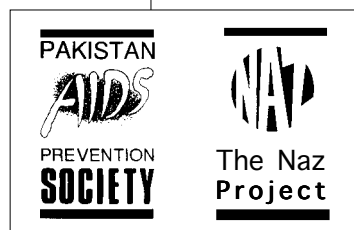


Developing Appropriate Strategies

Consultation Meeting Of Representatives From
Non-Governmental Organisations Working On HIV/AIDS
Prevention And Care Issues Within Muslim Communities

26th-29th October 1995, Karachi, Pakistan

Summary Report



Meeting co-organised by the Pakistan AIDS Prevention Society and The Naz Project

Sponsored by the WHO - Global Programme on AIDS

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The consultation meeting was organised to explore the specific needs of people living within Muslim countries and communities for accessible and appropriate HIV/AIDS prevention and care services, where Islamic values and beliefs play a strong cultural and social role and exert a considerable influence upon the nature and content of these services.

Representatives from non-governmental organisations working in the field of HIV/AIDS prevention and care in a range of Muslim countries and communities participated in a series of working groups to discuss and evaluate the personal, psycho-social, medical, political and religious impact of HIV/AIDS and the education, prevention, support and care services available within their countries/communities

Participants discussed the suitability and applicability of current HIV/AIDS programmes and services and the impact of cultural and religious values within Muslim countries and communities affecting such services. Issues explored included such of good practice, provision of appropriate HIV/AIDS education and prevention, behaviours leading to possible HIV/STD transmission, empowering communities to develop community-based AIDS service organisations and provision of appropriate care and support for people living with HIV/AIDS.

Identifying gaps and shortcomings in current service provision and exchanging visions of ideal standards and religious values, the participants developed a series of recommendations on good practice, appropriate education, prevention, treatment and care. These recommendations will guide government and non-governmental agencies in developing policies and practices in these areas.

Introduction

- Developing Appropriate Strategies** ■ A Consultation Meeting Of Representatives From Non-governmental Organisations Working On HIV/AIDS Prevention And Care Issues Within Muslim Countries and Communities, Karachi, Pakistan, 26th-29th October, 1995, was organised by the Naz Project and the Pakistan AIDS Prevention Society. The Consultation Meeting was sponsored by the Global AIDS Programme, World Health Organisation.
- Organisers** ■ Mr Shivananda Khan of the Naz Project and Mr Shouket Ali of the Pakistan AIDS Prevention Society formed the organising team for the consultation. Opening presentations were made by Mr Khan and Mr Ali as well as Dr Sharaf Ali Shah, Director of the AIDS Control Programme of the Government of Sindh, Pakistan. Closing remarks were made by Mr Khan, Mr Ali, Dr Sharaf Ali Shah, Dr. Birjees Masher Kazim, Programme Manager, National AIDS Control Programme of Pakistan, and the Chief Justice of Pakistan, His Excellency Sarjad Ali Shah.
- Participants** ■ 47 participants from Azerbaijan, Bangladesh, Egypt, Ethiopia, India, Indonesia, Malaysia, Morocco, Pakistan, Sudan, Tunisia, Turkey, as well as from Muslim communities in Canada, Germany, Norway, UK and USA, took part. They were selected in their capacity of working for community-based non-governmental HIV/AIDS organisations in providing education, prevention and/or support and care and with a view of including a broad representation from a range of Muslim countries and communities.
- Process** ■ The number of people affected by HIV and AIDS is increasing in many Muslim countries. Recognising that the political, social, cultural and religious frameworks of these countries create specific issues in developing appropriate education, prevention and support services, the aim of the meeting was to bring together representatives from non-governmental community-based AIDS service organisations working in a number of Muslim countries and communities in a consultative process. During the process, Muslim religious values and beliefs, psycho-social and cultural frameworks, personal behaviours that could lead to HIV transmission, medical practices, and human rights within a Muslim context, were identified and explored. Further, participants looked at a range of strategies to halt the spread of HIV within Muslim countries and communities, as well as ensuring that appropriate treatment and care were available for people living with HIV/AIDS, developing a series of guidelines and recommendations for implementation.

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| Working definition | 1. A working definition of reproductive and sexual health was developed which included family planning, maternal health (anti-natal and post-natal health), sex practices and behaviours, infertility, appropriate treatment and counselling for STDs/HIV/AIDS, breast feeding and implications for mothers living with HIV, nutrition and socio-economic conditions, inequalities and empowerment of women to take control of their own bodies and health. Reproductive and sexual health should include the physical, emotional and mental health of the person. |
| Custom and culture | 2. Traditional customs, cultural practices and private behaviours may often lead to sexual and other behaviours that are different from Islamic teachings and these practices may have a significant role to play in an HIV epidemic, while having a more powerful impact upon female and male reproductive and sexual health than religious values. These practices often have no Islamic sanction, but some are often given religious validity by patriarchal power structures and cultural beliefs. Further, many men have often used religiously framed sanctions to disempower women without any real Islamic basis. |
| Women and social reality | 3. Islam teaches the equality of women and men, and acknowledges women as sexual beings in their own right. However, the social reality for women is very different where women are not in a position to address their own reproductive and sexual health. |
| Marriage | 4. Issues of polygamy, the possibilities of the remarriage of women because of divorce or the death of the husband, and Mut'a (temporary) marriages, were also raised as issues of concern in the context of HIV/AIDS, where cultural practices will often conflict with religious ideals and so increase the possibilities of STD/HIV transmission. For many women, the ability to negotiate safer sex with their husbands, temporary or otherwise, does not exist. There were also concerns regarding the right to divorce if a spouse was HIV positive or living with AIDS. It was felt that this right was exercised more by men than by women leaving women more vulnerable. |
| Sexual behaviours | 5. Participants explored sexual attitudes and behaviours, including pre-marital sex, extra-marital sex, male to male sex, and illegal intravenous drug use and their potential impact upon male and female reproductive and sexual health. Also because of economic conditions, many young men will delay their marriage which may well lead to pre-marital sex. It was further recognised that different cultures may well have different frameworks of self identity. It was therefore important to separate behaviour from identity, not so much who a person is but what they do. |
| Public and private | 6. Participants agreed that in all Muslim countries these behaviours exist to some extent, that there will always be men and women who may call themselves Muslims in public, but whose private practices may well differ from the Muslim ideal. Further the sexual behaviours of men to some extent may be accepted as long as they socially invisible. With very little, if any at all accurate education on STDs/HIV, the awareness of risks is very low. This places women in a very vulnerable position. |
| Lack of sexual knowledge | 7. Women, men and young people have a tremendous lack of knowledge about their own, and each other's bodies, sexualities, HIV, STDs and AIDS. This can have a dramatic impact upon the mental, physical and sexual health of people, as well as on sexual beliefs, practices and behaviours. A great many myths and traditional beliefs exist about the body which need to be effectively addressed through education. This is further complicated with sex and sexual behaviours being taboo subjects which can lead to inappropriate and sometimes risky sexual practices. |

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| Drug rehabilitation programmes | 8. For drug users rehabilitation programmes may exist to some extent, but too often drug mis-use is treated as only a medical or criminal condition. Participants felt that these approaches do not address the issues effectively nor did they work in reducing the levels of drug use. There would need to be a more coherent and strategic approach to drug use and rehabilitation programmes. This would mean looking at the provision of employment for ex- drug users, vocational training, and access to education and effective after-care programmes. |
| Family values | 9. Issues for family values in terms of multiple wives, divorce, parental arguments, domestic violence and gender inequalities, all have a detrimental impact on family stability, creating an acrimonious environment which will affect any children negatively. Family counselling is not available. Many parents lack good parenting skills, and with the added shame surrounding sex and sexual behaviours, find it extremely difficult to communicate these issues to their children. |
| Economic change | 10. With rapid economic changes in a number of Muslim countries leading to increasing urbanisation, migration from rural areas to towns and cities, high unemployment, poverty, and very often poor education, many young people with a need to support their families and themselves, are easy prey to victimisation and abuse through employment and/or sexual exploitation. Many children do not have access to education or proper care. In other situations both parents may be working, and children have to fend for themselves during the working day with a lack of proper attention and supervision. |
| Poverty | 11. Poverty, social inequality and lack of empowerment lead to poor general health and access to medical and social care may be very difficult. Poverty may also generate behaviours that lead to increased risks, such as commercial sex work, drug use, lack of sexual hygiene, nutrition and diet, which all affect reproductive and sexual health. |
| Stigmatisation | 12. There is a lack of basic knowledge about STDs, HIV/AIDS, sexualities and sexual health issues within the medical professions, including hospital doctors, clinicians, general practitioners, and nursing staff. This leads to fear and stigmatisation of, not only those infected with STDs/HIV or those living with AIDS, but also those who may be attending a clinic for testing for STDs/HIV. Because of this, many of those who need such services are not accessing them because of a lack of confidentiality and because of abuse. As new forms of testing for HIV are being developed, including saliva and urine tests, the rapidity of results and the ease of such tests can lead to indiscriminate use with inadequate safeguards and counselling. At the same time costs of treatment, where they are available, can be very high and beyond the capacity of many people. |
| Medical facilities | 13. Medical facilities are often very poor, inadequate, and unhygienic, and can themselves create conditions for the spread of HIV. These include testing sites, blood banks, general injection procedures, surgical wards, operating theatres and so on. There is a lack of facilities for the diagnosis of HIV/AIDS, leading to possibilities of misdiagnosis and under-reporting of cases. |
| Blood donation | 14. The promotion of voluntary blood donation is inadequate while many blood banks have poor facilities for hygiene and sterilisation of equipment, leading to increased risks for transmission of HIV amongst blood donors as well as blood recipients. Testing of blood donations, either voluntary or commercial, is often poor, if existent at all, while in some regions, paid blood donors still provide significant amounts of the blood supply available. |

- Blood supplies** ■ 15. Because of poverty, paid blood donors are often at risk from the very system which pays them. Donors may also be practising other risky behaviours which could lead to HIV infection. Blood supplies can also be surrounded by levels of corruption where blood banks may be able to obtain their clearance certificates without having to ensure their facilities are appropriate or adequate. There are also significant issues around possible HIV transmission regarding organ transplants and donations of semen and ovum because of a lack of screening.
- Experimental trials** ■ 16. In poor countries, experimental drugs and vaccine trials often have inadequate protocols. The ethics of various trials should also be questioned. Sometimes drug companies wish to test a range of products in poor countries which will not be accessible to people in these countries because of the final costs.
- AIDS "cures"** ■ 17. Because there is no cure for AIDS and a lack of knowledge, people living with HIV/AIDS can be highly vulnerable to those offering "cures" for a price. Some doctors, "quacks" and traditional healers have given the impression that AIDS is a curable disease. This means that much needed finance, which should go towards supporting themselves and their families, is wasted on these "cures".
- Care and support systems** ■ 18. Very little counselling or support is available for people living with HIV/AIDS, or for their families and friends. Care and support systems need to be developed. Issues around death and dying, grief and bereavement, child care, adoption, financial support, access to medical care, funeral arrangements and so on need to be appropriately and adequately addressed. If it is a parent, or parents, living with HIV/AIDS, they will have concerns about the future of their children. Issues of institutional homes, adoption, other family members taking care of the children, financial support, education of the children, and so on, will also need to be addressed.
- Isolation** ■ 19. Because HIV/AIDS is often seen as a medical issue only, the psychological and social dimensions are ignored leaving individuals treated as a medical condition and not as human beings. One of the consequences is that people living with HIV/AIDS are isolated where there is a need to meet others also living with or affected by HIV/AIDS for mutual empowerment and building self-esteem. This coming together enables HIV/AIDS affected people to share information, explore models of developing care, find out about the latest treatments, and develop networks for mutual support. Encouraging the development of mutual support systems and self help groups can offer people living with HIV/AIDS an enabling environment and develop a sense that they are cared for as individuals and families.
- Home and community care** ■ 20. As the numbers of people living with AIDS increase in many Muslim countries, medical care systems will become increasingly overwhelmed. This will mean that many people will die from AIDS at home or on the streets. Home and community care systems are lacking in this area of services and urgently need to be developed.
- Agencies AIDS phobia** ■ 21. There are a growing number of non-governmental agencies working on HIV prevention, but there are very few concerned with people living with HIV/AIDS. Some of these agencies are at times AIDS phobic themselves and will not deal with people living with HIV/AIDS, increasing the sense of stigmatisation and isolation. Religious and community leaders also display ignorance and fear and can generate psychological, if not physical, violence in the community against those affected by HIV/AIDS.

- Consultation** ■ 22. Government institutions at national, regional and local level, as well as others, often develop policies and strategies around HIV/AIDS without consulting those most affected, and those most likely to be affected. Agencies are often isolated from people living with HIV/AIDS and therefore cannot truly represent their interests or develop appropriate strategies for care, support and treatment.
- Rights and obligations** ■ 23. Participants discussed the rights and obligations of the individual, constitutional law and religious guidelines, and community rights, in regard to human rights. While there appears to be an apparent conflict between the rights of the community for protection against HIV infection and the rights of the individual in the context of confidentiality, participants felt that these two frameworks need to be seen in a complimentary context, particularly because so much shame and fear is attached to the issues of HIV/AIDS.
- Human rights abuse** ■ 24. Such shame and fear has led to lack of confidentiality and substantial human rights abuses, such as unnecessary isolation, imprisonment, loss of, or denial of employment, loss of housing, insurance and denial of access to medical treatment. Often they may well be legal sanctions against people with HIV/AIDS. Passports may be stamped. Movements may be curtailed. Marriage refused. At the same time access to charitable funds is very difficult because of religious and community attitudes towards AIDS.
- Mandatory testing** ■ 25. Furthermore it has also generated calls for mandatory testing of those defined as “high risk groups”, even though it has been shown in countless studies that mandatory testing is not justified medically, socially or economically and is an abuse of human rights. These issues must be addressed through education and awareness, and where necessary through legal approaches, if we are to ensure that people affected/infected with HIV/AIDS or living with AIDS are supported.
- Minority communities** ■ 26. Participants recognised that whilst Islam states that there is only one Muslim community, the reality of people’s lives in many countries is that minorities based on religious, ethnic, cultural, and linguistic and behavioural differences do exist. These minorities will often be treated differently from the majority community, and for many, are stigmatised and vulnerable. This is because minority communities often make up the poorer sections of society, are politically powerless, and often with less access to education, health and social services, housing and employment. Because of their disempowerment, these communities have a lower level of community-based organisational development.
- Access by minority communities** ■ 27. Where there is any service development around HIV/AIDS it has been contextualised within the needs of the majority culture, society or community. This has meant that minority communities cannot access these services because of social, cultural and linguistic differences. This can lead to minority people living with HIV/AIDS being doubly stigmatised. Too often minority communities find services imposed upon them and cannot actively participate in the decision making process.
- Isolation of agencies** ■ 28. Groups, networks, and service agencies often operate in isolation from each other leading to duplication of education resources, ineffective methodologies of working, lack of appropriate information and, to some extent, competition for resources. Agencies working with Muslims in one locality, region or country may have learned a wide variety of lessons dealing with the complexities of the issues. Other agencies in other parts of the world may be able to learn from these experiences and implement them in their own programmes. It is therefore very important that agencies should work together, form alliances, actively network with each other, and share information. HIV/AIDS while being localised is also a global pandemic.

- Networking** ■ 29. Networking enables the development of appropriate skills, empowerment, access to appropriate training, as well as availability of appropriate education and prevention materials. Mechanisms would be needed to develop a range of forums which could lead to sharing of skills and information for the development of effective management, expertise, methodologies, cost-effective utilisation of resources, and strategic approaches. These networks should look at local, regional, national and international forums which community-based agencies could access and actively participate in through appropriate mechanisms. In particular, as agencies working with Muslim communities, the issues of concern can be more readily understood, appreciated and articulated within shared and mutual agendas.
- Knowledge of the Qu'ran** ■ 30. A major concern was expressed that many people have no knowledge of what the Holy Qu'ran has to specifically say about these issues. Too often religious and community leaders make statements based on cultural taboos and traditional customs, rather than on Islamic teachings. It was understood that the Holy Qu'ran does speak of both reproductive health and the wife's right for sexual pleasure with her husband, and that these were seen in the context of both an individual's and the community's physical, mental and social health.
- The Shari'a as a deterrent** ■ 31. In societies where frameworks of shame predominant, where discussions of sex are taboo, and where the Muslim ideal of sex only within marriage is promoted, where Islam condemns pre-marital and extra marital sex, men who have sex with men and drug use, such behaviours will always be hidden and difficult to access. Using the Shari'a as a deterrent strategy was considered a worthy aim, but participants also felt that while this may work for some, for others, it would only drive these behaviours further underground. Use of punishment and deterrence were felt to be a partial solution and would not eradicate such behaviours totally. Participants felt that what was needed was the development of a more pragmatic approach towards STD/HIV/AIDS education and prevention. This was defined by having two on-going strategies, one with public campaigns that promoted the Muslim ideal on sexual and other behaviours, the other a "discrete" prevention strategy that addressed the actual behaviours being practised by some people.
- Differing social spaces** ■ 32. It was also understood that in any education and prevention strategy it should be recognised that people exist in many different social spaces, including homes, schools, colleges, working environments, and on the streets. They also exist in different living environments, rural or urban, and in different economic groups. It would be important to address all these social spaces with appropriate education.
- Discrimination** ■ 33. Islam prohibits discrimination against Muslims who are ill and promotes community duty to take care of all people who are ill. Muslim societies have a moral obligation to enable people with AIDS to live and die with dignity.
- Civil disturbances** ■ 34. In several Muslim countries there are significant civil disturbances which are placing considerable strains on medical and social systems, increasing the need for blood supplies and blood products. At the same time participants also believed that the political use of Islam has created social tensions and conflict which form barriers to the development of appropriate and effective programmes on HIV/AIDS education, prevention and care. Governments sensitive to these tensions often find it inappropriate and difficult to develop HIV/AIDS prevention strategies particularly where they deal with sexual and drug using behaviours. The issues of religiously illicit behaviours makes the social and political environment difficult to openly discuss sex, sexuality, and sexual behaviours, and because of these contentious issues, shame, and the myths around HIV/AIDS, there is a marked social tension between HIV/AIDS workers and religious leaders. This has meant that HIV/AIDS programmes cannot be properly implemented to best ensure a reduction in the rate of increase of STD/HIV transmission.

- Lack of data** ■ 35. There is an immense lack of data on actual sexual and drug using behaviours and their diversity within Muslim societies. Too much reliance is placed upon ignorance and assumptions based upon Muslim ideals. This creates difficulties in developing appropriate strategies for the prevention of HIV. Such programmes cannot assume that sexual behaviours are only taking place between husband and wife (or wives). But without such data it is very difficult to plan and develop effective education and prevention strategies.
- Lack of skills** ■ 36. Participants also recognised that many people working in HIV/AIDS service organisations do not have appropriate skills around management, financial control, monitoring and evaluation, developing appropriate programmes and outreach work. Actual knowledge of HIV/AIDS within these agencies is at times very low.
- Funding** ■ 37. Many HIV/AIDS agencies are dependent upon funding from a range of local, regional, national and international donors. Concerns about the sustainability of non-governmental organisations were expressed, both in terms of access to funding as well as to the lack of technical skills. At the same time participants expressed concerns regarding the application of international guidelines on a range of HIV/AIDS issues at local, regional and national levels. Monitoring, ensuring appropriate and just implementation, and the existence of legal frameworks and penalties for non-compliance were concerns that were raised.
- Safe environments** ■ 38. Participants also strongly felt that unless there is a “safe” environment to work in, HIV/AIDS education and prevention will be extremely difficult. Achieving such an environment will mean working closely with religious and political leaders. Religious leaders, families and communities would need to be provided with extensive education and awareness for this to occur and be encouraged to provide support services for those living with HIV/AIDS.

Moral predicament ■	HIV/AIDS affects all aspects of human concern, including personal reproductive and sexual health, medical practice and treatment, religious values and ethics, politics and human rights, the individual, family and community. However, this moral predicament is nowhere as pronounced as in Muslim countries and communities. Politicians, religious leaders and policy makers may often deny the impact of HIV/AIDS, stating that AIDS is a curse of western decadence or that it poses no threat, since it is confined only to drug users, homosexuals and sex workers whose existence in Muslim countries or communities is often denied. This means that some Muslim countries and communities are often inadequately prepared to deal with HIV/AIDS and its consequences where strategies and programmes to provide education, prevention and support are often ineffectively developed. Such denial creates ignorance and fear which can lead to increasing rates of infection and death.
Denial ■	Participants recognised that these denials were based upon upholding the Muslim ideal of sexual behaviour as an act only permissible within marriage. This should be viewed as a denial of recognition to those who transgress the limits of the Muslim ideal, for to follow Islam means a strict adherence to its religious rules and behavioural mores. However, based upon experience of working in the field, participants believed that the existence of other behaviours which do not follow the Muslim ideal exist in Muslim countries. Like any other country or community, there will be those who use drugs and alcohol, there will be men who have sex with men, women who have sex with women, and both female and male sex workers, although these activities may well be more limited, less visible and contoured in different psycho-social frameworks.
Cultural taboo ■	Further, the public discussion of sex, sexual behaviours and sexualities is a cultural taboo which adds to the invisibility of such behaviours and the denial of their existence. Participants felt that this muteness on sex and other behaviours is leading to many unwarranted deaths because of AIDS. The Consultation Meeting strongly felt that this silence needs to be broken to save lives.
Ideal versus reality ■	Participants clearly understood that the chasm between ideals and realities is the biggest challenge for Muslim countries and communities in facing the implications of HIV/AIDS. It was strongly felt that there was an urgent need for all Muslims to recognise these issues, and that Governments should address these problems, informing their citizens about HIV and AIDS and develop appropriate local strategies and programmes to reduce the spread of HIV infection within their countries, as well as ensuring the provision of compassionate and appropriate care and support for people living with HIV/AIDS and their families.
Social frameworks ■	Within Muslim countries and communities, dealing with issues of reproductive and sexual health, where religious values, beliefs and practices play a strong cultural and social role can be very problematic. The political, social, cultural and religious frameworks of these countries and communities create specific difficulties in developing appropriate discussion, education, prevention and support. Participants recognised that HIV/AIDS forces us to focus on highly contentious issues since HIV is primarily a sexually transmitted infection. Further in many Muslim countries, there are other issues, such as ineffective blood screening, inadequate testing facilities, lack of knowledge by the health care profession, social stigmatisation and victimisation. As a consequence very little has been done to develop compassionate and appropriate models of prevention and care in such settings.
Muslim community ■	Participants realised that while religious leaders will speak of a one world Muslim community as a Muslim ideal, the reality can be different. As one participant stated “being a Muslim woman living in Indonesia is not necessarily the same as being a Muslim woman living in Saudi Arabia”. While different countries and communities share certain Islamic values, beliefs and practices, local cultural traditions and customs also play a significant role in the shaping of behaviour and practice. Policy makers and organisations need to understand the differences between basic Muslim ideals and local, as well as personal, practices in the development of appropriate education, prevention and care strategies.

Conclusions

- Promotion of Muslim ideals** ■ Participants believed the promotion of Muslim ideals should be a central part of any education strategy to raise awareness of HIV/AIDS by following the teachings of the Qu'ran, that is through abstinence, and faithfulness within marriage. However, it was also recognised that there will be those for whom these are essentially public acts of obedience, while in private, other behaviours may well come into play. This implied that a strategy based **ONLY** on an Islamic response to HIV/AIDS by promoting the Muslim ideal for personal behaviour and practice, would not necessarily significantly reduce the spread of HIV. Other strategies would **ALSO** be needed that could address the difference between the Muslim ideal and the actuality of some people's individual behaviours.
- Empowerment of NGOs** ■ It was felt that nongovernmental agencies should be empowered to deliver locally appropriate prevention and community care services, where Governments and religious institutions may feel restricted by the political, religious and social implications of the issues involved, particularly in the arenas of sexual and drug using behaviours which are often not visible to the broader community, and thus much more difficult to access. This would require affected individuals and groups, to be empowered towards developing responsible behaviours, which can only be achieved if they are actively involved in appropriate STD/HIV prevention strategies. Further marginalised groups and communities, such as women, youth, ethnic and cultural minorities, migrants and immigrants, low income groups, as well as behaviourally specific groups, and those living with HIV/AIDS should also be actively involved in developing appropriate prevention and care strategies for their communities, if such strategies are to be effective. Such processes of empowerment would require adequate funding, access to appropriate training and skills enhancement, as well as programmes for networking at local, regional, national and international levels, with advocacy support for those affected by or living with HIV/AIDS.
- Blood supplies** ■ However, issues around the non-sexual transmission of HIV are within the scope of government through public discussion and action. They reflect public health issues for adequate testing of blood and blood supplies and adequate sterilisation procedures in health care and blood giving settings, and appropriate treatment and care. Governments should ensure that their populations are adequately protected and provided for through appropriate legislation and enforcement in terms of medical practice, access to appropriate testing, counselling, treatment and care, blood supplies and the provision of culturally and linguistically appropriate HIV/AIDS awareness and education which would involve religious leaders and the promotion of the Muslim ideal.
- Individual or community** ■ Participants recognised the issues regarding individual rights and community rights. While many see these rights as oppositional, it was felt that they were complimentary and should be seen as working together to protect the individual, the family and the community. Legislation and its enforcement, with appropriate advocacy structures should be developed to deal with abuses.
- Compassionate concern** ■ Further, participants strongly felt that it was religiously incumbent upon all Muslims to ensure support for compassionate concern and care in providing support for people living with, and affected by, HIV/AIDS.

The Challenge of AIDS ■ The challenge of AIDS confronts all countries and communities globally. Governmental and nongovernmental agencies, as well as secular and religious institutions, should work together to face this challenge if we are going to reduce levels and rates of infection, and the numbers of people that may die from AIDS.

AIDS as a complex issue ■ AIDS is not only a medical condition. It involves personal, social, cultural and religious issues that are complex, diverse and challenging. HIV/AIDS confronts people with their religious beliefs, sense of morality and ethics, relationships with each other, gender relationships and inequalities, family and community, economic empowerment and development, political frameworks as well as personal psycho-social issues. Developing appropriate strategies that confront the challenge of HIV/AIDS means approaching prevention and care services in ways that ensure a holistic understanding of these issues, where strategies are based taking all these factors into account.

AIDS pandemic ■ Muslims are not immune to HIV. The impact of AIDS should no longer be denied. While it is recognised that there are many other priorities that confront governments and communities, the development of the AIDS pandemic will have a devastating impact upon health, social and economic structures of Muslim countries and communities unless it is confronted now. Developing appropriate strategies to effectively deal with HIV/AIDS requires understanding, compassion, pragmatism, cooperation, goodwill and a willingness to learn from each other. The following recommendations are aimed towards developing that sense of goodwill and cooperation.

Recommendations

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| Cultural diversity recognised | 1. For effective implementation of strategies and services related to HIV/AIDS programme managers should take into account the differences between religious values and cultural practices where the cultural diversity in and between Muslim communities and countries should be acknowledged. |
| Contribution of religious leaders | 2. The valuable contribution that religious leaders and mosques can make in promoting Muslim ideals and behaviours, such as sexual abstinence before marriage and faithfulness within marriage, is clearly recognised and should be a part of any education strategy, taking into account the sound principles of freedom, human rights, social welfare and cohesion, personal relationships and family life. |
| Religious education | 3. This would also mean ensuring that women and men are fully educated on their true rights and obligations as based upon the Qu'ran. Misconceptions arising from cultural values and traditional customs which have been incorporated into personal and social practices and given religious sanction need to be exposed and challenged. This would include female circumcision and gender inequalities. It is the duty of every Muslim to acquire knowledge, including knowledge on HIV/AIDS, and to work in their communities to promote healthy living. |
| Working together | 4. It is essential for the whole community to work together to ensure that education strategies are effectively implemented to prevent the spread of HIV. Society as a whole should be mobilised in creating appropriate awareness of HIV/AIDS. These education and prevention strategies should utilise a wide number of formats including posters, electronic and print media, leaflets, videos, audio-cassettes, cinema, theatre and so on, and involve political and religious leaders, doctors and hakims, and business and union leaders. Religious, political, medical, social, community and business leaders should all be offered awareness programmes on HIV/AIDS and related issues in order to incorporate them into community education. |
| Targeted resources | 5. Specifically targeted resources for a wide variety of work should be developed that are aimed at, social, economic and behavioural groups, including medical staff, family planning clinics, religious teachers, educational staff, factory workers, hotel staff, sex workers and so on. This would also mean educating and updating all health and social care workers skills with regard to prevention, care, management, counselling and related issues on HIV/AIDS. It is essential that policy and public opinion formers as well as the media are educated in the issues of HIV/AIDS. |
| Development of educational materials | 6. This will require the imaginative development of educational materials that are appropriate to the behavioural and educational levels of the targeted audience. Learning resource materials should incorporate several ways of achieving safe behaviours including abstinence, faithfulness of partners, cleaning needles as well as condom use and changing behaviours where deemed appropriate. Such campaigns should also acknowledge the differing levels of literacy in communities, gender issues, differing sexual behaviours, and religious frameworks. |
| Inadequate protection of blood supplies | 7. Such campaigns should recognise that religious teachings on their own will not stop the spread of HIV infection completely. Inadequate protection of blood supply, and inadequate surgical and injection procedures will all need to be addressed through appropriate legal frameworks and their enforcement, with adequate training of medical staff, financial support,sterilisation of needles and surgical equipment in health centres, and all blood supplies screened for HIV. |

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| Working with marginalised groups | 8. To be fully effective, prevention strategies should incorporate the means to stop the spread of HIV infection. Strategies which focus on abstinence and faithfulness as the Muslim ideal, should also look at harm minimisation for those who do not always abide by the Muslim ideal. However many of these issues are taboo, and to publicly discuss them creates issues of shame, fear, anger and hostility which will lead to resistance and denial. It will therefore be necessary to ensure that such HIV prevention programmes should work with marginalised individuals and groups who are legally and religiously prohibited, including people who have pre-marital and extra-marital sex, drug users, sex workers and men who have sex with men. Cheap, good quality condoms should be made easily available, with targeted programmes that work by modifying risky behaviours in terms of the transmission of HIV/STDs, and “needle exchange services” linked to treatment programmes for intravenous drug users. Individuals and members of these groups who share specific risky behaviours should be empowered to address these issues for themselves. |
| Active involvement | 9. However, for effectiveness it is very important that HIV/AIDS services, should not be imposed upon communities but arise from affected communities themselves. Programmes should be specific to the needs of the community and individual members of that community. Members of these communities should be actively involved in developing responses to HIV/AIDS by encouraging them to form their own nongovernmental education, prevention and support agencies. This requires a financial commitment from funding bodies towards long term planning and support for these initiatives. |
| Confidential phonelines | 10. To facilitate such work, free confidential telephone lines should be made available where individuals can access appropriate information. These lines should be staffed by individuals adequately trained in dealing with reproductive and sexual health issues, as well as intravenous drug use. |
| Non-public strategies | 11. Because of the religious political and social issues that such intervention work may raise, it will be important to recognise that different and non-public strategies may need to be developed for such interventions. |
| Sex education | 12. Part of the strategy should involve sex education as part of “life education”, in educational establishments such as schools, colleges and universities, as well as the education of parents. Within Islam it is recognised that it is the parent’s responsibility to provide their children with effective sex education but this is not always done. Appropriate peer education initiatives should be encouraged and supported and individuals and families should be able to access premarital counselling on reproductive and sexual health issues. Safe spaces should be developed where individuals and groups can gain access to confidential information as well as discuss issues around sexualities and reproductive and sexual health within an appropriate religious and cultural context. |
| Legal rights of women | 13. There should be religious and civil education programmes on the legal rights of women and children. Opportunities for formal and informal education of girls and women should be enhanced and made more accessible as a right. This right should also be available for marginalised women, such as rural women, women involved in commercial sex and migrant women. Such education should include reproductive and sexual health as a part of family planning and HIV/AIDS issues. |
| Minorities | 14. With the growing urbanisation of Muslim societies, there have been mass movements from rural to urban areas, as well as movements of people from one country to another. Within some countries, there are significant minorities. Programmes should be developed that address the specific needs of minorities and migrants that are appropriate to their languages, beliefs and cultures. This may well involve international as well as local cooperation in addressing these needs. |

Recommendations

- Needs assessments** ■ 15. In order to understand and map out possible routes of HIV transmission in any given community, it is essential that a variety of needs assessments and action-based psycho-social behavioural research should be conducted, so that effective education and prevention strategies can be developed. It is essential that culturally appropriate methodologies be developed for such research, and that this research should be conducted through peer interventions and community-based groups in order to ensure the validity of data, an appropriate analysis of the data, and adequate protocols on confidentiality.
- Prisons** ■ 16. Prisons and other forms of incarceration should develop appropriate services around HIV/AIDS. This policy would include children's homes, mental institutions, and drug rehabilitation centres, while all hospitals, clinics, and community care centres should ensure that HIV/AIDS services are available, appropriate and specific to the needs of individuals and the communities they serve.
- Allies** ■ 17 Regular meetings, negotiations and confidence building measures should be conducted in order to develop trust, empowerment and rapport with key people in the community as well as governmental, nongovernmental, community-based organisations and with community and religious leaders. Allies at all levels, including religious leaders, influential people, the business community and the media should be identified and mobilised so that they can support and legitimise the work of nongovernmental and community-based agencies and aid in the dissemination of appropriate information to the community.
- Consultation** ■ 18. National AIDS Programmes, in collaboration with other government and nongovernment agencies at local, regional and national levels, should work together to formulate effective and appropriate policies on HIV/AIDS. They should consult the affected communities on issues to do with drug use, sexualities, sexual behaviours and HIV/AIDS and empower them to participate in decision making to develop appropriate policies and programmes. In order for this to effectively occur, specific strategies should incorporate and integrate the issues of HIV/AIDS into the priority agendas of communities and government, for example, alleviating poverty, women's issues, youth education, reproductive health and family planning and within the existing health care systems.
- Monitoring of agencies** ■ 19. All agencies providing HIV/AIDS education, prevention and support should be effectively monitored for the quality of their services, their accessibility, and financial accountability. Effective models of peer evaluation of local community based HIV/AIDS services should be developed in response to concerns as to whether such organisations have the skills, knowledge and expertise to provide such services, especially around sexual and drug-using behaviours and related issues.
- Skills training** ■ 20. In order to ensure that these agencies can deliver a high quality of service, it is essential that appropriate skills training be offered to the policy makers of these agencies, management boards, staff and volunteers. Such skills training should include issues on developing appropriate outreach programmes, community involvement, designing education and intervention strategies, needs assessments, project management, grant writing, financial management, monitoring and evaluation, and educational resource development.

- Protection of human rights** ■ 21. It is essential to develop effective advocacy programmes for the protection of the human rights of people living with HIV/AIDS and other affected individuals and groups of families, women, children, and men . There should be a range of campaigns to educate the general population against discriminatory attitudes towards HIV/AIDS and there should also be a review and repeal of any discriminatory laws affecting women, children and men, whether based on gender inequalities or personal practices. Women’s social, economic and political status makes them extremely vulnerable to HIV infection, so there should be effective development to engage with women’s organisations in uplifting the socio-economic-political condition of women, while the development of HIV/AIDS policy should not negate in any way the evolving achievements of women’s rights.
- Surveillance** ■ 22. An effective surveillance system should be established to find the prevalence of HIV/AIDS both within communities and amongst those who may be engaged in high risk behaviours. However, such HIV antibody testing must be approached in the context of confidentiality and human rights. Inadequate testing protocols can lead to discrimination, victimisation and the abuse of human rights.
- Religious duty** ■ 23. All people living with HIV/AIDS have the right to appropriate and compassionate treatment, care and support that respects confidentiality and human rights. It is a religious duty of all Muslims to ensure that infected and affected people have access to good quality care and support whether medical, psychological, social or economic. A balance needs to be maintained between the rights of the individual and the rights of the community. Government regulations and laws should be formulated and made enforceable with regard to any discrimination and abuse. Legal and human rights should be protected by these laws and regulations and advocacy programmes for people living with HIV/AIDS with regard to their legal, civil and human rights need to be encouraged and financially supported.
- Counselling** ■ 24. HIV/AIDS can have a devastating affect on individuals and their families. Stigmatised through infection and illness, the psychological, economic and social impact has major implications for their continued wellbeing. Specially trained counsellors should be available to provide psychological and practical support for infected and affected individuals, friends and families. Part of this process of counselling would include access to appropriate treatment and care, financial support, the rights and responsibilities of people living with HIV/AIDS, and referrals to appropriate agencies, including support and self-help groups. Such groups should be encouraged and facilitated through financial and social support, where confidentiality can be maintained in their provision. This range of counselling and support systems should be developed with government and nongovernment agencies as well as the community, creating enabling and supportive environments.
- Financial support** ■ 25. The economic impact upon individuals and families affected by HIV/AIDS can be devastating. The loss of income can create major burdens in terms of accessing health care, food, housing and other needs. Support programmes for people living with HIV/AIDS should not only include psychological, medical and social frameworks, but also financial support, both for themselves and their families, to ensure that a reasonable quality of life is maintained. Access to health care should be made affordable and accessible. Funding should be provided to enable families affected by HIV/AIDS to access resources with regard to their specific needs. Such needs may well include housing, home-help, drop-in facilities, trained counsellors, economic support, and medical care. This could be achieved through a Social Care Fund established by governmental and Muslim institutions.

Recommendations

- Community care** ■ 26. As the numbers of people living with AIDS increases, so the development of effective community and home care programmes becomes an urgent necessity. This requires the training and support of care providers from within families and extended family networks to ensure an acceptable degree of home base care for people living with HIV/AIDS creating enabling conditions for the provision of such support. Community care programmes should offer counselling, financial support, home care, befriending services, and safe, confidential social spaces for people living with HIV/AIDS who can come together for mutual support and self-help. Counselling should explore grief and bereavement, family values, access to adoption, rights and responsibilities, and other issues that affect people living with HIV/AIDS and their families. Vocational training and employment opportunities should also be made available for individuals and families affected by HIV/AIDS where necessary, so that the economic impact of HIV/AIDS can be limited.
- Traditional medicine** ■ 27. Access to non-allopathic forms of treatment should be considered a right for people living with HIV/AIDS and be made accessible and affordable. Research on traditional medical systems should be strengthened and supported in terms of their impact upon HIV/AIDS. This means that information on such treatments, as well as those allopathic drugs currently available should be available in appropriate languages. Access to information is vital if the person living with HIV/AIDS can effectively participate in making appropriate choices about treatment and care. Alternative methods of support and care should be encouraged, such as befriending, self-help groups, affected family networks and so on. Alternate family structures could be devised and accepted where parents may have died from AIDS, and children, infected or otherwise, have no family support because of their status. Appropriate support and care programmes for children affected by HIV/AIDS is an urgent necessity.
- Testing facilities** ■ 28. Facilities for testing for HIV/AIDS should be made available in all major hospitals and clinics, and remain accessible to every one. This will mean ensuring that the principles of confidentiality are maintained and that appropriate pre and post test counselling is offered to all. All needles and invasive instruments should be sterilised before use. All blood supplies should be tested for HIV infection before transfusion. Voluntary blood donations should be encouraged, while organ, semen and ovum donations should be tested for HIV infection before transplantation. Health care standards must be improved in order to ensure prevention of non sexual transmission of infection.
- Moral predicament** ■ 29. Where trials of new treatments and drugs are carried out there should proper protocols with legal enforcement, and that such trials should be carried fairly and equitably. Information about these trials should be made available to all in an equitable manner and that all people should have access to the results irrespective of cost. Inadequate protocols on these experiments means that people's rights to access to appropriate information and withdrawal from such treatment and drug trials are abused. Further, the costs of these new treatments and drugs are also often prohibitive, which makes them inaccessible to people living with HIV/AIDS in the countries in which the trials were first conducted.
- Long term funding** ■ 30. Development of educational, prevention, treatment and care programmes should be adequately funded and resourced for the broad range of communities in appropriate languages relevant to the differing communities. Funding strategies should be on a long term basis supporting community development as a process and should be made available to develop effective services which are managed by members from the affected communities. There is a need to ensure that HIV/AIDS strategies include a commitment to work in partnership with people living with HIV/AIDS in a supportive environment.

- Networking** ■ 31. Networking is an essential component for the development of appropriate strategies and their implementation in HIV/AIDS education, prevention and care. Such networking involving community based agencies providing these services should be financially supported and appropriate forums for local, regional, national and international meetings should be developed. These networks would enable community based agencies to share information, resources, and skills regarding HIV/AIDS and Muslim communities. An international network of Muslim community based agencies should be developed, and an international network of Muslim peoples living with HIV/AIDS should also be established. Funding should be given to establish these two networks, and that further meetings of the participants of the Consultation meeting, with others, should also be supported.

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Working papers

1. 1. The Silent Killer: AIDS and the Muslim World
Dr. Munawar A, Anees
Paper presented to the 8th International N+Bioethics Symposium, Tokyo, December 1993
2. Response to the above paper by Shivananda Khan for The Naz Project, April, 1995
3. The Role of Religion and Ethics in the Prevention and Control of AIDS - Consultation Document produced by WHO Eastern Mediterranean Regional Office, 1992
4. Sexuality and Sexual Health in South Asia
Document produced by Shivananda Khan for The Naz Project, 1993
5. A Dialogue Between Two Believers - a discussion on Muslims and homosexuality.
Reproduced from the Abu Nuwas Newsletter, 1994
6. Cultural Constructions of Male Sexualities in South Asian Cultures
paper produced by Shivananda Khan for The Naz Project, 1995
7. Sexuality & Eroticism Among Males In Muslim Societies
Edited by Arno Schmitt and Jehoeda Sofer
A collection of essays. Booklet printed 1995
8. Compact on Human Rights Initiative -
APCASO, 1994
9. AIDS, health and human rights
Professor Jonathan Mann, March 1995, reproduced from the RS Journal
10. Planning and Evaluating Strategies for AIDS Health Education Interventions in the Muslim Community in Uganda
Paper reproduced from AIDS Education and Prevention, The Guilford Press, 1995
11. AIDS - The Epidemic Past, Present and Future in the Middle East reproduced from TB & HIV, January, 1995
12. Can Culture Stop AIDS In Its Tracks?
Article reproduced from The New Scientist, 11 September 1993
13. The Islamic Perspective On Sex Education
Reproduced from the Sex Education Forum Report, 1995
14. Report on the International Community of Women Living With HIV/AIDS
Pre-Conference Meeting at Cape Town, South Africa, March 1995
15. Information Document: a collection of a number of relevant press articles from:
Global AIDS News, AIDS Analysis-Asia, WorldAIDS, AIDS Action

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