

AT THE GRASSROOTS: AIDS AND PEOPLE IN SOUTH AFRICA.

Squire, C (2007) **HIV in South Africa**. London: Routledge. ISBN 978-0-415-37210-7. Pages 229.

Alan Whiteside

HEARD (Health Economics and HIV/AIDS Research Division)

University of KwaZulu-Natal

Durban

The HIV/AIDS epidemic in South Africa has been well documented. There have been books that tried to understand why the epidemic is so serious and what has driven the response, in particular the baffling politics of AIDS. These included the classic ethnography by Campbell (2003), Fourie (2006), Nattrass (2007) and Lawson (2008). Biographical accounts included Cameron (2005) and McGregor (2006). The epidemic makes an appearance in South African fiction, from books specifically centred on it (Steyn, 2007); to those where it is in the background (Morojele, 2006); to mentions in detective fiction (Meyer, 1999). There have been moving exhibitions, both photographic and in other media, documenting the scale and effect of HIV/AIDS. Most of these books are written by white South Africans. The voice of the people is generally not heard, although the perceptive book by Nolen (2007) (a white Canadian journalist living in Johannesburg) goes some way to redress this.

Squire's book attempts, in a very academic way, to redress the omission. The back cover states **HIV in South Africa** is the first book to analyse detailed personal, and often very moving, accounts from the South African epidemic, and to link individual experiences to this epidemic's wider social and political context ... using a narrative approach to analyse and understand people's accounts of the HIV epidemic in South Africa". In this review I will assess the legitimacy of the work; the value of the research; and how it might be transformed into policy relevant findings.

Corinne Squire is a Professor in the School of Psychosocial Studies at the University of East London where she co-directs The Centre for Narrative Research (CNR). According to the website the Centre "brings together work on narrative that is being pursued in a variety of contexts across the social sciences ... including ... analyses of the structure of social stories and the processes of social storytelling, and explorations of the relationship between narratives and the social world". This is far cry from the type of work I do or that is undertaken in my unit and so my key question was: to what extent can this book influence my thinking and outputs, and help us respond to the HIV/AIDS epidemic in South Africa?

In a truly British way Squire begins by excusing herself: "This is a book written by someone who is British and HIV negative. Being South African and having direct

experience of living with the virus would not guarantee a full picture, but it would undoubtedly have allowed richer insights into key questions". (p6). This is a pity as she could equally have said the distance may lead to clearer insights!

Of more concern, regarding the value of the book, is the number of people interviewed. The research was carried out mainly in three township areas around Cape Town. In 2001 Squire and her research assistants interviewed 37 people, 29 women and eight men. Of these, 34 were HIV positive. In 2003-4 she revisited the sites and carried out eight follow-up interviews with people from the original sample. All the interviews were either in English or Xhosa and all interviewed were black South Africans. Only 16 of the interviews were one on one; the rest were in groups of two, three and four. Interviewees were paid a fee for their participation and were given refreshments. These points do not de-legitimise the research. However the research is entirely qualitative and the numbers are small. Effectively this is the story of HIV positive people living in the township around Cape Town from 2001 to 2004. A reviewer from the same discipline as Squire could comment on her methodology and interpretation. I can not, so let me rather focus on the value of the work to South Africans engaged in battling the epidemic and seek out policy applications.

The book reflects a particular period in the epidemic in South Africa. In 2000 we saw the huge denial around the epidemic with Mbeki's appointment of a Presidential Panel to investigate the epidemic. However in the Western Cape, where this book is located, the provincial government had launched a programme for prevention of mother to child transmission (PMTCT). In late 2000 Medicins sans Frontiers launched a pilot treatment project providing anti-retroviral therapy (ART) in one of the townships outside Cape Town. By 2004 PMTCT was widely available across the province and ART was becoming available in the public sector clinics. It should be noted that the Western Cape was ahead of all the other provinces, and frequently was working against the wishes, if not express decisions, of the national government. If there were to be a second edition of the book then Squire might consider putting a time line to locate local events in a national context.

The stories of the people of the Western Cape resound with our experiences in other parts of the country. For example Squire's third chapter is "Talking about the big thing". It is not just in the townships and among those living with this disease that we have difficulty in naming HIV/AIDS. Even in the Health Economics and HIV/AIDS Research Division (HEARD) we find our selves, at times, using phrases like "this thing", "the disease that is killing us". It would be useful to know quite how unique this is in relation to other diseases.

In general the book does a credible job of exploring the major issues and adds to the literature. There are, for me, two major gaps. The first is around the politics of AIDS. Although Squire includes a chapter "Talking politics", it is superficial. It would have been good to have more on peoples' political beliefs and how they engaged in politics outside of the HIV/AIDS arena; we do not have a sense of any political engagement from the local party structures. It may be that there was none, but as Squire recognises AIDS in South Africa is intensely political, in terms of what is said as well as what is not.

My second concern is with the interpretation of religion and where it fits into the discourse on HIV/AIDS. Squire notes: "As Nosipho, an interviewee strongly connected

to religious life described it, HIV will never be a disease like others, especially for women, because it is connected to a sexuality that is out of synch with a measured ethical life". (p149). It is difficult for a person not involved in any faith community to understand how complex the issue of HIV and religion is. AIDS "finds you out", no matter how forgiving the religion the reality is that those who are infected have either done something or had something done to them which goes against the rules of religions. The fact that most people have more than one partner; many are not married but are sexually active; and some are married but have, or their partners have, extramarital relations, is irrelevant because under normal circumstances people don't have to know. AIDS can not be hidden and I suspect in the highly religious communities of Southern Africa this is a real issue. It is also gendered, in the small sample "no men told stories of the sexualised shame attached to HIV positivity that appeared in many women's accounts". (p40).

Finally what about policy application? This book will not be read by officials in the Western Cape or at the national level. So what do we take from it? For me it has three messages. First, the people in the townships are dealing with the epidemic in their lives, and it is leading to the development of both "bridging" and "bonding" social capital. Can this be harnessed and guided? Secondly, poverty is grinding and overarching. The people are battling, and the importance of social grants, which is not explored, needs more attention. Finally, we do need to listen to the voices of those most affected – but not just those living with HIV. We need to hear from the carers and grandparents as well as policy makers. For South Africans this type of research is not a luxury, provided we can look for policy, and learn from it what we can and should do.

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