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Awake Arise and Aware 3 Make India Sickle Cell Free: A Supportive Initiative

Chirag Desai

Research Scholar, J.T. University, Jhunjhunu, Rajasthan, India

ABSTRACT:

Sickle cell anemia is a hemoglobin disorder which is most commonly prevailing in tribal areas of the India. Many states of India like Gujarat, Maharashtra, Orissa, Tamilnadu, Madhya Pradesh where the prevalence rate of sickle cell anemia is between 5-34%. As there is no standard of care to cure for sickle cell anemia is available so there is a dire need of cost effective management for improving quality of life of patients. Public awareness and health education can play a crucial role in controlling the disease and it can motivate population towards such activities like establishing newborn screening and premarital screening and genotype identification for sickle cell anaemia. In current article highlight the importance of awareness if created in proper channelized manner in general population may enhance adherence to health maintenance guidelines and increase knowledge and awareness among those affected and also those not affected so they can be alert enough to provide management in crisis condition and overall improving healthcare access and utilization with support of pharmaceutical healthcare provider. This program will eventually help in lifting up the level of community pharmacist and change the spectrum of population towards healthcare awareness.

KEYWORDS: Sickle cell anaemia, Hemoglobin disorder, community pharmacist, awareness, health education.

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INTRODUCTION:

Sickle cell anemia is an autosomal recessive disorder with phenotype variation. As some sickle cell patients have frequent vaso-occlusion and complications while others have little affected by sickle cell and have normal life. It seems to be a global health problem that presents major challenges to our health care systems. There is no doubt much need for more public education, counselling and awareness on Sickle cell anemia in the India especially the tribal parts of the country.¹⁻³ In comparison with other chronic diseases and Hemoglobinopathies, sickle cell anemia remains one of the least understood and confusing medical conditions by health care workers and the general population.⁴

Current options to reduced Hemoglobin disorder

Hemoglobinopathies can be efficiently reduced through a strategic balance of disease management and prevention programs. Sickle-cell anemia is an autosomal recessive type of disorder so it cannot be cured; however the condition and symptoms can be managed by: High fluid intake & healthy nutritional diet and folic acid supplementation & pain-killer medication. Prophylactic antibiotics are used for preventing infections.^{5,6} The most cost-effective strategy for reducing the burden of hemoglobinopathies is to complement disease management with various preventive

For Correspondence:

Mr. Chirag Desai

Research Scholar, J.T. University, Jhunjhunu,
Rajasthan

Email: Chiragdesai112@gmail.com

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preventive programs. Inexpensive and reliable blood tests can identify couple at risk for having children affected with sickle cell anaemia. This genetic screening is really helpful in before marriage or before pregnancy, to allow couples to discuss the health of their family. Subsequent genetic counselling informs carriers of sickle cell anemia that is risks that may be passed along to their children and the treatment might be needed, if affected by a haemoglobin disorder. Prenatal screening of any genetic diseases raises precise ethical, legal and community issues that require appropriate consideration.^{5,6}

What activities for preventing & controlling Hemoglobinopathies?

Increase awareness in the community of the global burden of sickle cell anemia. Generally main emphasize should be on try to promote reasonable access to the health services in community sector. Provide scientific and technical support to the areas for the prevention and management of the sickle cell anemia. And last but most important is to promote and encourage and support research work to improve quality of life for those affected. One of the researches on sickle cell anemia concluded that between 19-30 years age individuals are having lack of basic understanding of the sickle cell anemia.⁷ So the current program was an initiative to educate students from their schooling or teen age period where they can have basic knowledge and awareness about the most prominent conditions of sickle cell anemia. So the purpose of the study is to spread awareness in students of tribal area who are at the risk of having this blood disorder.

Sickle cell anemia control program:

Government of Gujarat was the first to take initiative in controlling the sickle cell anemia. The objective of the program is no sickle cell disease childbirth by 2020. Prevention of death from sickle cell crisis. To improve health status and quality of life of sickle cell anemia patients. The main components of the program are early diagnosis through screening of new born baby, antenatal screening and prenatal screening, adolescent screening, mass screening on mission mode, prevention through the counseling session before marriage, genetic counseling & building awareness in local community.⁸ So if proper awareness to the general population is created another feather will be added in to the current controlling program. No doubt creating awareness in tribal areas or people is a tough task for the government. Government needs support from other external healthcare supportive system to involve voluntarily in such activities to control efficiently and that's why the current review is done to spread awareness in peoples mind that anybody can help government in supporting and creating awareness.

How we can create awareness?

In recent times we know that it is not so difficult to encourage people to accept a new practice because the psychological perception of population is changing. Various systematic efforts through social, political, technological or psychological way can be implemented to bring such new practice. One such good example through political variable is Swachata Abhiyaan. Every person has perception which guides action. Many villages and population and community do not have a link between health and current sanitary practices and therefore there is no reason to modify such practices. If general population start supporting in spreading awareness in tribal areas it will help in improving the overall health related outcomes.

How can create awareness with impact?

To develop faith in a concept and topic attention must be generated. The film stars are the best way to reach to the people and create such faith and awareness. Superstar Amitabh Bachchan can create awareness on Polio and super star Mr Amir Khan can create awareness on Kuposhan and Vidya balan can explain importance of clean sanitation. So in same way if a superstar who is star Mr Amir Khan can create awareness on Kuposhan and Vidya balan can explain importance of clean sanitation. So in same way if a superstar who is involved in such a noble cause and who is having a huge fan following can be an ideal choice to create awareness even across the country in general population which is the prime importance. So currently the star doing such noble deeds for human beings is only being human Mr. Salman Khan, the one who always supports the needy people.

How media can reach to the population:

Support from the local newspaper and news channels can be most helpful in creating such kind of awareness on a regular basis for creating awareness in general tribal population. To aware pharmaceutical professionals online journals are the good choice for creating awareness into them so they can utilize it to spread awareness to others.

How to utilize industrial resources for creating awareness:

Small scale industries like sugar factory where the major tribal population are in daily contact can arrange a awareness stall and posters for supportive initiatives to the government. Companies like which supplies milk can add a tagline on awareness on its milk bag as a supportive initiative to the government for at least once in a month. Local and most selling brand like wafers and general good selling companies also can be a good support in such kind of initiative. Various stationary manufacturing companies can arrange poster

making competition to promote awareness in school going children.

How non-government organization can help:

The non government organization can arrange a awareness camp and start a campaign to create awareness in various communities on a regular basis and in various areas like school and colleges and gram panchayat or government offices where people get more access to such program.

Who can be the target of sample for creating awareness?

India is mainly relying on its youth and higher secondary school students and teachers are the best choice as they are going to be the future of our country. Proper education and awareness into them can guide them in a proper direction. Because everyone knows that the teen age is the perfect age to absorb any message and we can mould any students towards a proper direction because they have good grasping capacity in teen age.

Who can create awareness?

Community pharmacist is the best one to do such kind of education and awareness related activities. Because community pharmacist is the link between the public and health care sector so he/she can guide the population very well about the disease and its complications. Blood bank and pharmacist working at primary health care center can also aware the population but it will increase the burden on their overall responsibility.

Why Aware 3 group: Aware3 group is designed by the research scholar and providing platform to perform essential role as pharmacist in local community. The mission of group is to spread awareness chain & achieve healthy India by 2020. The vision is very clear 'healthy India can make wealthy India'. As we know day by day the quality of life by the population is decreases and prevalence of number of new disease are increasing. Like swine flu and Ebola which was studied by students only in textbook are now striking in various states of the India. Health care sector needs to be emphasizing on control program which doesn't require more funding. Proper implementation of ideas and concept into the field of community pharmacy with a stand-up responsibility by every pharmacy colleges and students can add a great improvement in health department. If every pharmacist once tries to aware community about health it will be a great help to the society. The aware 3 program concept inspired from Swami Vivekananda Slogan Awake arise and do not stop till you reach the goal with a group of 26 students initiated to spread

awareness in community on various disease and its causes and symptoms and management and inform about government facility available for it. Till date this group had started spreading awareness in community on various disease and its causes and symptoms and management and inform about government facility available for it. Till date this group had started spreading awareness on various parasitic diseases like malaria, dengue, Leptospirosis, Chikunguniya and current prevailing disease like Ebola and Swine flu. Other common youth problem like Acne and old age problem like joint disorder and importance of calcium in old age is also covered. The program also achieved support from hospital in studying drug prescribing pattern in diabetes and hypertension. All the work carried out is already published in international journal of pharmaceutical science and bio-scientific research for providing platform to the students and to mention the importance of awareness to the social world. Since last fifteen years Indian pharmaceutical industries expand lot in terms of turnover but in terms of new molecular research still we are far behind than other countries. India became the hub for the clinical trials few years before may be because we have number of patients who ready to participate in trials for the money. Now the time comes when even clinical trials are shifting to china may be the population is the reason. Investing millions of rupees in research needs an output at some point of time so the aware3 program initiated with a vision to healthy India to become wealthy India. If continues awareness at village level with door to door communication spread on regular bases it will impact on vision and belief of the population at one day. If proper support and platform provided to this program it can become the national initiatives for the better development of healthcare system in India.

Current status on awareness on sickle cell anaemia:

Various researches was done on assessing knowledge, attitude and behaviour of youth on sickle cell anemia in African and American countries but in India very few studies were carried out but that too not in general population. Blood samples were collected and the involved participants were generally aware.^{9,10} So if the population at risk, tribal population especially the youth at starting age if being aware on regular basis might be the better option for future of better sickle cell control program in India. The community pharmacist at graduation level if enforce to in such kind of activities it will great help to the healthcare department and the education system too. In such activities government should encourage the graduation level community pharmacist and provide open galaxy to explore their creativeness to help government in developing healthy India. Such kind of activities are still lacking

or not yet implemented in tribal areas so Aware3 program the initial pilot program will provide a example to the government and healthcare department through creating awareness in higher secondary school students on sickle cell anemia in valsad district.

What future prospective of such initiative:

- The current awareness study will be beneficial to the government to have a database on a micro level for valsad district about the current status of the awareness of the youth about the disease.
- The study will help government to implement the same program in their control program so the screening program can become more efficient and effective and at least people remain aware about the screening reason.
- This kind of program will be also helpful to assess the awareness of existing and prevailing conditions in rural area of Valsad district.
- The program helps in development of rural youth development.
- Awareness study may create attention from the other non profitable organization and media and may able to get more attention which will be helpful.
- The importance of pharmacist in health education may justify the importance in creating awareness and may be utilize it on a large scale.
- May be government implement a session of education on sickle cell anemia awareness in their upcoming education schedule.
- This current aware3 concept may become sparkling event in this fight against sickle cell anemia program for the nation.
- If all goes well all the non profitable organization and industries will start participating in such initiative for the better healthcare and healthy India.
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