

Report

NEW PARADIGM OF MEDICAL CARE FOR PERSONS WITH DISABILITIES

The study was initiated in Mumbai, India in the month of January 2007. Persons with specific disabilities that require medical care were involved in this study with support from various organizations – Government and NGO's working for specific disabilities. The institutions from where the groups of persons with disabilities were formed are as follows: Lok Seva Sangam, Kshitij, and Urban Health centre.

Groups of persons with Diabetes, Leprosy and Schizophrenia participated in the meetings organized to study about the needs and necessities, knowledge they had about specific disability , most common symptoms, place from where they seek medical care, knowledge of prevention, promotion of health condition, regularity in treatment, knowledge on self care/ management..

We formed two groups of persons with Diabetes, two groups with leprosy and one group with Schizophrenia. All the groups except the schizophrenic group were formed with persons belonging to the same geographical area. All the participants in this group were given an introduction about the objective of the study and their consent taken to participate. Total of 56 persons with diabetes, leprosy and Schizophrenia were involved in this study.

The professionals from the respective organization participated effectively. Professionals like doctors, physiotherapists, psychologists, caretakers, nurse, lab technicians form the part of the team. They show their eagerness and provide inputs to plan and organize meetings with persons with specific disability. They give their support by enabling us to interact with the patients, sparing their time for discussion and are taking efforts to improve self care practice in patients

Area of the project	Intervention	Kinds of disabilities present in the group members	No. of different groups	No. of meetings held
Mumbai, India	Kshtij Lokseva Sangam, Urban Health Center	Schizophrenic Leprosy Diabetes	One Group Two Groups Two Groups	8 12 15
No. of persons with disability in each group		Schizophrenic Leprosy Diabetes	12 17 27	

Group Formation and its working:

The schizophrenic group consists of all male participants. All members attending the mental health center were included in the study. The participants are in the age group 25-29 years. Totally 12 persons attended the meetings regularly. They are all literate and training programmes with them were effective. At least one or two members of the group have leadership quality. They take initiative in sharing their experiences with others. The group met approximately eight times formally during the study period. They narrated their experiences as to how they felt about being a patient and their expectations of medical and non medical interventions they were looking forward to. Most of them said that their first episode was tumultuous. They were confused with the sudden onset of symptoms. Symptoms included bizarre thoughts, hearing voices. Suspiciousness, violent behaviour, anxiety and agitation and thought of suicide were not uncommon either.

Some confessed that they were taken for a ride by faith healers while others by their family physicians. All of them reported that the severity in the symptoms reduced within 2-3 weeks but new symptoms set in. These included lethargy, sleepiness, sadness, lack of motivation and concentration, inability to do simple tasks, decline in personal hygiene. All were on medication so with different therapies at least some were able to overcome their negative symptoms. The group while sharing their thoughts felt that they realized that theirs was not a unique experience and others in the group have also had similar experiences. This led to instant bonding as was evident when they voiced to be a part of the group and be led with confidence.

Needs of the participants:

The participants came to know they were ill through their parents. Except one participant the others accepted that they are suffering from the illness-schizophrenia. Four of them were hesitant in revealing their needs. A few expressed that they had fear in traveling alone, and they want to be occupied. They believed that by engaging in work they would not allow the mind roam. They said that by the visit to the Psychiatrist their condition is improved. They said that medication alone cannot improve the mental health condition.

Access to self care:

The participants shared with us the knowledge they had about self care. Initially they said that self care means self protection, for others it was personal hygiene, taking medicines. When interventions were introduced at least a few understood what it is meant by self care.

Interventions with this group:

Prevocational and vocational training

Activities for skill development

Craft activities

Anger management

Satisfaction of emotional needs through activities, interaction with therapist and other clients

Methods used:

Games

Puzzles

Physical exercises

Craft

Cleaning

Drawing

Yoga

Individual counselling

Group work

Family support group formed:

Regular parents meetings were held which was basically to educate them about the illness. In each meeting the parents were updated about the future plans. The parents meet provided a platform for families to put forth their problems, share their difficulties and support each other.

Various topics were discussed such as occupational activities that can be taken up at home, sheltered workshop activities, marketing of the products made by the clients.

Findings:

Through systematic follow up and intervention the participants who regularly attended the meetings enhanced personal hygiene, enhanced presentation of self to the outside world. Enhanced conversational skill like initiatives to talk, ease in traveling independently, prevention of relapse, decreased medication and lessened side effects of the medicine. One of the participants had a tendency to run away from home. He used to go to different places and he would be traced. He has stopped this after he has attended the intervention sessions.

OUR Impression:

It is necessary to integrate empirically validated psychosocial treatments into the standard of care for this group which is evident from the above interventions.

Diabetes group formation:

Diabetes group consist of all female participants. Majority are illiterate and are belonging to the under privileged section of the population and they belong to the same geographical area. All the participants were married. The patients were suffering from the same illness ranging from 6 months to 10 years. They need to be motivated frequently and except a few the others do not understand the importance of increasing the knowledge about the disease. They initially lacked leadership qualities and had less confidence in revealing information. Some participants talk much and dominate the others. In between discussions one tries to rectify what the other has said- even if they are not sure what they said is correct women argue and sometimes ask the others not to talk. They also say ‘we need not give information’ – let them tell us what they want to say.

The medical professionals were oriented about the study and with their support the group was formed.

Each members came to know that they are suffering from diabetes when they had gone for treatment - wound not healing, teeth gums swollen, frequent urination, high blood pressure, vision problems, giddiness, itching.

They are aware that they are suffering from a chronic illness. They get the blood sugar level checked once in 3 months, attend the clinic once in 15 days or earlier if need arises.

Two members said that they were facilitated by the hospital to get the eyes operated. They feel they have good vision after the operation.

They also said that they were not informed about the pros and cons about dietary practices and self-care. The participants showed keen interest in being in a group and they interacted well.

Methods used to improve self care practices:

Yoga

Exercises

Diet management

Manicure and pedicure to take care of the foot and hands

Training sessions

Quiz programmes to increase their knowledge.

By developing positive attitude to self

Findings:

Out of the 14 patients who were regularly followed up it is found that 12 were non vegetarians and two consumed vegetarian food.

Only five participants regularly followed the practices on self care taught.
Five patients developed other complications and medicines were changed.

Except one patient all were able to maintain their weight after following or even attending sessions on self care.

Three had tobacco chewing habit which they were not able to quit within the short period of the study.

Five patients had reduced blood sugar level.

Leprosy: Group formation

This group is mixed with both males and female. All are illiterate from extremely low economic background. They lack sense of confidence. They participate in the meetings organized. Most of them seem to be passive receivers. They generally do not ask any questions. Lot of probing is required to get information from them.

Issues

With frequent meetings and interactions with the group members both in a group and at an individual level lot of issues were identified. These information helped us in planning future activities with the group. Sometimes the participants came forward with innovative ways to solve some of the problem. The Professionals co-operation enabled to complete the pilot study successfully. The groups while sharing their experiences and thought felt that theirs was not a unique one and others in the group also had similar experiences. This led to instant bonding as was evident when they voiced to be a part to the group and be led with confidence.

Identifying medical needs:

- Review of literature
- Through books, articles in the
- Journal, internet, newspapers,
- Collection of reading document
- from institutions working on this particular disability
- Discussions with medical and non-medical professionals who had years of experience working with this disability.
- Training programme
- Interview with client
- Group work
- Discussions with clients

Specific medical care needs identified

Most of the participants had delayed treatment. They are in the older age-group and are already with disability. They are taking treatment regularly but have not learnt skills to help prevent and manage disability. The skin patches, the foot drop and the claw hand makes them continue treatment. Due to lack of knowledge some of them did not feel the loss of sensation and they landed up injuring the hand by touching hot objects. Some of them with loss of sensation on the soles of their foot were at risk for developing ulcers. By not taking proper care of themselves some of them had wounds which required dressing almost daily. Though treatment is given free of cost the patient's accessibility to reach the health care service provider puts them under difficult situation. Their physical appearance affects social acceptance and most of them seem to face the problem of depression. The stigma attached to this disease forced them to hide the disability. They have low self-esteem.

A brief note of a young girl suffering from Leprosy:

She is 17 years old. She has no experience of staying in a house. She hails from Karnataka and has lived her entire life in the pavement of Mumbai. Both her parents are dead. She has three sisters. She suffers from leprosy and has deformities in the left hand and left leg. She said that

she does not have any sensation on the left hand and left leg. Four days ago she injured her finger after touching a hot vessel while cooking. She said that she was not aware that she should not be touching hot things. She appear to be dressing in unclean clothes with nails on toes grown long and kept untidy. She was encouraged to dress well and keep herself clean.

She said that she attends the clinic once in a week. Dressing has done for her wounded fingers and feet.

Contribution of person with long experience of disability condition

Most patients who have been attending the clinic since many years encourage the others to participate in the meeting and training organized. They also teach the others on how to take care of the skin. They help in physiotherapy.

Contribution of health care professionals:

The medical doctors, medical social workers, psychologist, physiotherapist, community development officer, have contributed a lot in making this study successful. Their expert suggestions given at the right time enabled us to conduct training programme- on prevention of disability and self-care management. The role of the physiotherapist played an important role. Several exercise wax therapy, limb care, dressing, nerve care, eye care, stimulation, scar removals, soaking, ulcer care were taught to the patients so that they become aware of what should be done. The social worker and the psychologist helped the patients in counseling because most of them had expressed that they are undergoing depression. The community development officer played the role of an organizer.

Capacity building of the group with knowledge and skills:

The professionals played a key role in providing medical care for many years in a person's life time. Most of the persons with disability said that they have relief if they meet the doctor and if medicines are prescribed. They sometimes even denied attending the meetings. But if the doctor

was present they showed more interest in participating. It took a long time in convincing the client about the importance of self-care and how it will enable them to reduce the complications. Although they had misconceptions in treatment with frequent interaction at the individual, group level participation was ensured. Different skills for specific disability were dealt, yoga, breathing exercises, diet management, knowledge about blood sugar levels, eye-care, foot care, hand care, stress management. Their capacity was built up by professionals most of the time. Frequent meetings with the professionals facilitated in learning what skills should be imparted to the clients and similarly it was done. Although several sessions were held to impart knowledge certain skills we couldn't fulfill.

1. Because of time constraints.
 2. Lack of sufficient equipments to train them on how to assess blood sugar level on their own so that they can self check.
 3. We could provide knowledge of skill development to only a very small portion of the population which is insufficient in the longer run.
- To change the attitude of patients towards self-care practice takes a long time.
 - Monitoring is required

The roles and responsibilities of professionals were discussed. Most of them wanted to change their role of being only a prescriber. They came forward to teach yoga to the patients. They found time in taking interesting sessions on diet management, exercise. They also referred patients to undergo counseling sessions.

Overall findings:

The skill development on practices of self-care has made difference to persons who followed them. With our regular follow-up with clients we were able to find that persons who practiced breathing exercises, who followed diet, who took care of the foot, hands, and avoiding other complaints had found difference in their health condition. The professionals can only be trainees but the persons with disabilities should be in a position to practice what is taught. When yoga has

been introduced only a few follow them. The others say they do not have space at home to do it. Certain skills to be practiced require basic facilities. The health centres/community centers should be able to provide the space to facilitate them to follow the practices on self-care at least at an initial stage until they understand the importance of self care.

- More specialists who are having adequate knowledge and skills on self-care should be available to impart training.
- Most of the clients feel that there is lack of awareness being done to the public about chronic diseases like diabetes and schizophrenia which will lead to major complications
- Mass awareness campaigns to be undertaken
- Screening of public for Disabilities should be done. Most of them had been identified to have disabilities only after they had visited the clinic for other illness. So prevention was not possible.

They feel preventive steps have to be taken to avoid any one falling a prey to these drastic diseases.

Recognition of expertise of the group

At some instance the professionals recognized the knowledge that the group members have and they allow them to share this with others. Most of the time they are allowed to share their experiences about the onset of symptoms, where they went for treatment, what happens if they do not come for follow-up. The participants share their experiences with others suffering from the same condition. They also teach the others what diet they followed to reduce complications, taught the others exercise that they have learnt. There is mutual sharing of skills they have acquired. They help the others in doing physiotherapy. Sometimes emotionally also they support others. Most of them seem to be depressed in one way or the other. The group helps them come out of their problems to an extent. The group members have developed confidence but regular motivation and support gives a hand to come out of the problem because most of the time the clients have multifaceted needs along with medical care needs.

Suggestions to improve the self care practices:

Prevention is better than cure. For prevention of any disability and especially diabetes which complicates and worsens health conditions Awareness programmes must be carried out in a massive way. From our study it is found that most of them have been diagnosed to have diabetes when they visited the health centre with other illness. Screening of patients for diabetes must be initiated.

Facilities to be made available in the health centres /communities to practice self care

More professionals must be trained on aspects of self care. Medical professionals should also be trained to develop skills of stress management which they can impart to the patients. Most of the patients undergo depression in one way or the other. Mobilization of resources played an important role in practicing self care practices among persons with disability. More and more coordinated effort will facilitate this attempt.

We were able to successfully form groups of persons with specific disabilities- leprosy, schizophrenia and diabetes with support from NGO's and Government organizations working for the welfare of persons with specific disabilities. The professionals and the persons with disabilities have been oriented about the objective of the study and they rendered support in fulfilling the objective