

EDITORIAL

Govt.-NGO partnership for handling thalassemia / hemophilia disease burden

Muhammad Ashraf Majrooh

Foundation University Medical College Rawalpindi

Thalassemia and Hemophilia both are genetically transmitted lifetime crippling disorders. Both disorders require frequent repeated blood transfusions and lead to premature deaths and disabilities due to the complications of disease and risks of repeated transfusions. Both types of disorders share common strategies regarding prenatal postnatal diagnosis, blood and blood product transfusion services, carrier detection, genetic counseling, health education and social support (1). Both thalassemia and hemophilia require multidisciplinary interventions and a very well coordinated referral system for management of these diseases (2). Thalassemia is the most common inherited disorder in Pakistan and there are inadequate treatment facilities for over 4000 homozygotes born each year. The estimated carrier status is about 7% and the estimated numbers of patients in Pakistan are 14000, 50% of them reside in Punjab.

These childhood lifetime crippling diseases like thalassemia, hemophilia, epilepsy, mental retardation and Insulin Dependent Diabetes put unbearable burden on the families. In study by Health Economics Research Group, Brunel University, Uxbridge, UK, the lifetime management cost of treating a beta thalassemia major patient was estimated to be hundreds and thousands of pounds (3). The burden on the families with children suffering from thalassemia is greater in the developing than in the developed countries because, beside caring chronically sick child, there lives are dominated by the high cost of treatment, often 20-30% income for many families (4).

Non-government organizations (NGOs) have been a significant part of health sector in many developing countries for many years. Historically, the missionary provided health care, which often had dual motives of providing health cares to missionaries and their employees, and latter the servings were used as vehicle for evangelism. Around the eras of first and second World War international secular NGOs like United Nation Children Emergency Fund (UNICEF), World Food Program (WFP), International Labor Organization (ILO) and many others have been added (5).

Like other developing countries, in Pakistan NGOs culture is mushrooming for the last 2-3 decades but these are working without any liaison or regulatory control by the government. Most of the NGOs have very limited activities, unregistered and are concentrated in the big cities. There is no clear policy of the government for working relation and coordination with NGOs, even then the role of NGOs cannot be ignored. Many NGOs are already working in health sector of Pakistan and they are playing

significant role in provision of health services especially in women and children (6). Pakistan health sector at this point in time is in transitional phase of devolution, financial and managerial reforms, therefore, the role of NGOs must be studied regarding physical and human resources and their service contribution. Such studies will help in policy decisions for assigning the definitive role and contribution in health services.

Strengths and Weaknesses of Public Sector for Thalassemia / Hemophilia

Government institutions have pediatric units, diagnostic laboratories and a network of transfusion services in the form of well-equipped Blood Banks. All facilities in the public sector are having trained staff and consultants in each discipline. The buildings are owned by the government. The major weakness of the government sector are:

- Lack of registration of thalassemia / hemophilia patient for continuous management.
- Lack of referral liaison among various disciplines with the same institution or with the other institutions and disciplines.
- Lack of specific diagnostic facilities for the diagnosis of thalassemia and hemophilia.
- Non-existence of social services like health education, blood collection, rehabilitation service and psycho-social support to the patients and families.
- No coordination between NGOs and private sector.

Strengths and Weaknesses of Non-Government Organization (NGOs)

Non-Government Organizations have opened the thalassemia and hemophilia centers for provision of transfusion and therapeutic services. They have major contribution (90.0%) in registration of thalassemia and hemophilia cases for continuous management. Thalassemia Society of Pakistan Medical Association (PMA) is providing technical and financial support for thalassemia and hemophilia patient at Punjab level. Fatmide foundation is the key NGO working at Lahore and Multan for this purpose. Local thalassemia societies in Rawalpindi, Bhawalpur and Faisalabad are also playing a significant role in the management of these diseases. The centers working under NGOs are having very good transfusion facilities along with screening of donors and patients. The equipment is functional and supplies are regular. All the NGOs owned facilities have full strength staff. Most of the buildings owned by the NGOs are rented. The major weaknesses of NGOs sector related to management of thalassemia and hemophilia services are:

- Lack of physical infrastructure at provincial level.
- Working only in the big cities.
- Lack of specific diagnostic equipment supplies and services.
- Lack of consultation services.
- Lack of referral coordination with the government and other health institution for utilization of various disciplines.
- Lack of coordination with other NGOs.

Lack of coordination and liaison among the various disciplines, organization and various sectors is common in both NGOs and public sector. The usual practices of referral patients is that if the health facility/ discipline does not have the services for particular problem it just refuses for the service and ask the patient to seek service of the other health facility/discipline at their own resources. The health facilities/disciplines in both NGOs and public sector do not make any referral agreements with other facilities/disciplines or organizations. Specific diagnostic services and preparation of blood products are also deficient in both sectors.

Scope of the Partnership

In the light of above mentioned facts it is obvious that there is strong need of some sort of agreement or policy decision regarding the partnership and assigning the specific roles to NGOs and public sector to deliver the diagnostic and therapeutic services. The government owned health infrastructure can be coordinated with NGOs to strengthen the social and financial aspects of the services. NGOs and government health sector must have some documented agreement for referral services on both sides. The possible policy alternatives may be:

- Thalassemia and hemophilia centers owned by NGOs must be given diagnostic and consultation support from Public Sector Tertiary Care Hospitals through formal referral agreements.
- Registration, blood donation and financial services can be managed through NGOs.
- Public sector has very good physical infrastructure, therefore, it can provide premises for thalassemia and hemophilia centers for NGOs.
- NGOs are deficient in trained medics and paramedics that can be shared from public sector.
- Public health sector can provide training services for the staff engaged by the NGOs.

Correspondence: Dr. Muhammad Ashraf Majrooh
MBBS, DCH, MPH, FCPS (Com. Med)
Foundation University Medical College Rawalpindi
E mail: humas3@wol.net.pk - Ph: 051-5788254

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