Access to Anti-retrovirals
The Role of Treatment Activism in South Africa

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“I exist as a living embodiment of the inequity of drug availability and access in Africa. My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of about US$400 per month. Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can afford to pay for life itself.” (Edwin Cameron, International AIDS Conference, 2000)
I am tired of seeing profit taking priority over the right to health. I am tired of the logic that says, “He who can’t pays, dies.”….Must we now say to our patients “I am sorry, I cannot treat you: you will die of market failure.” (James Orbinsky, MSF)
Context

- Access to care for people living with HIV is one of the most complex development challenges of present time.
- This challenge raises ethical, political, economic, social, human rights issues.
- AIDS has become a chronic manageable disease in developed world, but access to anti-retrovirals (ARVs) is still very limited in most developing countries.
- Different groups are campaigning for ARVs, and highlighting the possible impact of international trade agreements on drug prices and access.
Context

• South Africa has one of the most devastating HIV/AIDS epidemics in the world (5.6 million infected)
• Most of the activities are aimed at prevention
• Limited number of people receive ARV through:
  -insurance /private sector
  -as participants of clinical trials
  -very few from public sector
• A strong treatment activism related to access to ARVs has emerged in the country
Research questions

• How the global campaign influenced the treatment activism in South Africa?
• What factors contributed to a strong treatment activism in South Africa?
Methodology

- Literature review
- Observation (visit to ARV clinics, participate in activities organized by campaign groups)
- In-depth interviews with activists, NGO workers, trade union members, academics, clinicians, legal experts, media personalities
- Study period: August 2001 and January 2003
The reality

- 2 billion people lack access to basic health care and millions die each year from preventable diseases
- Only 10% of global research and development is directed towards illness that account for 90% of the world-wide disease burden
Role of international NGOs

• Over the last two decades international NGOs have participated in public policy processes at international level (e.g. Jubilee 2000 campaign)

• The NGOs argue that the health gap between rich and poor countries is reinforcing wider inequalities, which undermines efforts to meet internationally agreed human development agenda
Role of international NGOs

• Consumer and public interest groups are long-term supporters of the essential drug concept, with particular emphasis on equity and access.

• Campaign groups expressed moral outrage that millions across the world are denied their right to medicine because they are not able to pay.

• Different NGOs have launched a moral and political campaign regarding access to ARVs.
Role of international NGOs

• MSF launched Access to Essential Medicines campaign
• Oxfam launched a campaign called Cut the Cost
• VSO called for price reductions in essential medicines as part of Treatment for Life campaign
• The Health GAP Coalition acts as an international point of contact and coordinate the activities regarding access to medicines
Outcome of international campaign

• The movement for more balanced policies on pharmaceutical patent and trade rules has seen impressive progress
• The crisis surrounding access to ARVs gained global attention
• The big corporations, governments, and international agencies started to rethink what is possible
International AIDS activism

• The early 1990s marked a period of community activism to address HIV related human rights issues
• AIDS movement was the first social movement in the USA to accomplish the conversion of disease-victims into activist-experts
• Gay activist groups have been successful in influencing HIV/AIDS related policies in some Western European countries
Background of South African activism

- Civil society played a major role during anti-apartheid struggle
- Civil society succeeded in persuading the government to adopt HIV/AIDS plan
- HIV/AIDS policies and the response became confused later on
Background of South African activism

• AIDS policy implementation post 1994 has been characterized by conflict between key players

• NGOs, human rights organizations, academics, and trade unions continued to play their roles in fight against HIV/AIDS
South African activism

- The AIDS activism in South Africa consists of a number of organizations and alliances.
- South African activists are well-networked with clinicians, community based organizations, locally based support groups, policy researchers, church organizations and trade unions.
- Treatment Action Campaign (TAC) was established in 1998.
Objectives of TAC

• To ensure access to affordable, high-quality treatment for all people with HIV/AIDS
• To prevent new infections
• To improve healthcare access for all South Africans
Major activities

- Building mass membership
- Treatment literacy and political education
- Public awareness and mobilization
- Local network building
- Health service support and monitoring
Major activities

• Creating and developing support groups
• Lobbying with councils and other institutions at local level
• Using different forms of communication (songs, newspapers, videos, television, newsletters, email listings, leaflets, posters etc)
Volunteers

- TAC has numerous members and supporters around the world
- Volunteers come from all races, age groups, and professions
- Some have lost family members and friends to HIV/AIDS
- HIV positive people have joined the campaign
Volunteers

• Some have experience of anti-apartheid struggle and gay rights movement
• They are extremely dedicated, passionate about the cause, and angry
• Volunteers are well informed, legally strong and well-networked
Comments of supporters

“If you are HIV positive and stay at home you always think of the disease. By joining TAC, I can talk about it to other people and help them to cope up with AIDS.” (HIV positive volunteer)

“TAC is an ideological struggle. There has been moral renewal in different parts of the world regarding people’s rights. TAC’s role should be analyzed in that context.” (Volunteer)
Comments of supporters

“There has been a demobilization of civil society after the election in 1994. TAC is bringing back some of the activities in voluntary sector.” (Academic)
Practical achievements and challenges
Court case: turning point in treatment activism

- In 1998, Pharmaceutical Manufacturers Association (PMA) filed suit against the government to block the amendment of Medicines Act
- TAC was admitted as friend of the court
- MSF launched Drop the Case campaign
- Activists around the world expressed solidarity on international day of action
- The case received extensive media coverage worldwide
Court case: turning point in treatment activism

- PMA dropped the case in 2001
- This case highlighted patent abuse and profiteering of pharmaceutical companies when public health is at stake, BUT
- Not enough practical steps were taken to make ARVs available in public sector
Mother-to-child transmission

- TAC won constitutional court case against government regarding MTCT
- This ensures that every pregnant woman has the right to be counseled, tested, provided with information on health options and given ARV therapy
- This was a huge moral victory, BUT
- The government was very slow in rolling out the program
Treatment plan

• Government endorsed treatment plan in August, 2003
• The announcement is a result of a lengthy civil society movement, led by TAC
• Huge challenges remain regarding drug supply, laboratory facilities, skilled health workforce, monitoring etc
TAC’s contribution

• One of the most dynamic and innovative movements in democratic South Africa
• Successful in bringing access to ARV in public as well as policy domain
• Recreated hopes that lives could be saved
• Won moral victory on the need of treatment for people living with HIV/AIDS
TAC’s contribution

- Empowered HIV positive people through treatment literacy
- Mobilized other stakeholders in the fight against AIDS
- Succeeded in focusing national attention on the issue of collective action and drug access
- Inspired various activist groups in different countries
Factors contributing to the activism

- Dynamic leadership
- Use of human rights framework
- Media visibility
- Use of legal arguments
- Urgency of the crisis
- Networking at national level
- Support from international activist groups
- Effective communication
- Political tradition of activism
Factors contributing to the activism

- Campaigners utilized human rights and constitutional arguments in access to ARV debate
- Legal instruments were used effectively
- The urgency of the crisis combined with the lack of govt action angered young HIV infected people
- Networking with national unions, employers, religious bodies, women and youth organizations, lesbian and gay organizations was critical to the success
Factors contributing to the activism

• South African activists linked successfully with international campaign groups
• Activists gathered information from a wide range of consumer and biomedical sources, and disseminated those
• Local political tradition helped in mobilizing township youth
• The leaders were very competent in utilizing legal framework, national and international network, and media successfully.
Conclusions

• South Africa’s unique history makes it difficult to draw generalizations
• The movement is creating a momentum for social mobilization
• Translating legal gains into policy formulation and implementation remains challenging
• TAC should maintain its advocacy efforts by active engagement with government and other stakeholders
“Why are poor people in South Africa allowed to die when they can be treated? For me, this is both an intensely personal question and a human rights issue.”

(Zackie Achmat, Founder of TAC)
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