research in the MH-NTD nexus is limited and measurement tools vary widely between studies. To the best of our knowledge, this is the first study to use SRH, ZLDSI, SMCDS and MSPSS in a MH-NTD context. DLQI has been used for skin NTDs previously, but may not be the best tool for assessing this study population, as the tool does not ask about edema, which is a common symptom of LF. Because the DLQI scale cannot sufficiently discriminate between LF stages, future studies aiming to measure the impact of LF on QoL may find it beneficial to use other tools (e.g. WHO Disability Assessment Schedule 2.0, Lymphatic Filariasis Quality of Life Questionnaire).³⁰

The results from this pilot study will be treated as observational and hypothesis-generating; a post-hoc power calculation for a stepped-wedge study with 100 persons in each arm, two steps, and baseline depressive illness of 50%, indicated the pilot only had 41.3% power to detect a 10% difference among obser-

vation periods with a Type I error of 0.05. Still, the CDSMP was adapted to LF in Haiti and successfully integrated into existing Hope Clubs.

Limitations

Challenges involving ongoing political and social instability in Haiti and the COVID-19 pandemic may have influenced results. Security concerns made traveling difficult, resulting in inconsistent Hope Club meeting attendance by both CDSMP facilitators and members during the intervention period. These concerns led many participants to leave the area, impacting attrition, and resulting in incomplete data; only 148 (70.5%) Hope Club members were surveyed at all time points. A loss to follow-up analysis was conducted and there were no statistically significant demographic characteristics or SRH, ZLDSI, SMCDS or DLQI score differences found among Hope Club members who completed all three surveys compared with those who missed the midpoint and/or endpoint survey (Supplementary Table S2). However, compared with Hope Club members who completed all surveys, Hope Club members who missed the midpoint and/or endpoint survey did have lower perceived support among family (mean score 19.1 vs 16.2, $p=0.002$), friends (mean score 14.8 vs 12.8, $p=0.077$) and significant persons (21.2 vs 19.5, $p=0.059$), as measured by the MSPSS.

Interpretation of these results should consider the demographic and implementation layout of the study. Hope Clubs were initially established for female LF patients only. It is unsurprising that significantly more females were Hope Club members than non-Hope Club members and targeted outreach to recruit males to the clubs may be warranted. Similarly, CDSMP sessions took place every other week although the original design of the intervention calls for weekly sessions. Gaps between sessions, along with other disruptions faced by the study, may have impacted participants' retention of workshop materials. This may have been compounded by inconsistency in attendance as participants received differing combinations of the planned sessions (Supplementary Table S1), depending on which workshops they attended. Thus, it is possible that participants' perceived self-efficacy was impacted by the parts of the CDSMP curriculum they received. A larger study assessing implementation of the CDSMP in Hope Clubs and its effect on mental health outcomes would allow more definitive conclusions to be drawn, including the significance of observed changes.

Not all tools were developed or validated specific to the Haitian context. As a pilot program, the applicability of these tools and their further use in MH-NTD contexts is a valuable addition to the knowledge base. Looking ahead, pilot data support the exploration of other mental health training for MMDP among community members or healthcare workers. After study onset, the program team identified the need for referral of study participants to behavioral health providers. In recognition of the dearth of behavioral health service providers in Léogâne and Haiti overall, the team carried out a workforce development initiative training of 10 registered nurses in the WHO's Creole-adapted mhGAP training, enabling identification, management and referral of mental, neurological and substance use conditions. The effective implementation and enthusiastic uptake of this training suggests a positive reception for future workforce development initiatives in

resource-constrained settings with populations living in chronic distress.

Conclusions

Results of this pilot provide evidence that CDSMP was successfully integrated into Hope Clubs with a positive, albeit non-statistically significant, impact on mental health outcomes. A decrease in mean ZLDSI scores was observed in both Arms after introduction of the CDSMP. This observation is consistent with previous studies assessing the efficacy of CDSMP, which have shown lesser symptoms of depressive illness in patients after receiving the intervention.^{24–26} More robust studies around the implementation of self-management among persons with LF are warranted and could show promise as a component of integrated care. The evaluation of CDSMP may prove useful in informing the development of future MMDP activities and essential care packages for national NTD programs. This study contributes to the growing literature on the prevalence of mental health burdens in NTD-affected populations.

Supplementary data

Supplementary data are available at *International Health* online (<http://inthealth.oxfordjournals.org>).

Authors' contributions: SS and KESH contributed equally. EB, GSN, VMBdR and LD conceived of the study. LD, VMBdR and MT supervised the study. KESH conducted the analysis. KESH, GSN, SBL and EB interpreted the results. SS, KESH, SK and SBL drafted the manuscript. All the authors read and critically revised the manuscript for intellectual content and approved the final manuscript.

Acknowledgements: We thank the study participants who made this research possible. We appreciate the efforts and support of the dedicated staff and Hope Club Facilitators at Hôpital Sainte Croix, Ministère de la Santé Publique et de la Population, the Project Advisory Committee, Kate Lorig and SMRC staff, and The Carter Center students and staff who were instrumental in the daily activities of this study including: Sarah Yoss, Abdul Malik, Cassandra Bryan, Lauren Paul and Tsion Horra. We remember and honor our colleague Stephen Blount, who passed in 2022.

Funding: This work received financial support from the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD), award #164D, which is funded at The Task Force for Global Health primarily by the Bill & Melinda Gates Foundation, by the UK aid from the British government, and by the United States Agency for International Development through its Neglected Tropical Disease Program; and The Carter Center.

Competing interests: SK is a Guest Editor of this supplement but had no role in the review of this manuscript.

Ethical approval: The study was reviewed and approved by the Haitian Ministry of Public Health and Population Bioethics Committee and the Emory University Institutional Review Board. All participants gave written informed consent at each study time point, which was documented electronically. All survey tools and consent forms were translated and administered in Haitian Creole. Study procedures were in accordance with

the ethical standards of the Helsinki Declaration made by the World Medical Association (1964).

Data availability: The data that support the findings of this study are available from the corresponding author, [S.K.], under reasonable request.

References

- Centers for Disease Control and Prevention. Neglected Tropical Diseases. <https://www.cdc.gov/globalhealth/ntd/index.html> [accessed 23 September 2022].
- Kuper H. Neglected tropical diseases and disability—what is the link? *Trans R Soc Trop.* 2019;113(12):839–44.
- World Health Organization. Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030. Geneva: World Health Organization, 2020.
- Person B, Bartholomew LK, Addiss D, et al. Disrupted social connectedness among Dominican women with chronic filarial lymphedema. *Patient Educ Couns.* 2007;68(3):279–86.
- Person B, Bartholomew LK, Gyapong M, et al. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. *Soc Sci Med.* 2009;68(1):30–8.
- Obindo J, Abdulmalik J, Nwefoh E, et al. Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria. *PLOS Negl Trop Dis.* 2017;11(6):1–10.
- Molyneux DH, Dean L, Adekeye O, et al. The changing global landscape of health and disease: Addressing challenges and opportunities for sustaining progress towards control and elimination of neglected tropical diseases (NTDs). *Parasitology.* 2018;145(13):1647–54.
- Ton TGN, Mackenzie C, Molyneux DH. The burden of mental health in lymphatic filariasis. *Infect Dis Pov.* 2015;4:34.
- World Health Organization. Lymphatic filariasis: Managing morbidity and preventing disability: An aide-memoire for national programme managers. World Health Organization. 2013; (1):1–67.
- Oscar R, Lemoine JF, Direny AN, et al. Haiti national program for the elimination of lymphatic filariasis—a model of success in the face of adversity. *PLoS Negl Trop Dis.* 2014;8(7):915.
- The Carter Center. Eliminating malaria from Hispaniola: A binational effort. Summary 2021 Virtual Program Review Hispaniola Initiative. https://www.cartercenter.org/resources/pdfs/news/health_publications/hispaniola/2021-carter-center-hispaniola-initiative-proceedings-summary.pdf [accessed 1 May 2023].
- Coreil J, Mayard G, Louis-Charles J, et al. Filarial elephantiasis among Haitian women: Social context and behavioural factors in treatment. *Trop Med Int Health.* 1998;3(6):467–73.
- Lammie PJ, Addiss DG, Leonard G, et al. Heterogeneity in filarial-specific immune responsiveness among patients with lymphatic obstruction. *J Infect Dis.* 1993;167(5):1178–83.
- Koschorke M, Al-Haboubi YH, Tseng P-C, et al. Mental health, stigma, and neglected tropical diseases: A review and systematic mapping of the evidence. *Front Trop Dis.* 2022;3:808955.
- van't Noordende AT, Wubie Aycheh M, Tadesse T, et al. A family-based intervention for prevention and self-management of disabilities due to leprosy, podoconiosis and lymphatic filariasis in Ethiopia: A proof of concept study. *PLoS Negl Trop Dis.* 2021;15(2):e0009167.
- Dellar R, Ali O, Kinfe M, et al. Effect of a community-based holistic care package on physical and psychosocial outcomes in people with

- lower limb disorder caused by lymphatic filariasis, podoconiosis, and leprosy in Ethiopia: Results from the EnDPoINT pilot cohort study. *Am J Trop Med Hyg.* 2022;107(3):624–31.
- 17 Yap JM, Tanton N, Wu VX, Klainin-Yobas P. Effectiveness of technology-based psychosocial interventions on diabetes distress and health-relevant outcomes among type 2 diabetes mellitus: A systematic review and meta-analysis. *J Telemed Telecare.* 2021;30(2):262–84.
- 18 Sesel AL, Sharpe L, Naismith SL. Efficacy of psychosocial interventions for people with multiple sclerosis: a meta-analysis of specific treatment effects. *Psychother Psychosom.* 2018;87(2):105–11.
- 19 Lorig KR, Sobel DS, Ritter PL, *et al.* Effect of a self-management program on patients with chronic disease. *Eff Clin Pract.* 2001;4(6):256–62.
- 20 Idler EL, Angel RJ. Self-rated health and mortality in the NHANES-I epidemiologic follow-up study. *Am J Public Health.* 1990;80(4):446–52.
- 21 Rasmussen A, Eustache E, Raviola G, *et al.* Development and validation of a Haitian creole screening instrument for depression. *Transcult Psychiatry.* 2015;52:33–57.
- 22 Zimet GD, Dahlem NW, Zimet SG, *et al.* The Multidimensional scale of perceived social support. *J Pers Assess.* 1988;52(1):30–41.
- 23 Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)—a simple practical measure for routine clinical use. *Clin Exp Dermatol.* 1994;19(3):210–6.
- 24 Ritter PL, Ory MG, Laurent DD, *et al.* Effects of chronic disease self-management programs for participants with higher depression scores: Secondary analyses of an on-line and a small-group program. *Transl Behav Med.* 2014;4(4):398–406.
- 25 Kim SH, Youn CH. Efficacy of chronic disease self-management program in older Korean adults with low and high health literacy. *Asian Nursing Research.* 2015;9(1):42–6.
- 26 Lorig KR, Ritter PL, Pifer C, *et al.* Effectiveness of the chronic disease self-management program for persons with a serious mental illness: A translation study. *Community Ment Health J.* 2014;50:96–103.
- 27 Santini ZI, Koyanagi A, Tyrovolas S, *et al.* The association between social relationships and depression: A systematic review. *J Affect Disord.* 2015;175:53–65.
- 28 Wang B, Xia L, Yu J, *et al.* The multiple mediating effects of health literacy and self-care confidence between depression and self-care behaviors in patients with heart failure. *Heart Lung.* 2020;49(6):842–7.
- 29 Nguyen HC, Nguyen MH, Do BN, *et al.* People with suspected COVID-19 symptoms were more likely depressed and had lower health-related quality of life: the potential benefit of health literacy. *J Clin Med.* 2020;9(4):965.
- 30 Thomas C, Narahari SR, Bose KS, *et al.* Comparison of three quality of life instruments in lymphatic filariasis: DLQI, WHODAS 2.0, and LFSQQ. *PLoS Negl Trop Dis.* 2014;8(2):e2716.