Original Research Article

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20233080

Role of inclusive self-help groups in prevention and management of diabetes and hypertension in Myanmar: a qualitative study

Win-Pa Sandar^{1*}, Hla Hla Win², Aye Sandar Mon³, Manna A. Alma⁴, Johanna P. M. Vervoort⁵, Jaap (J.A.R) Koot⁵, Martin Rusnak⁶, Poppy Walton⁷, Khin Hnin Swe⁷

Received: 07 June 2023 Revised: 01 September 2023 Accepted: 06 September 2023

*Correspondence:

Dr. Win-Pa Sandar,

E-mail: winpasandar1985@gmail.com

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ABSTRACT

Background: Noncommunicable diseases (NCDs) are a growing public health concern in Myanmar. Community-based self-help groups are essential for participating in health-related activities. However, little is known about the role of inclusive self-help groups (ISHG) in hypertension and diabetes management. This study aimed to assess knowledge and perception of health-related activities of ISHG and explore challenges ISHG group members encountered in performing hypertension and diabetes prevention and management activities.

Methods: The study included six townships from three different regions of Myanmar, where ISHG existed. Two focus group discussions (FGDs) were held in each township. A total of twelve FGDs were conducted. All discussions were conducted, audio-recorded and transcribed verbatim in Myanmar language. A thematic analysis was performed using inductive and deductive approaches.

Results: The findings revealed that ISHG members provided advice and counselling on behavioural risk factors for hypertension and diabetes prevention and screenings for those diseases. They also offered home care for the elderly and stroke patients who required their assistance. Community members regarded ISHG as a valuable community structure. Members of the ISHG identified a number of challenges, including lack of resources (funding, manpower, and time), lack of confidence, and lack of recognition and acceptance. Support and strengthening activities by local authorities and the government were critical to sustain ISHG's activities and efforts.

Conclusions: Hypertension and diabetes management activities of ISHG are appreciative. The public and government should recognize and support ISHG to strengthen their community activities.

Keywords: Diabetes, Hypertension, Inclusive self-help groups, Qualitative, Myanmar

INTRODUCTION

Community-based self-help groups, through the community resources, often play important roles in health-related services. 1,2 Self-help groups provide not

only a potentially useful resource for helping people cope with the effects of chronic illness but also a special kind of assistance based on members' shared understanding and life experience.³ They have the potential to act as the catalyst for the community to be actively engaged in the

¹The SUNI-SEA project, HelpAge International Myanmar, Yangon, Myanmar

²University of Public Health, Yangon, Myanmar

³Department of Biostatistics and Medical Demography, University of Public Health, Yangon, Myanmar

⁴Applied Health Research, Department of Health Sciences, University Medical Center Groningen, University of Groningen, the Netherlands

⁵Global Health Unit, Department of Health Sciences, University Medical Center Groningen, University of Groningen, Netherlands

⁶Faculty of Health Care and Social Work, Trnava University, Trnava, Slovak Republic

⁷HelpAge International Myanmar, Yangon, Myanmar

prevention and management of noncommunicable diseases. Chronic noncommunicable diseases (NCDs), such as heart disease, stroke, cancer, diabetes and chronic lung disease, are collectively responsible for almost 70% of all deaths worldwide. They are recognized as a major global challenge in the United Nation's 2030 Agenda for sustainable development. Low- and middle-income nations account for over three-quarters of all NCD mortality, as well as 82% of the 16 million individuals who died prematurely, or before reaching the age of 70.4

Myanmar has a high and growing burden of NCDs. In 2016, there were 291,600 NCD deaths, with a 24% risk of premature death between the ages of 30 and 70. The proportional mortality rates for cardiovascular disease, cancer, chronic respiratory diseases, and diabetes were 25%, 13%, 8%, and 4%, respectively.⁵

NCD management include detecting, screening, and treating these diseases, as well as providing palliative care to those who require it. It is vital to invest in NCD management. Delivering high impact essential NCD interventions through a primary health care approach can strengthen early detection and timely treatment.4 In Myanmar, only 26.4% of participants living in rural areas has had their blood glucose measured by a doctor or health worker, as compared to more than 43.1% of participants from urban areas.6 According to the needs of the country, Myanmar has adopted the WHO Package of Essential NCD interventions (PEN). However, the limited capacity of the health system still leads to substantial gaps in the implementation of these interventions. Basic Health Staff (BHS) are already overburdened as a result of the routine activities, and field work that have impacted PEN clinical services.⁷ Working with communities to prevent and manage NCDs would be an effective strategy because it empowers people to take responsibility for their own health and collaborate to strengthen health services.8

Inclusive Self-Help Groups (ISHG), which are community groups in Myanmar, can be used as a tool to address NCDs. ISHG are mostly led by older people and individuals with disabilities, with other vulnerable groups also actively leading and participating. They support the local community to improve their health through promoting healthy lifestyles, providing regular check-ups and referring people to health centers. This study aimed to explore both ISHG and non-ISHG members' knowledge and perception of health-related activities of ISHG and to explore challenges ISHG group members encountered in performing those activities mainly in prevention and management of hypertension and diabetes mellitus.

METHODS

Study design

A qualitative study employing focus group discussions (FGD) was used to assess knowledge and perception of

health-related activities of ISHG and explore challenges ISHG group members encountered in performing hypertension and diabetes prevention and management activities. Data was collected during January and February of 2020.

Setting of the study

This study was conducted in Myanmar, the second largest country in Southeast Asia. Myanmar is divided administratively into seven states, seven regions, and one union territory (Nay Pyi Taw). The states-Chin, Kachin, Kayah, Kayin, Mon, Rakhine, and Shan-cover mainly the upland areas. The regions-Ayeyarwady, Bago, Magway, Mandalay, Sagaing, Tanintharyi, and Yangon-are situated mainly on the plains. This study is a part of the Scaling-up NCD Interventions in South-East Asia (SUNI-SEA) project. This project is intended to help inform countries how to effectively scale up strategies to tackle NCDs through evidence-based research in Indonesia, Vietnam, and Myanmar.

Participant recruitment

Two types of participants were distinguished: ISHG members and non-ISHG members. Participants were recruited from three regions (Yangon, Mandalay, and Ayeyarwaddy) of Myanmar. In these regions, six townships where ISHG existed were selected purposively: East Dagon and South Dagon in Yangon; Pyin Oo Lwin and Mattaya in Mandalay; and Pathein and Kangyidaunt in Ayeyarwaddy. From each township, a ward or village with an existing ISHG was purposively selected. In each area, two FGDs were conducted: one with ISHG members and another with non-ISHG members. ISHG members were included if they were ISHG member for at least six months. Non-ISHG members were included if they resided in the study area for at least 6 months. We used purposive sampling to select the participants. Through the ISHG network and with the help of the ward or village headman, participants were recruited. The number of participants in each FGD ranged from 7 to 9, and the total number of participants were 95.

Data collection

Data were collected by means of focus group discussions. All FGDs were conducted in the local language (Burmese) using interview guides. The interview guides were developed based on literature review, and included open-ended questions, focusing on assessing knowledge and perception of health-related activities of ISHG and exploring challenges ISHG group members encountered in performing those activities with a focus on prevention and management of hypertension and diabetes mellitus. The FGDs also explored suggestions to improve ISHG and their activities. The topic, challenges encountered by ISHG group members, was only included in the interview guide for the FGDs with ISHG members. A detailed

discussion about the goal and objectives of the study and an explanation of the discussion guides took place between the principal investigator (HHW), coinvestigators (WPS, ASM), facilitators, and note takers. Each FGD was attended by three investigators: one facilitator and two note takers. All investigators had knowledge of the local context and had experience in conducting qualitative interviews. Duration of the FGDs ranged from forty-five minutes to one hour. All discussions were audio-recorded, and notes were taken during the discussions.

Data analysis

The audio recordings were transcribed verbatim in Burmese by the note takers and checked against field notes for consistency. A thematic analysis was performed using inductive and deductive approaches. Thematic analysis consists of six steps: familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up. The transcripts were read and reread by the principal investigator (HHW) and coinvestigators (WPS, ASM) to obtain familiarization with the data. Coding was done using ATLAS.ti 22. The initial coding and theme generation were done by two coinvestigators (WPS, ASM) and reviewed by the principal investigator (HHW). The themes were refined finally, and the findings were reported using "Consolidated Criteria for Reporting Qualitative Research (COREQ)". 10

RESULTS

Participants' characteristics

This study included 95 participants: 48 ISHG members and 47 non-ISHG members. Two-thirds of all participants were female. Almost half of all participants were over the age of 60. The majority of non-ISHG members are between the ages of 40 and 59, while the majority of ISHG members are 60 and older. Approximately two-thirds attained primary and middle school level education. Regarding employment status, two-thirds of all respondents reported that they were currently employed (Table 1).

NCD-related health activities by ISHG

With regard to awareness of the existence of ISHG, nearly all non-ISHG members stated that the majority of community members were aware of the existence of ISHG. A few non-ISHG members in some places, however, were unaware of ISHG since information on group establishment had not been provided to the entire community. Furthermore, some non-ISHG members were unsure about the activities available through ISHG.

"We are unaware of their activities because they are carried out the activities on their own. The village as a whole does not engage in the activities. In addition, we are not members." (46-year-old female non-ISHG member)

In terms of health-related activities, ISHG members claimed that they offer advice and counselling on behavioural risk factors in order to prevent hypertension and diabetes to both ISHG members and non-ISHG members. They also offered hypertension and diabetes screenings.

Table 1: Characteristics of the participants.

Characteristics	n	%
Gender		
Male	38	40.0
Female	57	60.0
Age (in years)		
30-39	4	4.2
40-49	22	23.2
50-59	28	29.5
60-69	26	27.4
70 and above	15	15.8
Education		
No formal schooling	18	18.9
Primary school	29	30.5
Middle school	30	31.6
High school	15	15.8
University	1	1.1
Graduate	2	2.1
Employment status		
Unemployed	34	35.8
Employed	61	64.2

"For the elderly, we take blood pressure and weight measurements. We also check blood sugar levels." (52year-old female ISHG member)

Non-ISHG members also described the different types of health-related activities carried out by ISHG. These include measuring height and weight, supplying nutritious foods and multivitamins, providing glasses, wheelchairs and walking aids, and offering eye care.

"They undertake home visits and surveys for those aged 40 and over. Following that, they perform height measurement and blood pressure checks. They finally do registration." (52-year-old male non-ISHG member)

"They supply wheelchairs for the disabled, walking aids for those who need them, and spectacles for all older people." (31-year-old female non-ISHG member)

ISHG offered home care for the elderly and stroke patients who needed assistance with everyday tasks like washing, clothing, eating, and nail trimming. ISHG also provided financial assistance to the elderly.

"Regarding health care, we give home health care for some elderly who had stroke." (47-year-old female ISHG member)

Some participants (both ISHG and non-ISHG members) pointed out that health-related activities are offered only to their ISHG members. On the other hand, a few ISHG members mentioned that they organize activities for non-ISHG members who need help too.

"They give support and care to the elderly. Regular check-ups are being provided mainly for group members of ISHG; sometimes for community. If necessary, they provide check-ups at home." (58-year-old male non-ISHG member)

Perceptions of the values of ISHG

The majority of ISHG and non-ISHG members stated that ISHG are valuable to the community. The majority of non-ISHG members expressed satisfaction with what ISHG members had done for them. They were pleased with ISHG's health-related activities, such as hypertension and diabetes screenings, as well as home care.

"They (ISHG members) look for homes with over-40-year-old residents and perform blood pressure and sugar checks. It is beneficial to the community because some members do not regularly check their blood pressure and blood sugar levels." (43-year-old male non-ISHG member)

"It is wonderful to be able to receive assistance from ISHG, especially for the elderly." As a result, we don't have to be concerned about our health." (50-year-old male non-ISHG member)

Some ISHG members perceived that being a part of an ISHG was a blessing for improving their well-being. Because of various trainings they received, they now have more awareness about diabetes mellitus and hypertension.

"We now have greater knowledge regarding health. Trainers demonstrate how to take blood pressure measurements." (55-year-old female ISHG member)

Challenges of ISHG in performing health-related activities

The theme "Challenges of ISHG in performing healthrelated activities" came only to the fore in the FGDs with ISHG members, as it was not discussed in the FGDs with non-ISHG members.

ISHG members expressed a wide range of challenges in performing health-related activities of ISHG, especially in NCD prevention and control. The challenges were related to resources, confidence, recognition, and acceptance.

Limited resources

Most ISHG members indicated various types of resource limitations in implementing and managing group activities. Funding was the most regularly described challenge. Many of the ISHG members mentioned that they need money for helping and supporting the elderly and hospitalized members, and also for purchasing medications like multivitamins to distribute to the elderly members. They also explored the issue of limited manpower and time for performing health-related activities. Most ISHG members highlighted that they have their everyday responsibilities, and they occasionally find it difficult to take part in group events.

"We lack sufficient funding. We run out of money after carrying out certain activities, such as providing financial assistance to the elderly. We are having difficulty performing activities at that time." (55-year-old female ISHG member)

"In NCD service, there were five members. Out of five, three left for different reasons. Just two remain." (61-year-old male ISHG member)

Lack of confidence

A few ISHG members in the study mentioned a lack of confidence and reluctance in performing screening activities. Lack of formal education and limited knowledge are the main reasons for low self-esteem.

"My education level is low. Because of my fear of making errors, I avoid using device for measuring BP." (46-yearold female ISHG member)

Lack of recognition and acceptance

Despite providing screening services, a few ISHG members stated that they were not recognized as legitimate by the community. This is because ISHG health volunteers do not provide any medications. The only reaction they got from the community was blame. ISHG health volunteers expressed dissatisfaction with certain community members' responses, which labelled their services as useless because they do not provide medication.

"We (ISHG members) have faced some difficulties. Some people ask for medicines, and they say that the services are meaningless without the provision of medications. I do not wish to provide that type of service if medications are not delivered. This is the issue I encountered." (64-year-old female ISHG member)

Low recognition of ISHG and their services was encountered in certain communities, particularly in wealthier ones. Some ISHG members in the study mentioned that it is difficult to gain the trust of the community because they are not health professionals.

"We have some difficulties. The community knows that we are not health professionals. We only receive certain training, and we have difficulties in building trust." (62-year-old male ISHG member)

Some ISHG members also expressed limited health knowledge among certain communities as one of the challenges. It limited the demand for screening services.

"Certain community members don't have health knowledge. They said that they are healthy and they don't need to do any check-ups. They even refuse to see us." (67-year-old female ISHG member)

Suggestions to improve health-related activities of ISHG

This study explored a wide range of suggestions for ISHG and their health-related activities. The suggestions were related to the delivery of services, human resources, funding, training, and collaboration with basic health staff and township health departments.

Expanding activities and human resources

Nearly all non-ISHG members believed that the activities offered by ISHG are beneficial to the community and suggested that all activities should be made available to everyone in the community, not only for ISHG members. Notably, the majority of community members asked for regular NCD (diabetes and hypertension) screening in their communities and they also demanded the distribution of medicine. A few non-ISHG participants emphasized that it would be better if ISHG could offer medications.

"If feasible, we would prefer to get medications in addition to screening services." (56-year-old male non-ISHG member)

Some non-ISHG participants emphasized the importance of elderly care and requested that basic health staff be assigned to elderly care so that they could collaborate with them.

"It would be better if government could assign a basic health staff to provide care for the elderly." (70-year-old male non-ISHG member)

Both ISHG and non-ISHG members suggested that it would be better if more active and younger people would engage in ISHG activities. Many of the ISHG members also mentioned that in spite of their willingness to perform activities, they were unable to do them because of their age.

"It will be better if more youths involve in ISHG activities. We, the elderly, are not active enough to do certain activities. The more the youths, the more convenient it will be in doing ISHG activities." (60-year-old female ISHG member)

Funding

Some ISHG members stated that they require additional funding not only to perform activities more effectively, but also to scale up activities and services provided.

"If ISHG had enough funding, they could expand their reach beyond ISHG members and provide better services and assistance to all community members." (57-year-old male ISHG member)

Trainings

Most ISHG members suggested that they needed more training on NCDs in general, as well as general screening for hypertension and diabetes and health education, in order to be more confident in providing health services to the community.

"We'd like to receive NCD training, especially for hypertension and diabetes. It would be better to provide services to the community." (61-year-old male ISHG member)

Recognition and collaboration

Some non-ISHG members suggested that raising awareness of ISHG by announcing the establishment of the group and promoting activities and services delivered by ISHG would be useful. A few ISHG members stated that local authorities' recognition and support were crucial to strengthening and scaling up their activities.

"We would like to get relevant authorities support to strengthen our activities. Additionally, we'll work to make our efforts better." (65-year-old female ISHG member)

In spite of having screening services and health education sessions offered by ISHG, some community members have requested doctors' involvement, and they do not want to rely on ISHG because some ISHG members are uneducated.

"In terms of undertaking check-ups and other health activities, it will be more appropriate if doctors are involved..... Some members of the ISHG have a low level of education." (54-year-old female non-ISHG member)

Some ISHG members probed that coordination with the township health department was necessary for providing better healthcare to the community.

"We want to work with doctors from the township health department. We'd like to organize medical check-ups for the elderly and provide them with medications." (67-year-old female ISHG member).

DISCUSSION

The findings of this study added to our understanding of the role of ISHG in health-related activities, particularly in the prevention and management of hypertension and diabetes. The study shed light on ISHG's NCD-related activities, perceived values for the community, challenges, and suggestions for improving ISHG activities.

Self-help groups are informal groups of people who come together to address their common problems. Self-help groups can serve a variety of functions depending on the situation and need, and they often play an important role in raising health-related awareness. 11,12 Their activities include community-based homecare services, health awareness sessions on communicable diseases and NCDs, and NCD screenings.13 Our study also highlighted that screening, homecare, and financial aid were all facilitated by ISHG members. Despite the fact that ISHG were involved in a variety of activities, some community members were unfamiliar with ISHG and the activities they were engaged in. Moreover, this study found that community members were demanding drug supplies from ISHG. However, self-help groups, are not intended to provide medication or treatment. They cannot take the place of professional health services.¹⁴ Undoubtedly, awareness-raising campaigns about ISHG and its activities are highly recommended to grow familiarity with the activities they provide including regular health awareness sessions, and screenings on NCDs, and community-based homecare services.

Self-help groups are effective organizations that can serve as an adjunct to clinical care while also providing tangible benefits to their members.³ By participating in the self-help groups, members were able to better understand their problems and acquire access to many welfare benefits to which they were entitled.^{3,15} Our study also pointed out the importance and benefits of ISHG in the community. ISHG members had the chance to take training sessions and take part in group health-related activities, which was consistent with the literature.^{3,16} As a result, they gained more understanding of diabetes and hypertension.

Despite the variety of activities undertaken and the community's perceived values of these activities, ISHG group members encountered some difficulties in completing their tasks. Financial difficulties were mostly expressed by ISHG members, and several studies have found that funding is critical in generating group activities and sustaining self-help groups. 17-19

Self-help groups are organized by the locals to discuss shared issues and work toward a common goal through social mobilization. ¹⁵ This study showed that members of the ISHG were merely volunteers from the local community who have their own responsibilities and duties in their daily lives. As a result, they did not always have enough time to participate in group activities.

Consequently, there were insufficient members to carry out activities including screenings. Recruitment of new members is therefore strongly advised to expand group activities. Considering recruitment, ISHG respondents recommended involving the younger generation in groups so that activities could be carried out more actively and widely. This suggestion may be due to the fact that two-thirds of ISHG respondents were 60 or older, making them less capable of performing certain activities.

When participating in group activities, self-confidence is essential, and members of self-help groups need to be confident. Knowledge is associated with self-esteem and confidence. ¹⁶ This study, however, found that some group members lacked confidence in performing screening activities. Capacity building through training could boost self-help group members' confidence, allowing them to gain additional influence within the community. ¹⁶ To gain knowledge and confidence, training for new members and refresher training for existing members is strongly recommended.

Self-help groups should be recognized and supported by the public because they serve an important function for people suffering from chronic diseases and/or other issues. ¹⁴ In line with this, the study discovered that ISHG members seek government and community recognition for group formation and sustainability.

The findings of the current study also highlighted the importance of collaboration with health professionals and the township health department. The government should incorporate ISHG into the current health system in order to improve screening activities and community health awareness on NCDs.

This study has some limitations. Since ISHG are organized with the local community, the findings could have been influenced by social acceptability bias. Furthermore, the transferability of this study might be limited due to the qualitative research design of the study.

Despite these limitations, this study provides a valuable qualitative exploration of ISHG in the prevention and management of hypertension and diabetes. The findings show the advantages of establishing community self-help groups, and it is advised that their activities should be encouraged in order to improve the health and wellness of the community.

CONCLUSION

ISHG makes a significant contribution to the local community by performing a variety of noncommunicable disease management activities, particularly those related to hypertension and diabetes. Local authorities and the government should support and strengthen their efforts toward sustainability.

ACKNOWLEDGEMENTS

We would like to thank all the participants for their valuable contribution.

Funding: This research was a part of SUNI-SEA project, and it was funded by European Union's Horizon 2020 research and innovation programme, grant number-825026

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Review Board of the Department of Medical Research in Myanmar (protocol code-Ethics/DMR/2019/145)

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Cite this article as: Sandar WP, Win HH, Mon AS, Alma MA, Vervoort JPM, Koot J, et al. Role of inclusive self-help groups in prevention and management of diabetes and hypertension in Myanmar: a qualitative study. Int J Community Med Public Health 2023;10:3517-23.