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Editorial

Social and behavioural research: tool for intensifying fight against AIDS in India

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The Millennium Development Goals (MDGs) adopted by world leaders in the year 2000 are aimed by 2015. The MDG-6 to combat HIV/AIDS and other diseases becomes very pertinent for HIV/AIDS research as it creates an evidence base that contributes to policy planning, implementation and advocacy for HIV/AIDS prevention, treatment, care and support. The MDGs are addressed both globally and are locally tailored by each country to suit their specific development needs (1). The HIV/ AIDS epidemic even in early eighties was beginning to be considered as much a social problem as a medical problem, thereby social aspects becoming an integral part of the biomedical research. However, Mann in 1987 identified three phases of the epidemic, that of AIDS, the second of HIV infection and the third phase related to social and behavioural impact it had on individuals, community and society at large; with the three running almost together, although identified in succession in the initial stage of the epidemic (2).

More studies have focussed on the epidemic of HIV and of AIDS in the first two decades and only in the late nineties few studies on the third epidemic have been taken up e.g. the studies on sexuality, economic impact and stigma (3,4).

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Thereby, a need to focus on the social and behavioural aspects of HIV/AIDS research becomes critical, much more so in traditional communities and in communities that have limited access to resources. However it is important to emphasize that in both sexual and vertical transmission, the major focus for prevention interventions are related to very basic human instincts that are socially governed. Evidence based research through HIV surveillance along with research insights in the studied group can help in sustainable prevention interventions to contribute to holistic development (3-5).

Globally, since the beginning of the epidemic, almost 60 million people have been infected with HIV and 25 million have died of HIV-related causes (6). In India, more accurate and better data from National Family Household Survey conducted in 2005-2006 and Integrated Behavioural and Biological Assessment surveys in India led to a major revision of the prevalence estimate in July 2007 (7). It is now estimated that around 2.4 million people in India are living with HIV. Of these, an estimated 39.3 percent are women and 3.5 percent are children (7-10). The current data indicates that the new infections have halved over last one decade, however, in some risk groups and geographical regions the epidemic still shows upward trend (7).

The interplay between interventions and healthy behaviour changes such as risk reduction, safer behaviours and long-term issues related to overall development is critical. Indeed, all these have to be done in the overall human rights framework. More evidences are required to better understand HIV/AIDS from these broader social and behavioural issues in the context of human development and developing theories. Such

developments and insights of the interplay could contribute to better planning, development of effective interventions and their implementation to achieve MGD-6. This special volume on social and behaviour aspects of HIV/AIDS research has been an endeavour to bring evidence from India, a country with second highest number of people living with HIV/AIDS (PLHAs). Ten papers are presented on varied aspects of HIV/AIDS research in this volume. Efforts to reduce the HIV/AIDS burden are a national priority. The compilation of research evidences and discussions that will stem from this special volume should help in giving directions to plan future studies that aim to combat HIV/AIDS by 2015 as envisaged in the Millennium Development Goals.

The National AIDS Control Organization (NACO) is a national body responsible for control of HIV epidemic in the country. NACO has established a framework to provide the services of prevention, treatment, care and surveillance through a network in each state of integrated counselling and testing centres (ICTCs), anti-retroviral therapy (ART) Centres, Community Care Centres (CCCs) and targeted interventions (TIs) operated through non-governmental organizations (NGOs) and community based organizations (CBOs) (10). In this volume Sogarwal, Bachani, and Venkatesh using NACO's sentinel surveillance data from 2004 through 2008 describe the current status of the HIV/AIDS epidemic among adults in India and highlighted success of NACP III in combating the HIV epidemic. Indeed the paper reflects a comprehensive, evidence based planning and implementation of NACP III focusing on prevention, care and treatment.

The prevention efforts under national AIDS control program (NACP) were supplemented significantly by Bill and Melinda Gates Foundation (BMGF) sponsored *'Avahan India AIDS Initiative'*, a programme implemented in six high prevalent states among the high risk populations. BMGF also instituted a project to monitor the major impact of Avahan programme through the Integrated Behavioural and Biological Assessment referred as IBBA (11). The first large-scale probability sample survey in India that included both behavioral and biological indicators among populations most at risk of HIV transmission in six endemic states of India and among four segments of the National Highways was led by National AIDS Research Institute (11). The methodological challenges in data collection for social and behavioural areas experienced by the research team during the implementation of the survey is the focus of Subramanian, Ramakrishna and Paranjape's paper that includes identification of target groups, sampling, harm reduction, feedback from community, maintenance of quality control and related operational issues.

HIV transmission in India is largely through heterosexual contact. The low socio-economic status of young and old women compounded by their lack of control on sexuality continues to be a major barrier for prevention efforts (3,4,8,9). The adolescents on the threshold of active sexual life remain vulnerable to HIV infection in the absence of appropriate guidance and information as they are more likely to experiment putting themselves to risk (3,4). They are also less likely to have information on the risks of contracting HIV and means of protecting themselves from the infection (3). HIV/AIDS prevention strategies in youth are urgently needed through a focus on health education, behavioural change communication (BCC), and ensuring safe sex practices. The government needs to respond to the desire for formal sex and sexuality education in context of HIV/AIDS through peer education, an effective and culturally appropriate way to disseminate comprehensive information in young population (3,4). In this volume in a review article of the current trend of premarital sexual behaviour among youth in India, Joshi and Chauhan emphasize that programs are needed to reduce the risk through friendly services and an enabling environment in the community. Access to health care and education to prevent unwanted health outcomes due to unsafe premarital sex is critical among young (3). This is shown in another paper based on study of rural college youth in Maharashtra, India, by Ghule and Donta who examine the relationship between knowledge and attitude towards reproductive health issues and sexual behaviour, underscoring the need for interventions through interactive discussions with rural youth on risky sexual behaviours, its prevention and reproductive health.

A wide variety of individual, interpersonal, social, and environmental factors may influence the risk of HIV infection (3,5). Individual factors that influence risk behavior may include age, self-esteem, age of sexual debut, self-efficacy to enact prevention behaviours, interpersonal factors including gender equity and female empowerment, partner status, and ability to

negotiate prevention with sexual partners (3,4). Social and environmental factors that influence risk behavior may include cultural and religious beliefs about sexuality and sexual behaviour, culturally proscribed gender norms, and marginalization of certain populations, such as at-risk youth, young widows, commercial sex workers, etc (3-5, 12-14).

Views expressed from program perspective in the article by Rajesh Gopal emphasize that HIV/AIDS is not a mere health issue: its occurrence is influenced by a number of socio-economic, cultural and ecological determinants where behaviour change communication can be effective instrument for the containment of HIV and AIDS. Studies reveal that HIV risk behaviors can be reduced in any targeted population through interventions that provide risk reduction counseling, assistance in problem solving and behaviour change, helping individuals to build the skills needed to reduce HIV risk (15). Mawar, Bagul, Sane et al in their study on Integrated Counseling and Testing Centre (ICTC) attendees demonstrate reduction in risk behaviour in men and women attending ongoing counseling at an ICTC during their regular follow-ups. The study shows that regular follow up visits provide a useful opportunity to reinforce behaviour change, like practice of safer behaviors through the dosage effect.

The availability of antiretroviral therapy (ART) has led to a dramatic decline in morbidity and mortality among HIV infected persons. With the rapid scale up of antiretroviral therapy in India both in the public and private sectors, more patients have benefited (10,16). It is estimated that about 1.72 lakh people died of AIDS related causes in 2009 in India. Wider access to ART has resulted in a decline of the number of people dying due to AIDS related causes. The trend of annual AIDS deaths is showing a steady decline since the roll out of free ART programme in India in 2004 (10). A study by Ajith, Neera and Rajani in South India in an ART clinic setting, describe the association of social factors highlighting the importance of family support and care givers in family that influence ART adherence in people living with HIV/AIDS (PLHAs).

The women's role within society and their greater biological vulnerability to HIV infection has exacerbated epidemic in a very different way (8,9,14). An understanding of the varied research studies on social and behavioural aspects needs to be assessed to plan focused research in future that can contribute to the millennium development goals. NACO's engagement with civil society and people living with and affected by HIV will prevent new infections and produce measurable impacts and protect people most affected (10). In their paper, Mukherjee & Das point that gender inequality is a critical factor fuelling the HIV epidemic in India and elsewhere in the world. While gender mainstreaming as a process finds mention in program plans and priorities, efforts to operationalize gender within HIV prevention programs have not been easy. They emphasize the need of gender sensitive indicators along with service delivery indicators to measure impact of program for reduction in structural vulnerability of women to HIV. Gender issue was an overarching principle for NACP III (10) and it is hoped that this continues to be reiterated with more rigor while planning the NACP IV as well.

The social and behavioral research could play a critical role in developing program delivery strategies keeping in mind social cultural realities for both HIV prevention and treatment. This insight is significant when any medical intervention like microbicide or a drug and vaccine is introduced in a community. While it is pertinent that studies on acceptability and adherence are important for implementation of new prevention methods i.e. applied research, it is equally important to understand the social and cultural environment where the product when available are intended to be used. Indeed it is an important area of enquiry where both social and medical scientist together could contribute significantly for the early and better acceptance of microbicide or vaccine in the community. This area of research, referred as basic research needs more priority to get community understanding and response of a product within the community (3,4).

Each of the behavioral and social science components plays a key role in HIV prevention research. When efficacious biomedical or behavioral products like microbicides or a vaccine are developed, their impact at a population level depends on people's access, acceptability, and use under real-world conditions. The interventions using these products would be influenced by existing social norms, values and social systems referred as structural determinants in epidemiological and bio-medical parlance. However, it is critical to look at '*practices*' rather than behaviours where the term practices convey the social dimension of the behaviours (17). Practical and socially induced behaviours are usually organized by culture. The significance for an intervention

using a product like microbicide within a cultural milieu has been underscored by Auerbach who differentiates the *"use"* and *"action"*. This is described further by her , *"use is a function of human behaviour and action is affected by an individual, interpersonal, social, and cultural factors that operate interactively in complex, dynamic and varied ways across settings"* (17) .

Studies are now being initiated in India to introduce a prevention product in the community and involving the community for HIV prevention research.

In their paper, Solomon, Morrow, Krishnan et al explore knowledge of HIV/STI risk behaviour and acceptability of microbicide by comparing the perceptions and behaviour in men and women with traditionally high-risk and low-risk behaviour; and emphasize that interventions are needed to improve perceptions of risk in order to promote use of prevention methods like microbicide and the ability of women to negotiate their use. Sexual and other behaviours related to HIV prevention are characterized by social norms (3,4). This is better understood by the involvement of the community from the formative stages of the clinical trials of new interventions. In their paper Sahay and Mehendale summarize processes and lessons learnt using formal partnerships with non-governmental and community based organizations for community involvement. They indicate that the community involvement is possible although is long, and an ever-evolving process that needs institutional support, adequate funding and commitment by researchers. It is important that such programs be developed in a way that they can remain to be sustainable.

The spectrum of activities described through these research papers highlight the directions needed for further research. It is imperative that increased funding for social and behavioural research on HIV/AIDS be made available to achieve the goal of MDG-6. In a recent review Nguyen et al advocated that research investments are required for operational and social scientific research to identify *"how drugs or vaccines will be most effectively used outside the laboratory and how best practices will be defined across different cultural contexts."* (18). This is a critical issue when it is known that HIV/ AIDS remain the leading threat to development affecting individuals, families and community. The evidence of ways in which social environments influence the disease transmission and its dynamics, and how socio-cultural, political and economic factors contribute to and are affected by the epidemic are now being initiated. However, it is critical to state that while major research investments for supporting the biomedical response to the crisis through the development of drugs, monitoring technologies, vaccines, and microbicides exist, same is not true for social science research. The solution lies with the research reviews being made valid through a *"true peer review"* process which according to Nguyen et al are by those with expertise in social sciences as well, *"rather than experts of bio-medical sciences alone reviewing it"* (18) .

The emphasis on social and behavioural research although now well recognized has often been used to support bio-medical research. While this support is indeed necessary, having its own independent identity to contribute to HIV/AIDS research needs to be strengthened through prioritizing, reviewing and funding social and behavioural science research. This way it would then contribute more effectively to both social scientists and bio-medical researchers' perspectives to enable concomitant interactions on still the unknown aspects of HIV/AIDS.

The research papers in this special issue are a window to the social and behavioural science research in the field of HIV and AIDS in India. They indicate the path the social and behavioural research should take for control of HIV and AIDS. However, a real success in terms of achieving MDG 6 can become reality when an integrated approach is taken for biomedical and socio-behavioural research on HIV and AIDS.

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