The Catholic Church and the provision of antiretroviral treatment

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Summary

The Southern African Catholic Bishops' Conference (SACBC) embarked over the past eighteen months on an anti-retroviral programme in twenty two sites, in South Africa, Botswana and Swaziland, three of the most seriously AIDS- affected countries in sub-Saharan Africa. The odds were against the Church's involvement in such a programme because of the high costs involved, the poor infrastructure, the lack of trained medical personnel, the inadequate medical expertise available within the Church, and the lack of pharmacies and laboratory services at local sites. Commitment to the value and sanctity of each human life, and to giving people hope in desperate circumstances when medical science has some partial solutions to offer, and an underlying faith commitment to the call of the gospel to continue the mission of Jesus underpin the gigantic task of attempting to bring treatment to some people.

Southern African Catholic Bishops' Conference (SACBC)

Since 2000 the SACBC AIDS Office has co-ordinated the response of the Catholic Church to AIDS in South Africa, Swaziland and Botswana, strengthening and building on existing programmes, and helping to initiate new ones. The continuum of care, a very visible aspect of the church's involvement in mission at local level, in most of the programmes and projects linked to the SACBC, has seen enormous grassroots commitment to prevention, care and support to people infected and affected by AIDS. In the past five years home based care programmes have extended their outreach to include increasing care to orphans and children made vulnerable by AIDS. Expanding into treatment became a real possibility in the second half of 2003 when the SACBC was invited to consider the possibility of becoming involved in the delivery of anti retrovirals (ARVs).

Funding Partners

Cordaid approved a proposal for the SACBC to begin treatment in twelve selected sites already providing home based or hospice care to the sick. This funding is also supporting patients in the diocese of Francistown, Botswana, and in the Siteki area of Swaziland. Ford Foundation funding has ensured that additional patients can be supported on treatment in KwaZulu Natal, in the dioceses of Ingwavuma and Dundee. President's

Emergency Fund for HIV/AIDS Relief (PEPFAR funding), received through a grant made to the Catholic Relief Services Consortium (also known as AIDSRelief), currently supports patients on treatment at the original twelve and an additional eight sites in South Africa.

Getting Started

Bristol Myers Squibb (BMS) Secure the Future programme was linked for five years to the SACBC through its partnership with the Catholic Medical Mission Board (operating out of New York). Halfway into the partnership BMS mooted the possibility of expanding its programme into treatment; because of this, initial identification of future SACBC sites occurred. The SACBC treatment proposal was drawn up with the help of various professionals since the SACBC itself did not have all the necessary expertise. Great support all round was given by the HIV/AIDS Clinicians' Society (in South Africa) which was as determined as the SACBC that everything would be in place to ensure a successful programme from the start.

Training of Personnel

The Foundation for Professional Development (FPD) and Kimera have provided training for doctors and nurses from the twenty two sites, and continue to support them clinically. This training has also been used and is recognised by the South African department of health. The SACBC has been able to ensure that practitioners receive Continuing Professional Development Points (CPD) for this training. The Treatment Action Campaign (TAC), a well-known advocacy and lobbying body, has assisted with adherence training for counsellors at several sites. AIDSRelief, the PEPFAR funded programme, continues to provide mentoring to doctors, nurses, counsellors, co-ordinators and other staff both at site level, and in larger training sessions. Doctors and nurses at sites have acquired the drug dispensing licences required under recent legislation.

Suppliers

The SACBC itself and almost all of its sites do not have the laboratory facilities so clearly needed in an ARV programme. After investigation before the programme began it was decided to outsource all laboratory work to Toga Laboratories in Gauteng. Blood samples taken at the sites are collected by courier on specified days and taken to the laboratory for required tests. Results are sent by email and fax to the sites, allowing doctors to make decisions regarding treatment. Most facilities also do not have pharmacies; and clearly neither does the SACBC. A procurement contract has been entered into with Motswedi Pharmaceuticals which deliver by courier drugs packaged with a month's supply for individual patients to the sites. At some sites in KwaZulu Natal, and in Swaziland, tests and drugs are provided by the department of health, with services related to adherence counselling being the responsibility of the sites. One site

has its own drug procurement agreement with a supplier, but with funds still provided centrally.

Department of Health

National department of health in South Africa has been supportive of the SACBC roll out, but has called for provincial buy-in and support. Catholic Relief Services and the SACBC are part of various provincial committees and task teams operating at provincial level; this allows for mutual information sharing, for effective referrals, for training opportunities. Collaboration at local level between the sites and local hospitals, clinics, and other facilities helps ensure that patients get the best possible treatment available in the specific locality. Local hospitals are on occasion the treatment centre at which patients from SACBC home based sites are treated. Sometimes local hospitals are the place to which patients are referred from SACBC sites for specific treatment and interventions. SACBC hospice sites are in turn the places to which provincial hospitals refer patients who cannot be helped further in hospital. Referral systems vary locally; some are better established than are others, and ongoing collaboration is needed in this arena.

Different models of treatment delivery

The SACBC is involved in twenty two sites, some of which operate very differently from others; eight different models exist, providing care and treatment according to local circumstances.

- Hospital: only one SACBC facility is a hospital.
- Clinic: some sites are clinics to which people have come over the years for a variety of treatment.
- Hospital outreach: one hospital has an outreach into more remote areas, allowing for patients who cannot travel to the hospital to be reached.
- Home based care project: some sites have been able to scale-up their home-based care support into treatment for patients who qualify for it.
- Home based care outreach: from a central location home based care teams move into villages and outlying areas. One SACBC site serves eight villages, with the doctor following nurses and counsellors who prepare patients.
- Private doctor's surgery accepts patients from three home-based care projects. Assistance with travelling, adherence counselling, preparation and follow-up are done by the home-based care teams.
- Hospice facility: a couple of hospice facilities have become treatment centres. Some patients who were admitted to a hospice to die have in fact been able to go home instead.
- Children's home: facilities which have been caring for babies and children with HIV/AIDS are gaining experience in putting some of them on treatment.

Monitoring and evaluation

The recording of data on patients over a life time is quite a challenge technologically in resource-poor settings. Even paper-based systems can be a challenge when one begins something new like treatment. Viral load and CD4 follow up are part of the monitoring done on individual patients to check on side effects, the efficacy of drug regimens, and patient adherence to treatment. A year into the programme we are able to report good adherence rates, in excess of 90%, with only small numbers of patients lost to treatment. An external evaluation, conducted by the University of Pretoria, examined the social impact of treatment in the first seven sites to begin. Among the findings are indications of a breakdown in stigma, a high rate of adherence where people are supported, and a vested interest in the payoffs related to staying on treatment especially where social infrastructure is supportive in one way or another.

Support for doctors

A twenty four hotline for doctors is part of the support provided to them, especially in the early stages of their treating people with ARVs; this is done as a follow up to the training offered to doctors. Ongoing professional training of doctors and nurses has been built into the programme. Telemedicine is a service being piloted at a couple of the SACBC sites; it provides assistance in the treatment of problems related to dermatology. ARV personnel in some of the newer sites have been able to gain from the experience of those that began earlier, and sites have been very generous in sharing their experiences with colleagues from elsewhere.

Spiritual and psychological support

For patients waiting for consultations with the doctor, there is at sites the opportunity for spiritual support provided by clergy and pastoral assistants. Ongoing pastoral counselling, not only in adherence-related issues, is part of the programme, within the home-based care set-up or within the context of ARV-related services. Clearly the Church is at work, through its membership, and reaching out to people in need of the healing love of Christ. This Church sometimes appears to defy definition: at times it is the hierarchical Church, evidenced by the very active involvement of bishops and clergy with parishioners and people supported by AIDS programmes. Sometimes the Church appears, to beneficiaries of assistance, to be the religious sisters and other care-givers working hands on the sick. My own sense is that because the Church is viewed by many as a positive role player in the provision of healthcare there is a recognition that it provides a yardstick against which some other role players do not measure: faith, commitment and walking the extra mile are key values not always found elsewhere. Church sites often do not have the same kinds of infrastructure one may find elsewhere, but the dedication to health care, often fuelled by a faith commitment, seems to underlie successful programmes.

Success Stories

- Heart-warming stories of children going back to school or going to school for the first time are emerging from sites where children are receiving treatment.
- Adults are returning to work, or returning to their homes, within a very short time of going on treatment.
- Patients are gaining weight, and regaining health and strength.
- Stigma has been seen to break down as people are given hope that they can live on treatment, and not die of AIDS-related causes.
- Hospices are discharging patients who had been taken there to spend their last days.
- Hospices are becoming treatment centres for ARVs, not necessarily only places where people die.
- High adherence rates have been very heartening. If the counselling works, and people do what they are supposed to do, the programme can work.
- People recognising the second chance they've been given, and making apprpriate choices accordingly.

Challenges

Forging so many new partnerships concurrently has been a very difficult challenge, one that has necessitated choices and decisions that impact on the programme as a whole. Some relationships with various partners would not have happened in another course of events. The medical expertise within the SACBC is limited, and we have had to seek assistance from elsewhere. Getting started at all, especially looking back, was perhaps the biggest challenge of all. There were times when the difficulties appeared insurmountable to people who didn't have huge medical and clinical infrastructure to back them up.

Effective monitoring and evaluation tools have also proved enormously challenging. Demands of donors have also been a headache. Everyone wants a share in the benefits of the programme, and some of the demands have not been helpful to sites. Uncertainty concerning future funding remains a concern. What happens after PEPFAR? Will the health systems of the various countries be willing to absorb patients who have been started on treatment?

Challenges around finding doctors, nurses, co-ordinators, and getting them trained have varied from place to place. Some sites have struggled more than others. Issues related to the treatment of children have been particularly challenging since no one has much experience yet in this area. Challenges in the area of ethics have often to do with who it is we put on treatment, knowing that the funding allows for specific numbers of people, no more. Particularly challenging is the recognition of how easily drug-resistance can be

introduced into particular patients or a whole programme if people are not properly counselled around adherence. Several sites have evidence to suggest that patients do not do well if different drugs interact with one another, and yet we know that some patients or their families wish them to use traditional medications at the same time that they are on ARVs.

Theological questions

Some people question the role of the church in AIDS treatment, sometimes seeing people with AIDS as deserving of their condition, and at others engaging in debate about the efficacy of treatment to start with. The first objection certainly taps into questions of stigma and discrimination, often present in the Church as much as in the wider society, as well as into questions of the responsibility people take or do not take regarding the transmission of HIV. The second brings to the fore the guidance that the medical and scientific community needs to give the Church and society as a whole about what works and what doesn't. Clearly though it also points to the value that the Church places on every human life; the Church, Catholic health practitioners would argue, can help give people a sense of hope and an opportunity to some to live longer than they would if treatment were not an option. This in turn raises moral questions again about future responsibility people need to take when their health improves for not spreading HIV to others.

Selecting sites and patients who will go on treatment at those sites calls for decisions that are not always easily made. Certainly a reasonable infrastructure is needed, and trained personnel who can do the job according to the best possible methods in resource-poor settings. Church programmes have guidelines in this regard, but decisions are not taken easily when sick people present themselves A decision made early on in our programme was the need to target women in particular, those who bear the brunt of HIV infection. Women delivering babies have come for treatment, as have others, but ironically it is men who need actually to be targeted since they have not come forward in the same ways as have women. Some of the funding at our disposal specifically targets foreigners (in Francistown, Botswana) or refugees (in the inner city area of Johannesburg and near the Mozambiquan border) who do not qualify for treatment provided by the relevant department of health.

The future?

The mission of Jesus must continue, and for the foreseeable future the work of the Church in healthcare around AIDS is cut-out. Clearly, given, the various issues involved, the challenges are not simply around healthcare in a narrow sense, but around strategic partnerships, dealing with ethical questions, and helping people to make the choices that are needed for wholesome living in our modern world.

Biography

Sr Alison Munro, OP, from Johannesburg, South Africa is a member of the Congregational Leadership Team of the Dominican Sisters of Oakford. She hold an Hons BTh (missiology), MA (counselling) and MTh (spirituality), as well as a high school teacher's diploma. She taught in Swaziland for several years, and has worked with seminarians and young people in formation. She has worked in the AIDS field since late 1990, and for the past five years has headed the SACBC AIDS Office in Pretoria. She has a number of published articles and chapters on AIDS-related issues in books, and co-edited "Responsibility in a Time of AIDS: a workbook for small Christian communities", published by the SACBC.