

Institution: The University of Hull
Unit of Assessment: C22: Social Work and Social Policy
Title of case study: The contribution of a socio-cultural understanding of the HIV/AIDS epidemic to its management and treatment
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>The research into the main socio-cultural causes, consequences and management of the HIV/AIDS epidemic in South Africa (undertaken by Dr Liz Walker, in collaboration with colleagues in South Africa) has had significant impact in South Africa on the development of the education and training of health and social care professionals working in the context of, and specializing in, HIV/AIDS. The programme of research has resulted in the production of an educational and training resource that is used in HEIs and other professional training settings. The educational resource is unique as it foregrounds HIV/AIDS as the context within which all health and social care practice is undertaken in Southern Africa.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The AIDS epidemic in South Africa has been the fastest growing epidemic in the world, with devastating personal, social and economic consequences. Understanding the social and cultural factors which have fuelled the epidemic has been paramount in changing behaviour and influencing policy and practice in the field. The research outlined below has contributed centrally to a social scientific understanding of HIV/AIDS in resource-poor contexts.</p> <p>This case study is built on a programme of research into the socio-cultural aspects of HIV/AIDS. This research has identified the dominance of HIV/AIDS in all health and social care practice in South Africa and shaped an understanding of the social dimensions of the epidemic which is critical to halting the spread of the epidemic and influencing its management. The educational resource, now in its 3rd edition (2010), was built on a body of scholarship which has three strands:</p> <ol style="list-style-type: none"> 1. The first strand focused on the role of culture and cultural practices in the treatment of HIV/AIDS. This was a collaborative research project between the University of Hull (Walker) and the University of the Witwatersrand, Johannesburg (Gilbert). The contribution of the research expertise located at the University of Hull was central to the successful completion of this project. The research project was entitled, 'The social and cultural complexity of adherence to antiretroviral therapy (ART)'. The research was conducted with health workers and people living with HIV/AIDS in a state health clinic in Hillbrow, Johannesburg, during 2005/6. The administration and management of ART, particularly during this initial period of state funded provision in South Africa, was highly complex – public health services were (in general) ill-equipped and under-resourced and the disease highly stigmatised. This externally funded research project aimed to better understand the social and cultural barriers to effective treatment and change the ways in which ART was delivered in HIV/AIDS clinics. The treatment of HIV/AIDS is thus also a cultural process, particularly in the South African context. This research identified the stigmatised nature of 'specialised AIDS clinics'; the ways in which ART 'marked' and stigmatised patients; created unwanted and forced 'disclosure' to employers / family members etc. The research focused on the need to incorporate these understandings into planning service provision. This project resulted in two journal articles in leading international public health / health journals and has been incorporated into the educational and training resource. 2. The second strand of research offered a gendered analysis of the HIV/AIDS epidemic. The research study which demonstrates this was a study entitled <i>Masculinities, Risk and HIV/AIDS</i>. It aimed to examine the ways in which men (in particular) and unequal gender relations more broadly are key drivers of the epidemic in South Africa (5.4). This research

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demonstrates how dominant hegemonic masculinities have led to men engaging in risky sexual practice (e.g. multiple sexual partners, unsafe sex), placing them (and women) at high risk for HIV infection. The field work for this study was conducted in Johannesburg, South Africa during 2002/3. The data was analysed and written up at the University of Hull, from 2004, drawing on the expertise at that institution (Walker). This research resulted in the publication of an edited collection, *Men Behaving Differently. South African men since 1994* (2005) and a journal article in a leading international journal in the field (Culture, Health and Sexuality). The edited collection was the product of research collaboration between the University of Hull (Walker) and the Wits Institute for Social and Economic Research, University of the Witwatersrand, Johannesburg (Reid).

- The third strand addressed the **historical and social causes** of HIV/AIDS in southern Africa and resulted in the publication of a book, *Waiting to Happen: HIV/AIDS in South Africa* (2004). The monograph was based on a wide range of research presented at an international social science HIV/AIDS conference, held at the University of the Witwatersrand, Johannesburg, in 2001. The book, commissioned by the History Workshop, University of the Witwatersrand, sought to popularise and make accessible, empirical, academic research. The conference on which the text is based was the first of its kind in South Africa and brought together academics, government ministers, HIV/AIDS activists and NGOs. This book was an important corrective to the predominant emphasis on bio-medical explanations of, and responses to, HIV/AIDS and argued for the need for widespread availability of Anti-Retroviral Therapy (ART) at a time when the government did not recognise its importance in treating and preventing HIV/AIDS. This text has strongly informed the third edition of the educational training resource identified above. It was published in South Africa and the US.

3. References to the research (indicative maximum of six references)

Liz Walker is the only researcher based at the University of Hull (from 2004). These publications are the result of collaborative research projects (identified above).

Gilbert, L. and Walker, L. (2010) 'My biggest fear was that people would reject me once they knew my status...' – stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa, *Health and Social Care in the Community*, 18 (2) pp 139-146. (Impact factor 1.054, ranked 9/32 in Health / Social Work related Journals).

Gilbert, L. and Walker, L. (2009) 'They (ARVs) are my life, without them I am nothing' – experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa. *Health and Place*, 15 (4), pp 1123-1129. (Impact factor 2.993, journal ranking 6/76 in public, environmental and occupational health category).

Reid, G. and Walker, L. (eds) (2005) *Men Behaving Differently. South African Men since 1994*. Cape Town: Double Storey/ Juta.

Gilbert, L., Selikow, T. and Walker, L. (2010, 3rd edn) *Society, Health and Disease in a time of HIV/AIDS*. Johannesburg: Pan Macmillan.

Walker, L., Reid, G. & Cornell, M. (2004) *Waiting to Happen. HIV/AIDS in South Africa*. Colorado: Lynne Rienner Publishers /Cape Town: Double Storey Books/Juta.

4. Details of the impact (indicative maximum 750 words)

The central impact which draws together all three research strands (2.1, 2.2, 2.3) is the education and training resource '*Society, Health and Disease in a time of HIV/AIDS*' (2010, 3rd edn). This resource has been widely used by health and social care professionals across South Africa since

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the first edition was published in 1996 (5.5; 5.6). The third edition (2010) involved substantial re-working, the addition of much new material and a change in title to reflect a more central emphasis on HIV/AIDS. Pan Macmillan records indicate that from 2002, 6594 copies have been purchased across southern Africa, 3608 have been sold since 2008 (5.3). The resource has a distinctive format, designed for training in both urban and rural settings in South Africa. It is interactive, it includes original research based material (written by the authors), key readings (including published research by the authors) and educational tasks (drafted by the authors) designed to help the student / practitioner work through the material and ideas presented (5.5). This training resource enables students and health care workers to understand the social and cultural basis of HIV/AIDS – transmission, treatment and management – thus influencing their practice with HIV positive service users in particular (5.6).

The resource has been prescribed in nine (of seventeen traditional and comprehensive) HEIs throughout South Africa since the publication of the first edition. These include: The University of South Africa, University of Kwa-Zulu Natal, Pietermaritzburg, University of Cape Town, University of the Western Cape, University of the Witwatersrand, University of Namibia, Baragwanath Nursing College, Democratic Nursing Organisation of South Africa. The main beneficiaries of this resource are health and social care professionals and people living with HIV/AIDS who receive a more culturally and social informed service (5.4). The success of the first and second editions led Pan Macmillan to support the production of the third edition.

The three research strands identified in section 2 (all of which influenced the production of the educational resource) led to other publications, thus having wider impacts on policy formulation and public debates on HIV/AIDS. This was particularly important in the context of initial government refusal to provide ART to people living with HIV/AIDS (see above references to the research). In the foreword to the book *Waiting to Happen: HIV/AIDS in South Africa*, Mr Justice Edwin Cameron stated 'The book draws on an impressive and authoritative range of papers that address the social, cultural and historical roots of the epidemic in a region heavily burdened by AIDS. It is therefore published at an acute time' (pg 7) (5.1). During the period in which the research was carried out and published, government policy in South Africa changed to adopt a centrally funded roll-out of ART, significantly changing the trajectory of the epidemic. This research was part of a body of social science research which contributed to this policy change. All of the projects have received external funding and have involved international collaboration.

Waiting to happen: HIV/AIDS in South Africa was also published in a separate version in the United States. In 2004, 1500 copies of this US edition were printed – only 63 now remain in stock (5.2). This text was recommended reading on a course at Yale University, Aids in Africa, between 2006/ 09.

The body of scholarship which has as its primary focus the socio-cultural context of HIV/AIDS has been published in different formats. The research has been published in leading international journals of medicine and public health thus informing academic and scholars working in the area. However, in the context of HIV/AIDS in resource poor countries it is incumbent on scholars to produce and reproduce strong research material in a way which will serve to combat the epidemic and improve the quality of life and services for those people living with HIV/AIDS. The training resource and the strands of research identified above have succeeded in doing this (5.4).

Other researchers contributed to this research. 'The social and cultural complexity of adherence to ART', was conducted jointly with Professor Leah Gilbert (University of the Witwatersrand, Johannesburg). It was funded by the National Research Foundation, South Africa (R192 000, 00). 'Waiting to Happen: HIV/AIDS in South Africa' was written jointly with Graeme Reid now Human Rights Watch (NY), Morna Cornell, University of Cape Town. Masculinities, Risk and HIV/AIDS, was funded by the National Research Foundation, South Africa (R34000.00)

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. Foreword 'Waiting to happen' by Edwin Cameron, Constitutional Court Judge and the first senior South African official to disclose his HIV positive status.
2. Email correspondence Lynne Rienner Publishers, Boulder, Colorado. The sample list of bookstores which ordered this title include: Syracuse Bookstore, Syracuse NY, Yale Barnes & Noble, Folletts Bookstore – NC Central, Durham NC, Luther College Bookstore, Iowa, Univ of Oklahoma Bookstore, Ratecliffe Textbooks in Oklahoma, Baker & Taylor, Amazon.com.
3. Email correspondence business analyst, Pan Macmillan.
4. Testimonial Chief Operating Officer, Anova Health Institute (HIV/AIDS NGO/Professional body)
5. Testimonial PhD candidate / lecturer, Department of Sociology, University of Witwatersrand, Johannesburg
6. Testimonial Emeritus Professor, Department of Sociology, University of Witwatersrand, Johannesburg