

## The Current Status of Research Bioethics in Pakistan

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The Islamic Republic of Pakistan is a developing country and has a population of more than 171 million people [1], although it has some large cities such as Karachi, Lahore, Peshawar and Quetta but almost 65% of the population is still living in rural areas, with a per capita income of \$ 408 per year. The overall literacy rate is estimated to be 41.5% but is much lower for women particularly in small of the provinces [1,2]. Majority of the population take advantage of the free healthcare facility provided by the government in the public sector hospitals and health care units due to low income, but these facilities are generally short-staffed, congested, overburden and incompetent which cannot meet the requirements of the people visiting these facilities however due to poverty and lack of national health coverage and health insurance schemes, a huge section of the population is deprived to have even access to any healthcare facility [3,4]. According to economic Survey 2009-2010, in Pakistan, Government has allocated only 2.0 per cent for the education which is very less in comparison with the other South Asian countries rather one of the lowest in the developing countries. 65 percent of enrolled students attend the public sector schools where education supposed to be free or less expensive. The quality of education in the public sector schools is usually very poor. The well privileged or those who can afford, go to the private sector schools where most of the cases quality education is provided but usually very expensive and beyond the reach of the masses, however education in low fee private sector schools is also not satisfactory [5]. Another segment of society who usually cannot afford to go to school usually go the Madrasas (institutions where usually religious education is provided) where they get free boarding and lodging along with education. Still not all children in Pakistan are in school and yet another majority of the children who don't go or cannot afford to go to any of the institutions rather they are on the streets or support their family by earning in different vocational palaces. According to the Pakistan Labor Force Survey (2007-2008), there are over 21 million children between 10 to 14 years of age out of which 2.68 million are employed [6]. There are too many local issues and problems including terrorism, poverty, joblessness and tension on the eastern and western borders, political and economical instability in the country. All these and other problems put the important sectors like education and health comparative in less priority and the government invests very less in these areas rather spends more in defense and to control the law and order situation in the country. Due to very less investment in education particularly in higher education and science the research bioethics seems to be luxury and no one speaks about this rather most of the time the politicians and the policy makers and even masses talk about the availability of basic needs and necessities. Bioethics or ethics in research is usually not thought as a separate subject at college or at university level, due which there is very less awareness and practices among the researches and professionals. Research is mandatory element to define success of a nation. The most challenging task is maintenance of highest ethical standards in research. Research on human subjects is very challenging in developed & under developed countries [7]. People are less willing to participate in research subjects unless well compensated in developed countries, this made research very expensive compared to developing countries. So the pool of

research is diverted towards developing countries but unfortunately outcome of the action has raised serious concerns to ensure the rights & ethical issues being well protected [8]. The primary aim of this paper is to report the current status of bioethics in Pakistan and try to propose guidelines to help to resolve controversial issues in a practical way that would lead to both scientific and ethical progress in research in the country. Issues administered during bioethics research unethical application of science & modern medical technologies, collusion of health professionals, the physician pharma nexus quiet an unholy alliance, international organ trade & transplantation. Finally, we will look at the need to implement guidelines in structural policy changes. The history of bioethics in Pakistan is a rather short one though in our country, there is a need for a major capacity building exercise in Bioethics and Research Bioethics. In Pakistan it is primarily members of the medical community, many trained in Western institutions, who take the lead in introducing modern bioethics into the country. The first proper move in this direction occurred in 1984 at the Aga Khan University (AKU) in Karachi, where biomedical ethics was introduced in the curriculum of medical students at AKU by the Chairman of the Department of Community Health Sciences and later extended into the courses of the University's School of Nursing. In Pakistan as other developing countries, there has been a great demand for research-ethics related programs. In 2001, the Pakistan Medical and Dental Council (PMDC), the certifying body for all graduating physicians and dentists, stipulated that biomedical ethics must be included in the medical curricula. However, this is still not the case in most of the country's research institutions, medical colleges, universities and many still limit themselves to a few informative lectures on the subject during rotation of students through community health sciences. In January 2004 the Pakistani government approved the formation of the National Bioethics Committee with 20-21 members chaired by the Director General of Health at the Ministry of Health. Whereas the Centre of Biomedical Ethics and Culture (CBEC) is the first such Centre in Pakistan established in 2004 in SIUT (Sindh Institute of Urology and Transplantation) which conducts Master courses in Bioethics and plays its role to promote bioethical education, research and training in Pakistan [9].

To date the AKU Hospital is the only institution with a formal ethics consultation service, which is one of the functions of its Hospital Ethics Committee (HEC), initiated in 2000 [10]. The Eastern Mediterranean Regional Organization (EMRO) of WHO has also

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shown its interest to strengthening research ethics and funding situation of research capacity for the country. Although most research proposals with bioethical implications endure ethical review in major research and medical institutions, but guidelines in daily research is not comparable with international standards. Controversies over proposed revisions to the Helsinki Declaration, the leading internationally accepted guidelines for research ethics, encouraged renewed interest in the ethics of research in low income countries [11]. Local researchers trained within the country have very limited concept of research ethics. The main problem is that scientists and medical staff are not properly trained, not only in terms of understanding the ethical principles related to their research work and also (especially for medical staff) in communication with patients. Bioethics is not taught to undergraduate students in government colleges and universities that educate the majority of students in the country and in many of the private research centers. Therefore, it is a difficult or almost impossible task to guarantee that patients understand all the relevant details of their treatment or the research in a meeting with medical staff or researchers. In addition, this is due to cultural and religious problems in Pakistan, which make it complicated to explain and discuss sensitive topics openly with particularly female patients; in fact, this is often more easily communicated to their family. Most physicians in the majority of hospitals and medical staff outside main cities and in rural regions do not have sufficient background knowledge and education to inform their subjects properly. In rural areas, medical treatment is often carried out by people who have little or no qualifications, such as local public health workers and quacks. Another major problem is corruption in the country, which ignore even the most basic of patients' rights. One can therefore safely conclude that the daily practice in most Pakistani research and medical institutions is not in accordance with basic ethical principles and existing bioethical regulations. Human resource with proper training, certification & knowledge to conduct high quality research is deficient. It will require substantial efforts to train scientific and medical personnel at all levels to ensure that they adhere to internationally recognized standards when dealing with patients or research subjects. WHO is one of such type of platform where the scientists can address issues that require global agreements, while ethics should be a core responsibility of WHO especially when we make international health and research policies [12]. The WHO Country Representative Offices should be more active. They should actively involve themselves with research institutions like WHO can help to promote collaboration between Pakistani institutions and institutions abroad especially those in the developed countries. Collaborative research is only way to build up research skills, acquire funds and produce good information which will be more useful relevant for the local scientists. Thus, the government needs to formulate clear policies, laws, rules and regulations through open debates, although the formation of the Global Forum for Bioethics in Research could be the key factor in this direction, it needs to develop further and include all component and legislative body from developing countries. In addition, it is inspiring to see the first moves towards understanding the religious and cultural ethical issues in many developing countries [13].

The following recommendations might be useful for enhancing the level of awareness among the university students, faculty and scientists:

\* Awareness needs to be created at all levels, however, university students, faculty and researchers are actual or potential opinion leaders, therefore they need to be well aware of the promising technologies and their ethical issues.

\* Cooperation between entities from developed & developing countries is the step forward but should be conducted in a manner that is ethical & drives on the strengths of all stakeholders & results in mutual benefit for everyone involved.

\* There must be an oath for the researcher and professional that they will abide the international rules and regulation and will follow the ethic code of conduct and will not be involved in unlawful activities.

\* Bioethics research should be collaborative, ethically sound & mutually supportive. It should protect human subjects & they should be sufficiently compensated for their participation.

\* Bioethical issues should be openly discussed through Seminars, Conferences and Workshops etc, that will convince interaction between experts, researchers, students and policy makers etc.

\* Curricula of educational institutions including Universities, colleges and schools should include advanced or introductory courses on bioethics.

\* The government should know their responsibilities and should provide the necessary legal and regulatory framework for dealing with bioethical issues and concerns.

\* Religious scholars should be consulted for their opinion while formulating laws concerning bioethical issues.

\* Inventories are required to infuse in framework development & support in developing countries.

Bioethics is very important global and local issue and there is a high need to take actions at right time, all the scientists and professionals of the country should be taken into in to confidence to set a centralized body at country level which will ensure the implementation of its own and internationally set standers.

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