Policy dialogue summary

Development of a national package for management of Sickle cell disorders

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The views expressed in the dialogue summary are the views of the dialogue participants; the template format for the dialogue summary was adapted from the McMaster Health Forum.

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Dialogue:
The policy dialogue about development of a national package for management of sickle cell disorder was held in December 2012 at the federal ministry of health Great Avenue. Khartoum, Sudan.
The policy dialogue was facilitated by Pro. Mustafa I, Albasheer, Dr. louran Z Ali, and Dr. Ahmed A, Aldaak.

Summaries of the deliberations:

Several dialogue participants noted that the most important problems regarding sickle cell disorders in Sudan are:

1. Sickle cell disease is priority because of it is seriousness.
2. Surveys are priority to fill the gaps in the data about the disease burden and prevalence.
3. Formation of a national committee for SCD disease to be chaired by the undersecretary of FMH.
4. Establishment of national program within the non communicable disease (NCD) department, for co ordination and management.
5. Community participation in whole process to focus on advocacy, premarital counseling and public awareness through national association of sickle cell anemia.
6. Development of appropriate legislations and screening programs for disease prevention.
7. Relocation of SCD Referral Clinic in Soba University Hospital, to be upgraded into a National Centre of Excellence for sickle cell Disease.
8. Establishment of satellite centers for SCD management at areas of high prevalence.
9. Provision of support to patients and affected communities

Back gourd to the policy dialogue:

The policy dialogue was convened in order to support a full discussion of the relevant considerations (including research evidence) about a high priority issues. Key features of the dialogue were:

1. Addressing an issue being currently faced in Sudan.
2. Focus on different features of the problem, including the mostly affected groups, areas, etc.
3. Informed by pre- circulated policy brief that focus on two options for the approach in addressing the policy issue.
4. Informed by full discussion about the problem factors and possible elements of an approach for addressing it;
5. Brought together many partners who would be involved in or affected by future decisions.
6. Ensure fair representation among policy makers, stakeholders and researchers.
7. Engaged facilitator to assist with the deliberations.
8. Allowed for frank, off- the- record deliberation by following the Chatham House rule " participants are free to use the information received during the meeting, but neither the identity nor affiliation of the speaker(s) nor that of any other participant, may be revealed"
9. Did not aim for consensus.
   Participants' view and experience and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights.

Sickle cell disease (SCD) in brief

Sickle cell anemia is an autosomal recessive genetic disorder; caused by a point mutation in the hemoglobin β-globin chain, in which amino acid glutamine is replaced by valine. This render the red blood cells to assume a sickle shape when exposed to low oxygen tension. Clinically; symptoms are highly variable including symptoms of anemia, or SCD crisis including vaso-occlusion crisis, sequestration crisis, a plastic crisis, hemolytic crisis or those due to Complications which are plenty affecting many systems and can be fatal. Diagnosis of SCD is by demonstration of abnormal hemoglobin by cellulose acetate electrophoresis. Prenatal diagnosis can be done by detection of abnormal gene in amniotic fluid sample. Management includes symptom relief, management of anemia and the complications, beside prophylactic immunization and patient counseling.

Deliberation about the problem:

The meeting participants discussed the problem; it is factors and implications in details. Problem found to be complex due to the nature of the disease itself, and the low community awareness about the disease cause and its management. It is a global problem, one of the major neglected disorders. Nevertheless, this negligence resulted in severe shortage in epidemiological knowledge of problem. Thus the resources and management of disease as whole is very low. Almost all dialogue participants agreed that SCD problem is a priority, not because it is the commonest, but because its effect is very serious. Some participants argue that the under estimation of the disease importance and seriousness comes from its consideration as anemia. However, it is a multi-systemic syndrome with the common complication of stroke resulting hemi and quadriplegias, and sudden deaths due to acute chest syndrome. It is considered as a RBC diseases, but it is not, there are abnormalities in the WBC, platelets also. Problem is beyond problem with hemoglobin. It is a chronic inflammatory disease due to oxidative stress and compromised immune response. In addition to this the patients and communities representative in the meeting reflected that SCD is serious as it is a familial disease, in the sense that if there is a single child with the disease will comprise the whole family, because there are frequent admissions which entails the parents interrupting their daily routine chores. Furthermore, the disease cause frequent deaths of the children especially in the high burden communities some families might lose up to four or five children.

Cross sectional surveys has been suggested to fill the gap in the knowledge with regards to the disease epidemiology and magnitude and its burden associated factors. Furthermore, is to identify the highly endemic areas in the country. Some participants suggested conduction of mapping in the already known areas or states, rather than national mapping. Others reiterate the importance of mapping the disease in the country – constructing simple epidemiological surveys. This will show the priority areas. Also, this mapping helps in knowing the behavior of these people towards the disease to know how they think. Establishment of the centers alone doesn't guarantee its utilization by patients. There is a need to know about the community cultures, believes and perceptions about the disease.

Other participants mentioned the importance of sensitize graduate and postgraduate students– should be taught extensively and encouraged to research in this area.

Community contribution is one of the major issues discussed in the problem part. The participants agree that the PHC has been the focus in MOH for the past years; however it is not working properly in Sudan–

the pillars of which are not enforced in Sudan. The community role is not recognized by system. Inter-sectoral collaboration is also weak. It is good to have a national centre for coordination of SCD activities and a national policy – but why should the setup be in the capital. Role of universities is not yet realized well for instance Iran handed over the health work in each state/region to medical science universities, in Sudan this is not the case.

Deliberation about the two policy options:

The dialogue participants discussed the two policy brief options. The participant of the meeting agreed on the SCD prevention and treatment package stated in the policy brief. It found to be important for prevalence reduction, improvement of the disease treatment and possible to be implemented. Furthermore most of the participants pointed to the importance of the legislation as good tool for enforcing the premarital screening, with this regards Saudi Arabia has been discussed as best example of Islamic country where legislation contributed to reduction of SCD. This approach adopted so as to avoid disease carriers marriage. It helps in parents' orientation about the disease, its complication and provision of advices to couples to avoid future disease complications to their children. If they wish to continue with pregnancy they are advised to consult the centre immediately. It is helpful in community enlightening about the disease and its complications. After deliberation on the options the participants agreed to adopt a third option for the SCD problem of Sudan this option is a combination of the provided two options advantages, this option focuses on a four pillars; research, services, training and prevention. A national programme also recommended under the umbrella of the NCD at FMOH. The program focus will be the states of SCD high prevalence in the country. In addition to, the option will address the following issues:

1. Strengthening and Promotion of primary health care activities with the prioritization of mostly affected areas (according to available data; these areas are: greater Darfur, Blue Nile, and North Kordofan states).
2. At the national level, it is recommended that a national program for sickle cell anemia is to be established and integrated under the umbrella of NCD system- with special priority position- its role will be policy development, strategic planning and advocacy as well as coordination with other sectors. Priority is given for states of higher prevalence. Initially; at treatment level.
3. Treatment:

- Updating and development of treatment protocols by experts from different disciplines build on the available national practice experience, with special consideration to omega-3 fatty acids.
- Treatment approach should take into consideration the limited resources of rural areas that carry most of the disease impact.
- Government support and supplementation of the blood banks especially in rural areas with essential materials and instruments to conduct the blood transfusion services.
- Integration of treatment services by specific package at each level of health care service.
- Evaluation of possibility of enrolment of sickle cell anemia patients and their families in national health insurance system.

4. Diagnosis:
   - Supply laboratories at different levels of services with essential materials and instruments required for simple and advanced diagnosis.
   - Training of laboratory personal.
   - Increase the number of clinical hematologist.
5. Prevention:

   Sickle cell anemia is preventable disease and good screening program early premarital diagnosis with counseling services can be established, the identified carriers can be informed about the possible complications that can face their babies and how to act if it occurs. Changing the bad practice and misbelieves towards the disease can prevent a lot of complications and decrease the morbidity and mortality of the disease.
6. Legislative and regulatory points:

   Development of a law approved by the national council about the legal points regarding insurance services, pre-marriage counseling and prenatal screening, Iran and Saudi Arabia experiences can be reviewed as they show a great success.
7. Development of centre of excellence:

   The centre will provide health care services, training of health care cadre beside the research activities. The centre is better to be in capital city where specialists from different disciplines are available.
8. Training:
   - The under graduate university curriculum about sickle cell anemia should be revised the graduated student should be sensitized about the problem and the role of universities in increasing the awareness should be enhanced.

- Training of the treating doctors how to deal with the affected patients.
- Training of laboratory personals.

9. Role of society:
    - Development of advocacy associations for rising awareness about the disease and attraction of financial support.
    - Strengthen the partnership with different stakeholders (Medical schools Ministry of welfare and social security with it is different councils e.g. National council for child welfare, El Zakah office, as well as private sectors) and enhancing their role in the policy development and implementation, rising awareness, training and financial support.
10. Research:
    - It is importance of sensitization of graduate and postgraduate students to contribute to SCD research; they should be taught extensively and encouraged to research in this area.
    - university researchers can help in providing information and data about the disease
    - Research studies about the behavior of the affected people and communities are needed to know their perception and attitude towards the disease. We need to know how they think and re-act.

Implementation arrangement and way forward

The participants supported University of Khartoum initiative of establishment of dedicated centre for SCD prevention and management to be housed at Soba hospital. This centre works in coordination with the other SCD centers that will be established in the states.

Federal ministry of health nominates a focal person for SCD to be hosted in NCD department within the general directorate of public health and emergency general directorate.

In addition to, the participants recommended development of a national committee, representing different stakeholders: deferent departments of federal ministry of health, medical schools, ministry of welfare and social security, national council and clinicians they have to follow up with the undersecretary the SCD policy development, implementation, the committee should focus on education and promotion and recommended to lead and coordinate the implementation of following activities:

- Development of a national policy for SCD prevention and management

- Development of a national guidelines on SCD management based on the existing guideline in Abunaof Hospital clinic
- Writing report that contains the current information regarding SCD and to be forwarded to decision makers as soon as possible.
- Conduct epidemiological survey about the disease. The participants recommended Prof. EL Fatih EL Samani and Dr. Ahmed El Daak to lead this part of the future work in SCD.