

OROFACIAL CLEFTS RESEARCH IN AFRICA: CHALLENGES AND POSSIBILITIES

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INTRODUCTION

“The people of Africa carry an enormous and disproportionate burden of ill health and premature death. The health of the people of Africa must therefore be the key indicator of the performance of WHO” (Dr Margaret Chan, WHO Director-General Elect in 2006). This statement underscores the need to address health inequality, quality of care and prevention of disease most importantly in Africa where all these variables are presently below set standards.

Orofacial clefts and the Global Burden of Disease

An important approach towards improved health in the world especially in deprived regions like sub-Saharan Africa is through the WHO Global Burden of Disease project (GBD). The GBD collects and compares health data from across the globe in order to describe health problems, identify trends and help decision-makers set priorities. Through this project, the health needs can be estimated based on information obtained and policies will then be formulated according to geographical needs. Birth defects including orofacial clefts have been identified as the most common cause of neonatal death (ICBDDW Beijing,, 2005), but this is not so in Nigeria and most parts of sub-Saharan Africa. Mortality due to birth defects, genetic and congenital conditions accounted for an increasing proportion of infant mortality (30-50% of perinatal deaths and 20-30 % of infant mortality). In 2005, craniofacial anomalies including cleft lip and palate was included amongst list of birth defects being addressed by the WHO and in 2009 it was included in the GBD project.

In sub-Saharan Africa, however, there is still a high prevalence of communicable diseases (70%), particularly AIDS. HIV / AIDS, malaria and TB and these are significant priorities in most Africa countries being responsible for the high rate of infant mortality in Africa which has been reported to be eight times that of developed countries (Population Reference Bureau, 2001). As a result little or no attention has been given to orofacial clefts and other birth defects and the standard of care in most sub-Saharan African countries apart from South Africa is poor and the infrastructure available to support care are either non-existent or in a deplorable state. This has made the prevention and control of disease very difficult and limited the attention of the health ministries and agencies to focus on them.

Birth Defects Registration

Orofacial clefts (OFC) are the most frequent congenital malformations of the head and neck with a reported prevalence rate of 1/1000 births (Mossey and Little, 2002). The causes of OFC are heterogenous regarding the genetic and environmental factors that interplay. In Africa, the gene pool is unique compared to other ethnic groups, the exposure and response to environmental factors may also be different leading to a unique disease profile for OFC. Various prevalence rates have been reported for OFC from individual studies without a systematic way of obtaining data on births including OFC. These means there is either no ascertainment in most part or there is under ascertainment (Butali and Mossey, 2009)

Research in Sub Saharan Africa

There is paucity of literature relating directly to research limitations in Africa. In 2003, the possibilities and limitations relating to research in Africa was highlighted by Jaffe in one of his articles on the research and limitations “Yes, it is possible to do science in Africa, but it is not that easy” (Jaffe, 2003). The difficulties encountered in research conducted in Africa are similar to those observed in developing countries around the world. In addition, cultural, economic and socio-political factors in Africa may play an additional role in attitudes and perception of people to research.

Selman et al. (1998) reported that the problems with biomedical and health care research in developing countries are complex, interrelated and often poorly understood. They identified lack of research education and training for health professionals; absence of value for health care research as an important tool for progress; shortage of funding and research resources; special bioethical standards and concerns; limited access to health informatics; and individualism and lack of team approach as some of the problems. Abu Zidan et al (2005) identified the

lack of collaboration between individual biomedical scientists and academic health units as another reason for difficulties encountered in research.

Nigeriacran

In Nigeria a project on craniofacial anomalies (Nigeriacran) was established in 2006 to investigate the genetic and environmental causes of clefts , A number of difficulties arose in the course of the research including a lack of priority given to birth defects by the authorities; difficulty in ascertainment since studies were limited to hospitals, tendency for a large number of births taken at home and in rural areas, poor dissemination of information, and limited expertise for genetic research regarding birth defects. Despite these obstacles, the research project was successfully completed and the infrastructure for future studies established.

Butali and Mossey (2009) concluded after their experience with Eurocran that problem with ascertainment can be improved by establishing birth defects registries through collaboration amongst various stakeholders involved with cleft care in Africa. Abu Zidan et al (2005) suggested that an improvement in education and training of health professionals and promotion of societal appreciation of the value of research as an important tool for progress. This also requires funding and provision of research resources; increasing health care researchers' awareness of their social, altruistic mission and need to adopt strict ethical guidelines in collaborative research protocols. Access to biomedical knowledge and information; and encouraging a paradigm shift in the prevailing research culture towards more positive collaboration are also necessary to enhance research potential.

Future research potential

In 2002, the WHO reported little or no research in OFC in sub Saharan Africa and identified South Africa as the only country with a birth defects registry in sub-Saharan Africa. These reports have led to the establishment of the Pan African Cleft Lip and Palate Society (PACCLIP) and development of research collaborations in some African countries co-ordinated by the WHO collaborating centre in Dundee. The Nigeriacran project which started in 2006 is an example of a research project established to develop infrastructure, improve expertise and stimulate research amongst cleft carers, in order to improve ascertainment through birth defects registration and provide an example of research into the aetiology and possible avenues for prevention of a birth defect, orofacial clefting. The authors conclude that possibilities for research in Africa are enormous and only domestic research will provide solutions to the domestic health problems.

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