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THE MYCETOMA RESEARCH CENTRE, UNIVERSITY OF KHARTOUM, SUDAN: A SUCCESS STORY THAT NEED SUPPORT

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Background

Mycetoma is a common health problem in many tropical and subtropical regions. Yet and despite its devastating deformities, disability, high morbidity and negative socioeconomic impacts, it is one of the most neglected diseases worldwide and it is even neglected by the neglected diseases initiatives across the globe (Fahal and Hassan, 1992; Fahal, 2004; Fahal and van de Sandy, 2012; Fahal; 2010).



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Figure 1: Massive Foot Mycetoma

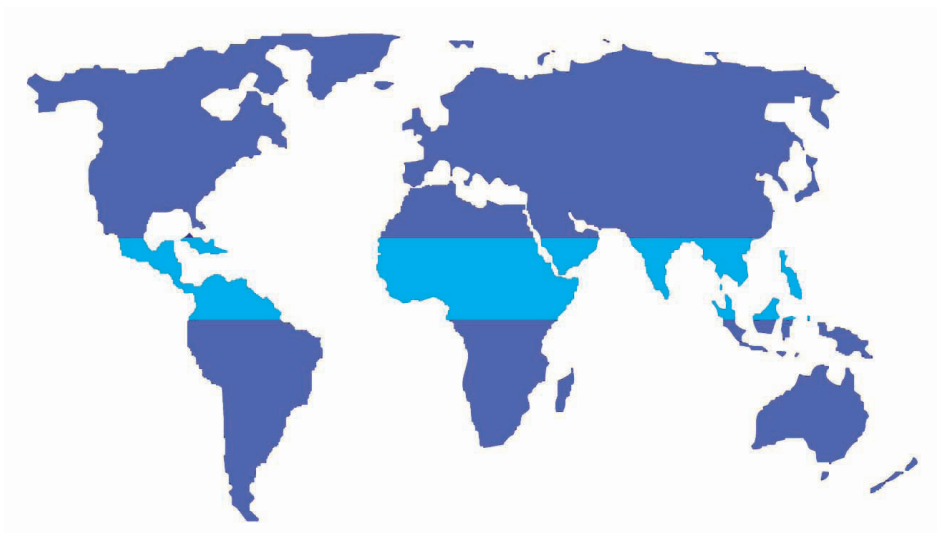


Figure 2: World distribution of Mycetoma
across the Mycetoma Belt

To date the disease incidence, prevalence and route of infection are not well characterized, likewise, its susceptibility, resistance and response to medical treatment (Fahal et al, 2011; Zein et al, 2012). This has been reflected on the available treatment modalities which proved to be ineffective, have many serious side effects and are not cost effective for patients and health authorities in endemic areas. Therefore this knowledge gap has significantly and adversely affected patient management and proper planning for mycetoma preventative measures. To bridge this serious gap the Mycetoma Research Centre was established in the nineties of the last century.

THE MYCETOMA RESEARCH CENTRE

The Mycetoma Research Centre (MRC) was established in 1991 under the auspices of the University of Khartoum, based at Soba University Hospital to provide an integrated high quality medical care, structured education and training and to conduct research in the various aspects of mycetoma. In addition, exceptional community development activities were planned.

The MRC is one of its kind worldwide to holistically deal with mycetoma patients and has enriched the medical literature. It is globally recognized as a world leader and an authoritative advisor in mycetoma management and research.

MRC VISION & MISSION

The MRC is dedicated to the continuous discovery and development of scientific knowledge and clinical skills pertained to the care of mycetoma patients. The MRC mission is to eradicate mycetoma, a life-mutilating disease, through the advancement of medical care, research, education and community development.

THE MRC JUSTIFICATIONS

There are many justifications for the MRC. Mycetoma is a common health problem; it is endemic in many tropical and subtropical regions and is also sporadically reported throughout the globe. Sadly Mycetoma receives meager attention by the medical, health and social communities across the globe resulting in a suboptimal care, as it is not a glamorous disease. In addition mycetoma patients are usually young active individuals of low socio-economic classes and thus call for a special care and support. All these facts justify the MRC establishment and its continuity.

MRS OBJECTIVES

The MRC has formulated clear objectives in providing an excellent holistic approach to patient care, conduct outstanding research, offer energetic and effective programme of teaching and education and deliver effective community development activities.

Early patients' recruitment for early treatment, objective health education, and sympathetic social and financial supports helped in reducing the burden of the disease. Attraction of national and international support for basic, clinical and epidemiological research and ignite donors' interest, drug supply and capacity building is also another objective.

MRC COMMITTEES

The MRC has four committees to plan and monitor the center activities and these are the Scientific, the Research, the Education & Continuing Professional Development and the Community Development Committees.

MRC STAFF

The MRC staff members are of medical, health and science backgrounds who are interested in all facets related to mycetoma. They have rich track records in patients' management, teaching, learning, research and community development activities. The center staff is committed to explore new patients' management approaches through evidence based clinical and basic research.

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MYCETOMA RESEARCH CENTRE ACTIVITIES:

Patients Management

MRC has a good track record of providing exceptional care for the mycetoma patients by putting the welfare of patients first. The medical care at MRC is one of continuous change and challenge.

MRC has achieved numerous national and international recognitions and it is a renowned worldwide as a referral center for mycetoma. More than 6200 patients with mycetoma are registered in the center. Most of them are young patients of low socio-economic status and most of them are unemployed due to illness. Lack of health education and poverty are the main causes of their late presentation with advanced disease, deformity and disability. The patients are from the Sudan and overseas including Ethiopia, Somalia, Yemen, Saudi Arabia, Chad, Bangladesh, India, Kenya and USA.

MRC has managed through the support of few donors to provide drugs to poor patients. All patients had free medical consultation at the center and some of them had free surgical treatment at Soba University Hospital.

THE MYCETOMA CLINIC

These patients are seen regularly at the Mycetoma Clinic of the MRC. They are managed according to established guidelines produced by an expert MRC panel of clinicians based on sound and valid research results (Fahal, 2001). The clinical services are provided by a group of well-trained clinicians, pathologists, microbiologists, radiologists and expert team of nurses and social workers. Health education sessions, organized by health workers, are conducted regularly at the clinic.

Patients' counseling is provided by the MRC social workers. The number of patients seen in the Mycetoma Clinic in 2012 was 6789 patients.

NEW DIAGNOSTIC TOOLS FOR MYCETOMA DIAGNOSIS

MRC has developed for the first time many new diagnostic tools and techniques for accurate, sensitive and safe diagnosis of mycetoma that included: Fine Needle Aspiration for Cytology and cell block technique, Ultrasonic and Magnetic Resonance Imaging as well as Molecular Identification of mycetoma causative organisms (Fahal et al, 1997; Yousif, Fahal and Yahia, 2010; Ahmed et al, 1999; EL Shamy, 2012).

PATIENTS HEALTH EDUCATION

The MRC has produced many leaflets and booklets providing information on many of the important issues related to patients' management and care. MRC in collaboration with many Non-governmental organisations has also produced many CDs, video films, booklets and posters on mycetoma for public health education. The problem of mycetoma was presented several times to the public through the Sudan National and Khartoum State TV, Sudan Broadcast and the local press. The MRC has educational websites at www.mycetoma.edu.sd. & <http://mycetoma.uofk.edu/>. They has helped in raising the public awareness on the serious complications of mycetoma.

COMMUNITY DEVELOPMENT ACTIVITIES

Many patients tend to present late with advanced disease where amputation of the affected part may be the only possible treatment. Most of these patients are from under-developed communities where the local community hygiene is extremely miserable and disheartening and hence one of the important MRC objectives is to develop the mycetoma endemic areas local communities.

To execute this, staff members have conducted many field trips to various mycetoma endemic areas. In these areas, out-patient clinics were established, house to house surveys were conducted and patients were encourage to attend these clinics. Patients were treated and complicated cases where referred to MRC or nearby general hospitals for further treatment.

Funds were raised by the MRC in collaboration with many NGOs and drug companies to establish in one endemic village, a small surgical theatre and surgical staff from Soba University Hospital were recruited to man the theatre and performed many surgical operations in the village and the nearby villages. This has dramatically reduced the patients' treatment travel journey and accommodation cost.

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The center had established the Mycetoma Patients Support Society and The Mycetoma Research Center Foundation aiming at the patients' financial, social and medical supports. The MRC has signed many agreements with numerous Funding bodies to cover the poor patients' medical insurance.

MEDICAL & PARAMEDICAL STAFF TRAINING

The MRC has trained a core of medical, nursing and health personnel from different part of the country in various medical, health and nursing aspects of mycetoma and now they are the change leaders in the management of mycetoma patients.

RESEARCH ACTIVITIES & PUBLICATIONS:

The heart of MRC mission and objectives is to improve the patient health through state of the art scientific research results. To achieve this, the MRC conducted many scientific research projects across the biomedical spectrum, from fundamental basic science and experimental to clinical trials and field survey. That was conducted locally and in collaboration with many highly reputable international centers mostly in the Netherlands and United Kingdom.

MRC gives a high priority to research that is likely to make a real difference to clinical practice and the health care of mycetoma patients. MRC is committed to produce skilled researchers and to advance and disseminate knowledge and technology to improve the life quality of the mycetoma patients and humanity in general.

MRC has published over 70 original articles in exceptionally distinguished journals and textbooks. A guideline for patients' treatment was also produced. The MRC publications have notably contributed to the world literature. MRC is currently conducting several research

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projects addressing different mycetoma problems by different research groups locally and in collaboration with different international centers and institutes (Fahal, 2013 and Fahal, 2006).

INTERNATIONAL COLLABORATION

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The MRC has collaborated with many highly reputable international institutes and centers in the field of mycetoma and other endemic and tropical diseases. This has resulted in knowledge and experience exchange, technology transfer and the conduction of high esteem research and publications.

STUDENTS TEACHING & EDUCATION

The MRC staff is highly committed to provide enthused and inspired teaching for under-graduate and post-graduate students as well as continuing professional development for medical and health professionals.

MRC offers international students from different parts of the world especially from Europe the opportunity for teaching and training in the center. The MRC has students' corner at the center website where active learning opportunities are offered.

The center has created several online virtual mycetoma patients for teaching and learning and as part of the continuing professional development activities for medical health professionals.

Post-Graduate Training & Education & Career Development Programme:

The MRC provides research opportunities and training for graduate students for PhD and master degrees. MRC provides training & career development programme for young clinicians and biomedical scientists at every stage of their careers to improve their capacities' to plan and conduct sound and high-quality research.

MRC offers a comprehensive training programme on research governance, ethics and methods for MRC researchers and researchers nationwide, and continually assess the training needs of researchers and

update the training strategy accordingly. Many workshops and training courses are regularly conducted and includes research methodology, research ethics & good clinical practice, bio-statistic principles, scientific and proposal writing and literature search as well as different laboratory techniques

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SCIENTIFIC MEETINGS ORGANISATION & PRESENTATION

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The MRC has organised many international and local conferences, seminars and meetings in association with various bodies which aimed to act as a media for medical and health members and scientists who are interested in mycetoma to maintain contacts, to exchange and update knowledge and experience, to provide continuous medical education in mycetoma and also to provide advice and recommendations to the concerned authorities. To mention but few, the Third and Fifth International Conferences on Mycetoma were organized in the Sudan.

THE MYCETOMA RESEARCH CENTER FOUNDATION

The MRC has established a non for profit foundation as a registered charity aiming at promoting the treatment and care of affected patients, research and education in mycetoma.

The Foundation office is responsible for the day-to-day management of MRC Foundation funds and fund raising. The Foundation welcomes the support of private individuals, companies and charitable trusts.

SUDANESE TRADITIONAL MEDICINE MUSEUM

To preserve the Sudanese medical heritage, The MRC had established a Sudanese Traditional Medicine Museum at the center where a number of items used in treating different diseases and mycetoma in particular in the Sudan were collected and displaced.

THE MYCETOMA NATIONAL PROGRAMME

The National Mycetoma Control Program (NMCP) was recently established. It is a service integrated program which is a joint venture between the National Ministry of Health & Mycetoma Research Centre, University of Khartoum.

Its aim is to eradicate the Mycetoma from Sudan through the provision of high quality treatment and averting disease complications. To achieve this goal, the program focus on improvement of Mycetoma patients treatment through provision of free treatment, capacity building of health providers in diagnosis and management of patients, provision of information about disease burden and impact of treatment to help in publishing and distribution of country's experience to the globe.

The program policy is focused around six strategies; and these are early diagnosis and management of patients to prevent disease complications and reduce the disease toll to the patients and program, training of health personnel to ensure adoption of the program guidelines and proper treatment of patients with competent teams, regular supervision to maintain good performance, problem solving and sharing of knowledge and experience, timely and regular supply of drugs to ensure patient access to care and avoid interruption of treatment, recording and reporting system to ensure flow of information about disease burden, appropriateness of used regimen and assessment of program performance to shape the appropriate strategies and increase the community awareness on the disease and its complications through adequate health education.

MEMORANDUMS OF UNDERSTANDING & AGREEMENTS

Due to scarcity of funds and budgets to execute the MRC objectives and activities, the center had signed many memorandums of understanding and agreements with many national and international bodies and associations for collaboration and partnership to promote the welfare of the mycetoma patients, to promote scientific research and community development.

CONCLUSIONS

The MRC is an important landmark in the care of mycetoma patients. It needs an enormous support and backing to continue. It is crucial that support is sought to combat the terrible human suffering caused by mycetoma. Mycetoma is a thorn in the human flesh and it is our duty to remove, it is a scar in the human conscious and all should work together to heal it.

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ABOUT THE AUTHOR

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Prof. Fahal trained in medicine at the University of Khartoum, Sudan. He then pursued his post-graduate surgical training in Khartoum and London leading to a consultant surgeon position at Soba University Hospital, Sudan. He is general surgeon with special interest and track record in endocrine, breast and tropical surgery. He is a high volume researcher in mycetoma, he has published and presented extensively in this area. Has is involved in collaborative research work in mycetoma with many national and international institutes. He is the founding Director of the Mycetoma Research Centre, University of Khartoum and Mycetoma Control Programme, Ministry of Health, Sudan. He has served as the Director of Educational Development Centre for Medical & Health Professionals, University of Khartoum. He was the Founding Director of the Self Evaluation and Quality Enhancement Administration, University of Khartoum and the University of Khartoum Academic Secretary. He sits on various curricula, research ethics, accreditations and administrative committees at national and regional levels. In medical education, he is actively involved in teaching and organizing workshops, training courses and conferences for medical and health professionals in the Sudan and the region. He has special interest in E-Learning, medical informatics and teaching and learning innovation. He is a WHO consultant in Medical Education. He published more than 130 peer-reviewed articles and edited a book on mycetoma and many textbooks' chapters, booklets and clinical guidelines in a number of themes in surgery, mycetoma and medical education. He is a board member and reviewer for many national and regional scientific journals. He is a member of many national, regional and international academic and scientific associations and societies. Prof. Fahal has strong commitment to research, training and education. He is actively involved in the teaching and research supervision of undergraduates and postgraduates. He is an external examiner in surgery for many national and regional medical schools. Prof. Fahal received several awards and medals, to mention but few, the State of the Sudan Golden Medal for Excellence and the Promotion of Scientific Innovation in Medicine in 2000. He was also awarded the fellowship of the Royal College of Physicians, London for his distinctive achievements in medical education, teaching and scientific research.



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Figure 3: Mycetoma Research Centre, Khartoum, Sudan



Figure 4: Research Laboratory in the MRC



Figure 5: Field trip to an endemic village for patients care and community health education