TB PATIENTS EMPOWERMENT

ACTIVITY REPORT

“Orientation Session with TB Patients in Lahore”

July 1, 2010
Background

Tuberculosis is one of the world’s best kept secret which kills 2.7 million people every year with death of one person with TB in 20 seconds. Pakistan ranks 8th among the 22 high burden countries and has the highest incidence rate of TB in the East Mediterranean Region. The Empowerment and Involvement in TB services of TB patients/former patients and affected communities is still an underdeveloped area in the fight against tuberculosis. The term ‘empowerment’ appears in many different contexts. Its meaning varies, but usually has two aspects: (1) having and sharing of power, and (2) sources of power and ways to increase power. Patient empowerment, in the first sense of having and sharing power, refers to patients' power over a range of decisions such as provider and treatment choice. Patient empowerment, in the second sense of sources of power and ways to increase patients’ power, refers to patient education (i.e. diagnosis, treatment, care and support), legal rights, patient friendly services and others. The World Health Organization defines empowerment as ‘a process through which people gain greater control over decisions and actions affecting their health’.1

Patient involvement and empowerment is a phenomenon termed as “enabling TB patient to take control of their lives, making right, healthy and timely decisions by understanding their rights and responsibility starting from initiation to monitoring and evaluation of actions, programs and policies”. It means transfer of knowledge and power to TB patients; fill the services gap and develop patient friendly environment and policies until the TB patients start to take care of themselves. This step begins with the public awareness campaigns because it is vitally important for members of at-risk populations to understand TB, its impact on the community, how it is diagnosed, treated, and prevented, what and where services are available and who service/care providers are. These populations should be able to influence TB programs directed toward their communities”

Rationale

Pakistan like many other countries is lacking in directly working with TB patients and there is a large population of TB patients who are not connected with TB control services. There are number of reasons and having no TB patient’s group or organization is one of them. Identification of TB patients, developing their groups or organizations and linking them with health care services in public and private sector can support in TB control.

Activity

TB Patient’s Orientation Workshop

National TB Control Program has designed a Patient Empowerment Program with the objective to establish TB Patient’s Groups in four provinces and AJK to provide physical, social and economical rehabilitation to TB patients by empowering them. With the help of ACSM provincial coordinator, 10 TB patients (men and women, cured and under treatment) were identified from Punjab Province who were invited

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1 WHO 1998
to participate in a one day orientation meeting at Provincial TB Control Program Lahore on July 1, 2010. The provincial TB Control Program Lahore hosted the meeting and provided its venue for the meeting. All the participants were provided with financial assistance to attend the meeting.

**Objectives**

The objective of the orientation workshop was to:

- Establish TB Patient’s group in Lahore-Punjab
- Build the capacity of TB patients to understand and manage TB disease in a better way

**Process**

The workshop started with the recitation from the Holy Quran. The Provincial ACSM coordinator introduced him and requested participants to introduce themselves. The participants introduced them by telling their name, place and their disease status. The facilitator also introduced him by telling his name, affiliation, roles and responsibilities and about the Patient Empowerment Program.

Based on the questions, it was noticed that none of the patient knew about patient’s charter and patient empowerment. Only two out of 10 patients knew the name of medicines he/she was taking including cured TB patients.

The facilitator shared the definition of empowerment of TB patients and said “improving TB patient’s capacity to better control their health and life by knowing their disease (causes, symptoms, after affects, medicines, diagnosis and treatment centers etc), their ability to assist other TB patients in improving their lives (peer support) and their ability to assist TB control programmes and health care professionals (by establishing their own groups, organizations and sharing success stories)”

The facilitator generated a discussion on “TB Control and Patient’s Roles and Responsibility”. He linked this with Patient Charter and gave a detailed briefing about Patient Charter.

With a mutual consensus, a group of TB patients was established. A debate was generated on the structure, mechanism and focal person of the group. One of the participants suggested to conduct a “knowledge check test” and the person who will give correct answers of the questions asked will act as focal person of the group. The other participant suggested first going back with some task and reporting back in the next meeting.

The ACSM coordinator in Lahore was initially appointed as liaison person and all the participants took the responsibility to come for the next meeting.

All the participants agreed to bring one TB patient with them for the next meeting.
A next meeting was proposed on August 2\(^{nd}\) 2010 at the same venue. The entire group of patient presented at the meeting took the responsibility to liaison with ACSM coordinator for the next meeting.

**Conclusion**

The involvement of tuberculosis patient in the treatment and active discussion regarding choices and possibilities increases the sense of being in personal control of the disease. The doctor patient relationship must change from directive to collaborative for the long term treatment and cure. Doctors must increase their understanding of the context of the tuberculosis patient as they discuss the disease. The positive feelings exuded about the treatment and conscious involvement of the patient in developing a treatment regimen are essential to success. The patient's feeling that the final cure lies in their own hands increases the sense of responsibility for self care that is so essential for the management of tuberculosis.

**Patient's Complaints and Recommendations**

- The National and Provincial TB Control Programs should not only work with “easy to access” patients but should also include/engage most vulnerable and neglected segment of the society like people living in far flung and remote areas.
- One of the patient shared that TB is a stigmatic disease and none of the patient is ready to share his/her status openly. He suggested to organize such seminars, meetings and events with TB patients so that they can share their status openly with public.
- One of the participants suggested engaging other stakeholders like religious leaders, scholars, family members and friend for TB patient's support.
- The program should recognize our problems. We are getting free medicines but there are other expanses like our travel from home, a day leave from our job etc.
- There is no guidance in the hospital and we have to search for hours to find out the right place for diagnosis, treatment and medication.
- We need some material in our local language to understand the disease.
- The doctors should also be trained in order to have better patient-doctor relations.
Recommendations/Suggestions

- It was suggested to have a brief presentation/discussion on DOTS program and TB disease to enhance the knowledge of the participants.
- There is a need to develop TB patient’s groups and build their capacity to act as patient’s advocate.
- Patient Charter is needed to be developed in the national language i.e. Urdu and local language i.e. Punjabi.
- Patient Empowerment material is needed to be developed in Urdu and other local languages.
- There is a need to conduct patient education sessions on regular basis as only two out of 10 patients knew the name of the medicines.
- It is also important to build the capacity of health care provider so that they can also facilitate patients in knowing their type of disease, name of medicines, Psychological and emotional affects of the disease and his/her role in TB control.
- There is a need to facilitate TB patients within the health care facility so that they can easily get access to services.
- There is a need to conduct regular sessions on patient’s responsibilities as many of the patients were of the view only doctor is responsible for their health.

Follow up meeting

Next meeting will be organized on August 2nd 2010 at the same venue.