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# Role of Non-Government Organization in the Management of Tuberculosis in Disabled

Vandna<sup>1</sup>, Lakhvinder Kaur<sup>2</sup>

<sup>1</sup> Student, <sup>2</sup> Associate Professor, Department of Nutrition and Dietetics,  
Manav Rachna International Institute of Research and Studies, Faridabad, Haryana

## Abstract:

**Background:** NGO's are non-profit making agencies that are constituted with a vision by a group of like minded people, committed for the uplift of the poor, marginalized, unprivileged, impoverished and downtrodden. In India, a large segment of vulnerable groups- Children, pregnant women, elderly people, malnourished people, and people who are ill, including individuals with disability the disabled population seeks health care services from institutional private health-care providers- for management of Tuberculosis.

**Objective:** To understand the health seeking behaviour and challenges in assessing the knowledge about Tuberculosis among Health Workers working with disabled.

**Method:** The study was qualitative in nature. A total of 100 NGO workers were involved in this study. The study was conducted in Faridabad NGO's dealing with disability with the help of Questionnaire method.

**Result:** Of 100 subjects 90% were males aged from 26-45 years. Majority (94%) of subjects responded that Tuberculosis can be treated and TB patients can live a normal life. Mostly NGO workers (40%) reported that print media is the most effective i.e brochures and posters were the most effective way of sources of information on tuberculosis. About 66% respondents said that DOTS were the most appropriate method for treating Tuberculosis. About 58% respondents said that they fear working with TB patients because they may infect them. Mostly NGO workers (46%) reported that communication is the main barrier which was faced while assessing activities at community level.

**Conclusion:** It was observed that health workers associated with NGOs working for disabled do not have proper information, knowledge and management of Tuberculosis. They could not contribute much in the dissemination of knowledge among disabled and its management therefore they are not able to guide disabled.

**Key Words:** Role, Non-governmental organizations, Tuberculosis, Disabled people.

## I. INTRODUCTION

Non-governmental organizations are non-profit organizations which are composed of groups of like-minded people, independent of any government and are committed for the upliftment of needy people.[1,2,3,4]. NGOs work independently without any fellowship of the government although they work closer to the agencies of the government for attaining their objectives.<sup>[5]</sup> NGOs are task-oriented through people with a common interest. NGOs implement a number of usefulness and idealist functions to bring citizen concerns to government and encourage political participation through supplying of information. A few are organized around specific issues such as human rights, environment or health and arrange analysis and expertise, and help supervise and implement international agreements.

### A. Types of NGO

- 1) **Voluntary Organisations:** [VOs] that seek a social mission driven by a responsibility to shared values.
- 2) **Public Service Contractors:** [PSCs] that function as market-serving non-profit businesses serving public purposes.
- 3) **People's Organisations:** [POs] that represent their member, significance have member accountable leadership, and are substantially self-reliant<sup>6</sup>.

Tuberculosis is a disease which is caused by Mycobacterium<sup>[7]</sup>. Tuberculosis affects all parts of the body but is mostly affects lungs. Most of the infections do not show symptoms which is known as latent tuberculosis. About 20% of latent tuberculosis infections have chances to have active disease which, if left untreated, kills about half of those affected. People who suffer from latent tuberculosis do not spread the diseases.<sup>[8]</sup> Despite of new technologies for diagnosis and treatment of Tuberculosis, unfortunately people are still suffering.

In India a large division of population go to institutional private health care providers or NGO worker for health care. There is a wide gap between NGO workers or service providers and disability. Tuberculosis (TB) is one of India's major public health issues.



Every day, in India, over 20,000 people acquire the disease, and over 1,000 departed owing to TB.[9] TB is the seventh most common cause of mortality worldwide.[10] Tb patients face many problems in the community as TB is still a social stigma. Social Stigma is the disapproval of discrimination against a person based on perceivable social characteristics that serve to distinguish them from other members of a society".[11] Equity in health requires that all individuals and groups have access to health services of good quality, and that services are provided according to individual needs.[12,13,14] Health education always has a major role in control of any disease including TB.[15,16] In high-burden TB management in disability, NGO workers have assisted in reducing patient load on formal healthcare workers by taking over supervision and support of patients. NGO workers' success in influencing patient outcomes also depends on the quality of their training in developing a good knowledge base, as well as access to appropriate TB-related information to ensure constant maintenance and updating of knowledge.[17] Therefore, the aim of the study is the Role of Non-governmental organization in the management of Tuberculosis in Disabled people.

## II. METHODOLOGY

This study was qualitative in nature as it sought to understand the context of NGO workers' knowledge towards tuberculosis in disabled. The study was conducted in NGOs of Faridabad which was working with Tuberculosis management in Disabled., Haryana, India. The sample size was 50. Sampling technique was purposive sampling (Expert sampling). Inclusion criteria was NGO workers who are involved in Tuberculosis management in disabled and Exclusion criteria was NGO workers who were involved in tuberculosis.. A questionnaire was designed at the beginning of the study. The NGO workers were informed about the purpose of the study, and proper informed consent was taken. The study demographic variables were name, age, literacy, residence and occupation. The health workers were identified through the NGOs working with TB management in disabled. All interviews were carried out in the local languages. The answers related to knowledge were evaluated simple knowledge-based depending on questions.

## III. RESULTS

Table I - Knowledge and awareness for tuberculosis among NGO worker

QUESTIONS FOR KNOWLEDGE AND AWARENESS	N	%
<b>LEARNT ABOUT TUBERCULOSIS</b>		
HEALTH WORKERS	18	36%
FAMILY AND FRIENDS	10	20%
TEACHERS	2	4%
PRINT MEDIA(BROCHURES, POSTERS)	20	40%
ELECTRONIC MEDIA	0	0%
<b>SIGNS AND SYMPTOMS OF TUBERCULOSIS KNOWN BY NGO WORKER.</b>		
RASH	5	10%
COUGH	2	4%
COUGH THAT LAST LONGER THAN 3 WEEKS	25	50%
COUGHING UP BLOOD	10	20%
SEVERE HEADACHE	1	2%
WEIGHT LOSS	2	4%
FEVER	2	4%
CHEST PAIN	2	4%
SHORTNESS OF BREATH	1	2%
OTHER, PLEASE EXPLAIN	-	-%
<b>METHODS FOR TREATMENT OF TUBERCULOSIS</b>		
DRUGS GIVEN BY A HEALTH CENTRE	14	28%
DOTS	33	66%
HERBAL REMEDIES	2	4%



TRADITIONAL MEDICINE	1	2%
<b>Perception of NGO workers working with Tb infected people</b>		
I feel compassion and desire to help	19	38%
I fear them bcoz they may infect me	22	58%
Other, please explain	4	4%

Table II- Knowledge and awareness for Tuberculosis in Disabled.

Questions for TB in Disabled	N	%
<b>From how long NGO workers are working with disabled</b>		
More than 1-2 years	13	26%
MORE THAN 2-3 YEARS	23	46%
MORE THAN 4 YEARS	14	28%
<b>STAGES OF TB CASES NGO WORKER EXPERIENCED</b>		
EXPOSURE	13	26%
LATENT	12	24%
ACTIVE	25	50%
<b>INVOLVE IN THE ACTIVITIES DONE FOR THE COMMUNITY</b>		
YES	24	48%
NO	26	52%
<b>BARRIERS TO ASSESSING ACTIVITIES AT COMMUNITY LEVEL</b>		
EDUCATION	11	22%
MONEY	4	8%
COMMUNICATION	23	46%
ANY OTHER, EXPLAIN	12	24%

Table I concludes that 36% NGO worker learnt about tuberculosis from Print Media(brochures and posters) whereas 20% , 4%, 40% learnt from Family and friends, health workers , teachers respectively. 48 % NGO workers reported that brochures and posters were the most effective way of sources of information on tuberculosis, 13% reported that newspaper is the suitable way to reach information on tuberculosis whereas 16 % respondents said that Health workers are also good sources of information on Tuberculosis. 66 % NGO workers reported that DOTS i.e well known method for curing TB, whereas 28% and 4% Ngo workers reported that it can be cure with the drugs given by a health centre and herbal remedies and remaining reported 2% that it can be cured with the traditional medicine. that 58% NGO workers reported that they fear them because the TB patients may infect the health worker whereas 38% reported that they desire to help others with their health problems was the most commonly expressed reason for choosing to pursue the path of caring for sick people , remaining 4% said other statements. mostly people are working from 2-3 years that means volunteers are mainly indulge in TB not in disability , some of them are working from last 2 years and some of are working more than 4 Years.[table -III]. Nearly about 50% NGO workers are dealing with active TB in disabled, whereas 26 and 24% % NGO workers are dealing with exposure and latent TB as patient came having severe cases. 64% NGO worker report that patient family support the TB disabled patient whereas 36 % reported that some of family do not support with their disability. [Table-III]Mostly NGO workers involve in the awareness activities at community level whereas some of them do not. Communication is the main barrier which was faced by NGO workers while assessing activities at community level, remaining health workers were also facing education and money too for accessing barrier at community level.





#### IV. SUMMARY AND CONCLUSION

Out of all subjects 45 (90%) were male subjects and 5 (10%) were females subjects which aged from 26-45 years and most of NGO workers are twelfth pass. Many people were not wanted to involve in social activities like TB management as people considered TB a social stigma and do not want to come in contact with TB patients. NGO workers practice was most in males subjects than females subjects as. Most of the NGO workers were learnt about TB from print Media (brochures and posters) as people are able to see it easily on the roads and etc public places whereas some of them were learnt from Family and friends, health workers, teachers respectively. Mostly NGO workers reported that brochures and posters were the most effective way of sources of information on tuberculosis as it is easily seen by the community through pictures. According to NGO workers provision of DOTS is not only the only solution in controlling Tuberculosis as large no. of patients experiencing the disease owing to lack of awareness, social stigma, misconceptions, and discriminatory attitude toward them hampering their treatment-seeking behavior. Main finding is that lack of information and knowledge of TB, its cause and its proper treatment are the major barriers. Incorrect knowledge and missing knowledge influence on people's health care seeking behavior. Disabled people face different barriers that affect their activities of daily life. Thus they need more support from their families and from communities too. There is need to strengthen the Information Education and Communication activities through electronic media (mass media), inclusion of information about TB in the textbooks, and by giving health education to the patients and their family members by NGO workers.

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