International Journal of Community Medicine and Public Health
Regy MM et al. Int J Community Med Public Health. 2023 Aug;10(8):2884-2889
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040
DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20232383

Original Research Article

A qualitative review on the impact of enrolment in self-help groups for persons with disabilities in rural Karnataka, India: a comparative study

Minitta Maria Regy, Deepthi N. Shanbhag*

Department of Community Medicine, St. John's Medical College, Bangalore, Karnataka, India

Received: 24 May 2023
Revised: 13 July 2023
Accepted: 14 July 2023

***Correspondence:**
Dr. Deepthi N. Shanbhag,
E-mail: deepthi.shanbhag@gmail.com

ABSTRACT

Background: Self-help groups for persons with disabilities exist with a rather common objective to address problems, enhance their strengths, and improve their quality of life. Objectives were to explore the impact of self-help groups on persons with disabilities as a comparative approach among those enrolled in SHG versus those who were not enrolled in the same.
Methods: A community-based, qualitative study was done among persons with disabilities in rural Karnataka with a total of 7 focus group discussions, 5 key informant interviews and 2 in depth interviews. Topic guides, recorder and sociogram were used as aids. Themes and sub-themes were formed from the transcript and a deductive analysis was done.
Results: A total of 12 villages were covered and the age group of our study participants varied between 18 to 60 years with a mean age of 40.6±12.9 years. Out of the total 97 FGD participants, 36 (37%) males and 14 (14%) females were gainfully employed, out of whom, 12 (33%) males and 8 (57%) females were enrolled in SHGS. Also, 7 (58.3%) out of the 12 males and 5 (62.5%) out of the 8 females had begun their daily means of income post their enrolment in SHGs, thereby accounting for the awareness and efforts to be self-empowered. The KII and IDI were also in alignment with the different perspectives gained from the FGDs, respectively.
Conclusions: Self-help groups help improve socialization, and self-esteem of individuals with disability and helps them feel empowered to lead independent lives

Keywords: Disability, Self-help groups, Empowerment, Social inclusion, Self esteem

INTRODUCTION

According to the world health organization international classification of functioning, disability and health, "disability" is an integrative concept that represents the negative interaction between an individual's health conditions and personal and environmental contextual factors.[1] Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments where the interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[2] International classification of functioning, disability and health (ICF) defines disability as an umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).[3] In September 2015, the United nations general assembly adopted 17 sustainable development goals (SDGs) on the principle of "leaving no one behind."[4] Disability was referenced in five goals related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of SDGs.[5]

Self-Help Groups (SHGs) are novel and innovative organizational set ups primarily for the upliftment and welfare of people from rural background who face challenges in the social structure. These are basically small informal groups characterized by voluntary memberships, a democratic and consultative structure of governance, economic participation of members, autonomy, education and training, and concerns for the poor coming together for a common objective to gain strength from each other to deal with several problems they are facing on a day-to-day basis.[6] These groups are an attempt by people with a mutual problem to take control over circumstances that affect their lives. In general, self-help groups are based on principles of empowerment, inclusion, non-hierarchical decision making, shared responsibility, and a holistic approach to people's cultural, economic, and social needs.[7] Attending a self-help group (SHG) can be a meaningful activity for people attending a vocational rehabilitation program as such a group provides a secure setting for people to manage their sickness and pursue changes in their life situation.[8] In view of this perspective, the study was intended with the objective to explore the impact of self-help groups on persons with disabilities as a comparative approach among those enrolled in SHG versus those who were not enrolled in the same.

METHODS

This was a community-based, qualitative study done as a follow up to a prior cross sectional, quantitative study done over a period of 3 months (December 2020 to February 2021) assessing the same outcome variables using standardized questionnaires.[9] Purposive type of sampling was used for data gathering and a grounded theory approach was followed.

The inclusion criteria for the qualitative research, includes: Focal group discussion (FGD)- Persons with disabilities, aged 18 to 60 years enrolled in SHG (with participation of more than 6 months duration) forming group 1st 4 groups; and Persons with disabilities, aged 18 to 60 years, not enrolled in any SHG forming next 3 groups, respectively. Key informant interview (KII)- Resource persons with experience in the field of disability and rehabilitation with more than 5 years exposure and work expertise. In-depth interview (IDI)- Person with disability (one in SHG and one not enrolled in SHG) who are not a part of FGD.

The qualitative data was obtained using focus group discussions (FGDs), key informant interviews (KIIs) and in- depth interviews (IDIs) conducted in the local language (Kannada) using a pre-prepared topic guide. The study setting was based at rural Karnataka, covering a total of 12 villages under the Sarjapur PHC, respectively. All the discussions and interviews were done as an outreach approach, conducted over various gathering sites such as Anganwadis (during the monthly SHG meetings), Panchayat office, Mugalur Community Health Centre and 2 village school premises.

Consent was obtained for audiotaping each of the FGDs, KIIs and IDIs.

Focus group discussion (FGD)

A total of 7 FGDs were conducted with 4 FGDs done among persons with disabilities enrolled in self-help groups and 3 FGDs were done among persons with disabilities not enrolled in any self-help groups. There were 6 to 8 participants in each FGD. The duration of each FGD was 40-60 minutes. Sociograms were plotted during each FGD to ensure equal participation of the study subjects. A topic guide was prepared prior to the FGD and interview was based on the questions listed under the same. Each FGD had an interviewer, moderator, recorder cum sociogram in charge and one health worker to help adjust the stranger anxiety and respondent bias.

Key informant interview (KII)

A total of 5 KIIs were conducted. The interviews included the following: Healthcare worker, Social-scientist, Medico-social worker, Panchayat member and Taluk hospital doctor. Each interview lasted for 40-45 minutes.

In-depth interview (IDI)

We conducted 2 IDIs, one interview on a person with disability enrolled in a self-help group and one interview on a person with disability who was not enrolled in any self-help group. Each interview lasted for 30-40 minutes. Audiotapes were transcribed from Kannada to English (manually) and then entered into a word document. The transcripts were then manually coded using codes developed deductively and then analysed using a thematic framework.

RESULTS

A total of 12 villages were covered, namely- Mugalur, Matanahalli, Tiruvaranga, Kugur, Panditharahara, Rajiv Gandhinagara, Billapura, Handenhalli, Thindlu, Adigarakahalli, Dottadhimasandra, Kuthganahalli. The age group of our study participants varied between 18 to 60 years with a mean age of 40.6±12.9 years. The FGDs conducted were 7 in total, where 4 were among those with disabilities enrolled in SHGs and 3 among those who were not. Among the former 4 FGDs, a total of 26 (45.6%) females and 31 (54.4%) males participated; and among the latter 3 FGDs, a total of 18 (45%) females and 22 (55%) males participated, respectively. Out of the total 97 FGD participants, 36 (37%) males and 14 (14%) females were gainfully employed, out of whom, 12 (33%) males and 8 (57%) females were enrolled in SHGS. We also took a further step in asking the date of their employment initiation, to which we deduced that 7 (58.3%) out of the 12 males and 5 (62.5%) out of the 8 females had begun their daily means of income post their enrolment in SHGs and thereby the awareness and efforts to join the same as well.

The topic guide was based on the below points, Disability and acceptance in society, Disability and acceptance in family, Self-acceptance, Attitude towards self-help groups, Awareness of nearest self-help groups and its contributions, Health problems, Perception about benefits through self-help groups, Limitations of self-help groups.

Table 1: Focus group discussions.

Theme	Subtheme	SHG member	SHG non member
Communication	Relatable issues, Peer interaction	Being in selfhelp groups helped them relate more with people suffering with similar problems Those who gained benefits from being a part of SHGs motivated peers with disabilities to join the same as well	Those who were not in SHGs were not as vocal about their problems and were used to facing their difficulties alone.
Health	Individual care, Referral services, Screening of family members	People in SHGs were able to avail health services for themselves as well as seek referral services for their family members.	People who were not enrolled in SHGs were dependant on themselves/caretakers to avail health services.
Access	Healthcare professionals, Education, Training	Being in SHGs improved their chances at education and livelihood Training and employment at various industries such as candle factory, tailoring, organic coffee powder selling	As most of their families took care of their needs, they were not aware of the idea of a cooperative effort towards education and livelihood
Support	Finance, acceptance in society, livelihood	Financial help, acceptance in society and livelihood were the 3 main support initiatives mentioned by the participants of SHGs	The ones who weren't in SHGs complained that the disability allowance was too less and they did not know how to address it.
Personality development	Stigma description, isolation issues, self confidence	SHG participants reported to have improved confidence after consistent meetings and efforts taken by the peers of the groups	Those not in SHGs faced stigma for their disability on a daytoday basis, but still retained their selfconfidence

Focus group discussions: A thematic deductive analysis was done and the following themes were formed: communication, health, access, support and personality development. Associated sub-themes were framed and verbatims were categorized into each of the same. Communication verbatim example: “others tell us ‘Why don’t you join the group, all of us are also there” FGD1 (Members of SHG)**.** “how can we tell our family/ anyone and burden them Sir? It is our problem no; we should face it FGD5 (Non SHG members). While most of them who were enrolled in SHGs did agree that it was due to peer encouragement and spread of word that awareness of the various benefits from such groups followed, there were a few from the same groups who did have other opinions such as “ultimately it is our life and we are to face the rest by ourselves. Yes, such groups help. But for how long?” While such different perspectives occurred amidst the discussion, the collective opinions were in sync with the motive of SHGs.

Health verbatim example: “Also, the group leader calls all the doctors. Otherwise individually we have to go to various doctors.” FGD3 (Members of SHG)**.** “Whenever we get time, we go to the doctor” FGD6 (Non SHG members)**.** Most responses from the members of SHGs seemed dependent and habitual, however those who were new members had a different take on the same. For example, one of the new SHG member’s verbatim was as follows. “Not necessarily. There are times I don’t get notified about the meetings, so in that case depending on such groups to remind me about my health check-up or other health benefits are not a consistent path I would choose to depend on. Our children are taking care of such needs and that seems to suffice.” This reflection was also agreed by a few non SHG members from a few subsequent FGDs that were conducted. Access verbatim example: “We heard that some were given training in tailoring and other skills. This hasn’t yet begun here as our group has formed only recently. But all these are being discussed so even we are looking forward to this” FGD2 (Members of

SHG). "How is it possible to work together, we all have different timings and work." FGD7 (Non SHG members). The concept of empowerment was one of the prime motives of such SHGs, however not all seemed to be aware of that, and the supervising health-workers also agreed to this. Some of them blamed it on the recency of the SHG initiation while some related to the attitude of the individuals in hesitating to take up an unfamiliar task to livelihood.

Figure 1: Study area; a) Map of South India-Karnataka state, b) Study villages under Sarjapur PHC.[12,13]

Support verbatim example: "Money problem has reduced; our account is correct very low interests will be given to those who really need it and ask for it." FGD3 (Members of SHG)**.** "(shouts) the allowance is just Rs. 600, but that is too less, they have even given us low disability percentages." FGD6 (Non SHG members).

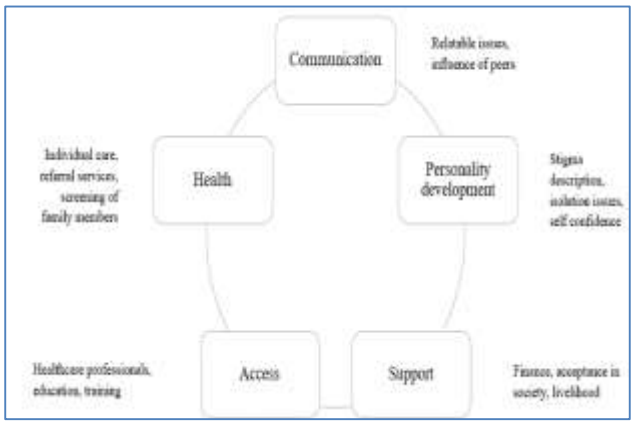

Figure 2: Thematic framework prepared after deductive analysis.

One of the most repeated views on the issue of support was mainly monetary concerns. The staring opinions of most of the participants were the lack of deserving economic aids thereby having them to 'settle' with whatever being given, rather than choosing to fight for more. "(shaking head) It's difficult. Who will come with us for convincing the authorities to help us? How can we prove that our disability in their eyes might be only 20% but for me it feels like 90%. How can they decide it is enough for us? We need to be able to help ourselves if not for others. We are uneducated, so as such getting an income is difficult" FGD7 (Non SHG member)**.** Personality development verbatim example: "Before coming here I used to be scared to come out alone. Now because in groups we are coming out I am not scared. I have got self-confidence." FGD1 (Members of SHG). "I've never felt low about myself, everyone has some difficulties, this (shows leg) is mine." FGD7 (Non SHG members)**.** This was one of the most versatile responses delivering theme addressal. We got mixed views on the impact of SHG on their individual personality development. A 50-50 take was recorded, i.e. some openly and strongly agreed to feeling better on their self-esteem and confidence, however some felt that despite the assurance of not feeling alone in this, certain environmental situations did make them differ in their opinion.

Key informant interviews: A total of 5 KIIs were conducted using a topic guide similar to the one used for the FGDs. A few key questions and their responses are given below. How were these self-help groups initiated? Who all played a role in it? "It is a very voluntary event. We initially went to the potential villages where it could be formed (based on the concerned health workers' report) and we educated the village heads regarding the benefits of having a self-help group in their village. In total we were a group of 3-4 individuals, that's all. All we did was, facilitate. Forming it and taking it from there was all the participants. Of course, we do pay monthly visits and help reviewing the various meetings" –Medico-social worker (KII 1)**.** What were the various reasons for the individuals to not join any self-help group? "We cannot force anybody. We have tried creating awareness but the membership is entirely voluntary. There are options for either the person with disability to join the group or either of their family members to join in their place. Some of them were very enthusiastic about it. Some of them have small amount of daily earnings, like shop/ training classes/agriculture, so they feel since that is their only source of living, they do not wish to compromise that time on any other activity" Healthworker (KII 2)**.** What were some of the prime benefits you have noted? "There are a lot of schemes and monetary benefits that they can avail. For example, the disability certificate, pension scheme and so on. The prime event being, if they go alone for any claim/cause, they are not taken seriously. But being a part of such groups, they go as a group and it is difficult to ignore the petition of a crowd with uniform demands. This way they are able to avail their due benefits" Social scientist (KII 3).

In depth interview: We interviewed 2 persons with disability (one SHG member and one non- member). The interview comprised of mixed reactions to the concept of SHG impact on their basic lifestyle. For example, there were instances where apart from stating the obvious benefits, a few other perspectives were also recorded. Some of them included. "Being a part of SHG did help initially but now the meetings have become stagnant and

we are slowly losing interest. Like, there was a time where we looked forward to share our stories and experiences, but now it has become a place where we end up only listening to woes and hardly any motivation is being gained. Meetings also last for hardly for a few minutes until and unless a village head or health worker visits, which is not very frequent of late" IDI 1 (36-year-old male, SHG member, owns a grocery shop, locomotor disability). "My family already owns a factory. I work there too. Also, with the basic income we get, they have managed to educate me up to high school. I can read and write. Sometimes the villagers ask me to read some newspaper article or paper clippings. I feel independent enough. I don't necessarily feel the need of SHG to make a difference in lives of people like us. It is up to us to make the best use of what we have instead of depending on others to make a living. I do not wish to burden anybody with my limitations" IDI 2 (42year old male, SHG nonmember, rice mill employee, locomotor disability). The concerns recorded from the FGDs were taken up as topic leads for the in-depth interviews and that gave us an idea of the pros and cons from the participant's perspective rather than the interviewer's understanding.

DISCUSSION

As per the UN Disability and Development report 2018, striving to achieve disability-inclusive development is not only the right thing to do, it is also the practical thing to do. Sustainable development for all can only be attained if persons with disabilities are equally included as both agents and beneficiaries as countries strive for a sustainable future.[4] Self-help groups pave way to be more inclusive of persons with such needs thereby addressing certain issues and try helping to bridge the gaps. A previous study done in rural Karnataka 2016 points out that children's needs increases significantly as they become older and should thereby be a priority area for rehabilitation especially considering education.[10] This study did focus on the various rehabilitation measures that were undertaken for the individuals considering the many Community-based Rehabilitation (CBR) programmes that were implemented in those villages to see the influence on those who were exposed to the same. Some of the problems faced by the self-help group's members mentioned in a previous study done by Nagesh et all in May 2018 were the male dominance during meetings, micro credit issues, irregularity in attendance and other financial tiffs. [11] Considering the same, in our study we tried to include questions on those aspects to which the participants did agree on most of the stated issues and also did mention a few other issues as well like- familial support, social stigma, peer pressure and prioritization dilemma between time for existing work and membership. In a qualitative study done by King et al in March 2000, the SHG organizational characteristics involving financial and other assistance to families and care-takers of children with special needs made a definite difference in meeting their changing needs.[11] In our study, most of the responses received did mention the financial support as well as participatory encouragement in various aspects that aimed to improve their approach to daily living, respectively.

Implications

The concept of impact on self-esteem and self-confidence greatly depends on various factors such as job security, social inclusion, livelihood measures and sustainable lifestyle in case of such individuals. Times have been changing and an appreciable number of reformative approaches to persons with disabilities have been noted, however, the contribution of a self-help group leads way more insight towards the method of such improvements.

Limitations

Due to the ongoing COVID-19 pandemic, gatherings and number of attendees had to be limited which influenced our study participation. Initiation of new SHGs and routine meetings in existing SHGs were also a little stagnant owing to the pandemic restrictions.

CONCLUSION

Self-help groups facilitate having opportunities that help improve socialization, self-confidence, and community participation of individuals with disability. It helps them feel empowered to lead independent lives and it also helps add to their social inclusion and self-esteem. It acts as a window to be more aware and accessible towards the benefits they can avail and thereby helps the family and community play an equal role of importance to help them feel self-motivated and rather independent.

ACKNOWLEDGEMENTS

Authors would like to thank Centre incharge: Dr. Deepthi Shanbhag and Dr. Naveen Ramesh, Resident interns: Dr. Elaina, Dr. Alex Fernando, Dr. Cyriac Jogi and Dr. Monisha Maria and Dr. Rathnakumari, Mugalur panchayat members, Mrs. Sandhya and all health workers and staff of the Mugalur St. John's, CHTC.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. O'Young B, Gosney J, Ahn C. The Concept and Epidemiology of Disability. Phys Med Rehabil Clin N Am. 2019;30(4):697-707.
2. Mercer SW, MacDonald R. Disability and human rights. Lancet. 2007;370(9587):548-9.
3. Disability and Health. Available at: https://cdn.who.int/media/docs/default-source/classification/icf/drafticfpracticalmanual. Accessed on 20 February 2023.
4. In Evaluation of Disability Inclusive Development at

UNDP. Available at: http://www.undp.org/publications/disability-inclusive-development-undp. Accessed on 20 February 2023.
5. Chowdhury S, Chakraborty P pratim. Universal health coverage - There is more to it than meets the eye. J Fam Med Prim Care. 2017;6(2):169-70.
6. Shrinivasa B, Janardhana N, Nirmala BP. Mental health orientation for self-help group members: A feasibility study. J Neurosci Rural Pract. 2017;8(3):395-400.
7. Finn J. An Exploration of Helping Processes in an Online Self Help. Heal Soc Work. 1999;24(3):220-31.
8. Hedlund M, Landstad BJ, Tritter JQ. Social Science & Medicine The disciplining of self-help : Doing self-help the Norwegian way. Soc Sci Med. 2019;225(7491):34-41.
9. Arulmohi M, Vinayagamoorthy V, R. DA. Physical Violence Against Doctors: A Content Analysis from Online Indian Newspapers. Indian J Community Med. 2017;42(1):147-50.
10. Shanbhag DN. Quantitative Evaluation of community based guidelines in a rural area in Bangalore District. Indian J Community Med. 2016;3(1):43-9.
11. Bhagyashree N. Role of self help groups in rural development-a study. Int J Trend Sci Res Dev. 2018;2(4):1454-9.
12. Karnataka information. Available at: https://the-india.fandom.com/wiki/Karnataka. Accessed on 20 February 2023.
13. Google Maps. Available at: https://www.google.co.in/maps/search/villages+under/@14.3701153,75.7888299,9.03z?hl=en. Accessed on 20 February 2023.

Cite this article as: Regy MM, Shanbhag DN. A qualitative review on the impact of enrolment in self-help groups for persons with disabilities in rural Karnataka, India: a comparative study. Int J Community Med Public Health 2023;10:2884-9.