

## **HIV/AIDS: MANAGEMENT AND STIGMA**

Deacon, H with Stepheny, D & Prosalendis, S (2005) **Understanding HIV/AIDS stigma: A theoretical and methodological analysis**. Cape Town: HSRC Press. ISBN 0 7969 2104 0 pbk. Pages 120.

Vass, J & Phakathi, S (2006) **Managing HIV in the workplace: Learning from SMEs**. Cape Town: HSRC Press. ISBN 0 7969 2161 X pbk. Pages 108.

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In the course of offering HIV/AIDS training I have had the opportunity to work with two particularly interesting groups of individuals; the first group included a number of artists, and the second a number of trainee farmers. On both occasions I was asked to cover the basic facts about HIV/AIDS and to discuss and debate possible ways in which each group could respond to the challenges of the virus within their areas of work. This proved to be a difficult task. While a few artists may group themselves into small businesses, many of them come together periodically for commissioned work (disbanding when the project is over) or are self-employed. The farmers, on the other hand, manage groups of workers, many of whom are contract workers and a relatively transient group. In preparing for this work I found it difficult to access relevant literature and information on how these individuals could respond to the epidemic. While there is a large body of literature on the impact of the virus on large companies and a number of existing HIV/AIDS programmes and services that have been designed around the needs (and budgets) of large companies, there is very little that deals with the impact and management of HIV/AIDS on, and in small businesses and even less on how the virus impacts on the informal sector and how this can be prevented and managed. The HSRC monograph **Managing HIV in the workplace: Learning from SMEs** is therefore a welcome, but long overdue, addition to the body of research and literature on HIV/AIDS in the workplace.

The monograph reports on the findings of in-depth case studies of six small and medium sized enterprises (SMEs). The qualitative case study methodology differs from the largely quantitative survey methodology of existing research and aimed to give voice to both the employers and employees of the companies randomly selected for the study. I was, however, disappointed to find that most of the companies (five of the six) included in the study were described as medium sized, consisting of between 150 and 250 employees. Only one company was described as small and consisted of 62

employees. In this way the needs and challenges of small companies, which can include considerably smaller numbers than 62 employees, were largely overlooked by this study.

If we consider the industry of many of the medium sized companies in this study (two of the companies are in the automotive industry) and that six of the companies are in a position to offer permanent employment it is not likely that they face the severe resource constraints of much smaller companies with smaller budgets. In a country with an increase in entrepreneurial enterprises there is surely a need to focus on the role of smaller businesses, with temporary and contract staff, and limited budgets, in mitigating the effects of HIV/AIDS. Going back to the discussion of the artists and the farm workers, how do we develop effective and sustainable interventions for these groups of individuals? While it is possible to draw on some of the ideas discussed in this study, I would argue that small companies run the risk of mimicking the programmes of medium sized companies who have an entirely different set of needs and challenges, just as the medium sized companies in this study were largely seen as mimicking the interventions of larger companies.

One of the reasons for the lack of programmes in SMEs was identified and discussed in the literature review, where it was argued that HIV/AIDS service providers tend to view SMEs as uncertain markets. This highlights Elizabeth Pisani's (2008:288) concern with what she refers to as the HIV/AIDS industry, where "most people do whatever projects pay them to do". While the literature review acknowledges that SMEs might be unwilling to pay for HIV/AIDS services, one cannot overlook the fact that many service providers are part of a larger HIV/AIDS industry and that they will design their services for larger companies who have the budget to pay and in the process the needs of much smaller businesses are overlooked.

Three interesting and valuable sources of information emerge from the findings of this study. Firstly, a wide range of possible HIV/AIDS risk factors for SMEs are identified and critically discussed. One of the more interesting findings was "a case in which the low HIV-prevalence rate contradicted the predicted outcome based on the company demographic profile" (Vass 2006:81)<sup>1</sup>. The workforce in this company is mainly made up of African and Coloured, semi-skilled females, which reflect a high-risk group, yet the HIV prevalence level was low amongst these employees. The study concludes that possible reasons for this contradiction are the age profile (the women were older) and the stability of employment (the length of continuous service was on average 13 years). While the latest DOH (2008) prevalence study suggests an increase in the infection rate amongst older women, the case study discussed above highlights how a number of factors interact in complex ways to either increase or decrease risk of HIV infection. For example, Vass suggests that long service may be key to life style stability, which in turn is considered to contribute to the adoption of safer sexual behaviours. In conclusion Vass argues that "it seems plausible that those in relatively stable long-term employment, in which they have accumulated considerable skills and experience, may be more likely to engage in risk averse behaviour to protect their own accumulated personal capital (a family, a home, personal status in community and social aspirations)" (p82).

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<sup>1</sup> While the monograph is co-authored by Vass and Phakathi, each author has identified which chapters they have written and I have therefore referenced them as such in the review.

Secondly, various approaches to managing HIV/AIDS by SMEs are explored, highlighting some innovative responses, while also acknowledging those factors that may be undermining the success of these programmes. Some creative responses included forming a partnership with an external service provider, another included developing a “co-funding arrangement” between management and the employees to pay for disease management. Disturbingly, but not surprising, was the lack of faith companies had in the government antiretroviral programme. Vaas (p89) states that “Perceptions of chaos in the rollout of the government programme” means that companies do not see it as a possible resource.

Thirdly, measures indicative of the impact and effectiveness are discussed alongside the challenges that constrain SMEs’ ability to develop appropriate and sustainable programmes. The most disturbing finding for me, and yet again not a surprising finding, is the role stigma plays in undermining the effectiveness of existing programmes. Vass comments that in the focus groups employees “seemed embarrassed to receive or give information on the number of people infected in the company” (p91). Vass also reports on a company who was considering the possibility of using self-administered HIV tests “to alleviate employees’ fears around failures of confidentiality” (p92).

In sum, the findings suggest that although SMEs are committed to responding to the HIV epidemic in the workplace, a number of internal and external factors, unless dealt with, will undermine the effectiveness of their interventions. One particular issue that needs to be further researched is the powerful role stigma and discrimination plays in preventing employees from accessing available services. Interestingly the HSRC has produced another monograph on the topic of HIV/AIDS related stigma.

The monograph **Understanding HIV/AIDS Stigma: A theoretical and methodological analysis** firstly, provides a critical overview of a large body of interdisciplinary literature on stigma, secondly, through the review process, identifies key areas in need of further research and thirdly, explores a number of appropriate methodologies that can be used to conduct this research. The monograph concludes by discussing some existing interventions that, although potentially useful, require further evaluation before being taken up in practice. The monograph will therefore be an excellent tool for those interested in the theory of stigma, the research of stigma and intervening to minimize stigma and its impacts. More specifically, it will be of value to those wanting to develop an advanced understanding of HIV/AIDS related stigma.

One of the strongest features of this monograph is its recognition of the importance of grappling with theories of stigma before deciding on a research agenda, research methodology and interventions. As Deacon (2005:3) argues, the way we “define stigma structures our understanding on how it operates and how to address it”. The first seven chapters of the monograph provide an excellent critical discussion of existing theories of stigma with the aim of developing a theory of disease stigma. These chapters cover a number of important conceptual areas. For example, the difference between stigma and discrimination is critically discussed, the importance of exploring stigma from the position of the stigmatiser and the stigmatized is highlighted, and the difference between instrumental stigma and symbolic stigma when trying to understand HIV/AIDS related stigma is debated.

Chapter 8 moves on to using the gaps identified in the theoretical review to develop a research agenda and questions for research on HIV/AIDS stigma in southern Africa. Deacon concludes that there is a need to change the kinds of questions being asked in research. She argues that there is a need to move away from researching questions that have already been answered, from simply measuring stigma or exploring the link between stigma and inequality. There is, for example, a need to develop improved theoretical models of stigma, to explore local beliefs around HIV/AIDS, the histories and politics of stigmatising ideologies, the relationship between stigma and discrimination, and how PLHA (people living with HIV/AIDS) respond to stigma and discrimination. In chapter 9 interdisciplinary methodologies that are considered to be appropriate for these research areas are identified and discussed. Deacon (p74) argues that “we need to expand our range of methodological tools beyond the standard interview and content analysis” and suggests the inclusion of innovative participatory approaches including body mapping and stigma mapping. Chapter 10 concludes the monograph with some preliminary thoughts about how, in Deacon’s words, “theoretical and methodological approaches could be translated into anti-stigma and anti-discrimination interventions” (p75).

I believe the strength of this manual is not only in the content it covers, but also in its “design”, that is, that it illustrates the importance of theoretically informed research and interventions. I will certainly use this monograph as a tool in research supervision with my postgraduate students. I will also use the content covered in my workshops with professional psychology students to develop their understanding of the theory and impact of stigma and its link to HIV/AIDS. Hopefully the Employment, Growth and Development Initiative of the HSRC will also make use of this theoretical and methodological analysis when thinking about the role of HIV/AIDS stigma in the workforce.

## **REFERENCES.**

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