ePrivacy, Surveillance and HIV/AIDS in the Workplace. A South African Case Study"
Z. Muskat-Gorska

Interview with dr Nikki Connellan, Senior Medical Practitioner, Lifeworks, 03.12.07

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date: 03.12.2007
time: 10.00-12.00

1. The VCT and ARV uptake is low. Wjat are the reasons? Is condifidentiality perceptions one of the important ones?
2. From the business perspective - how important is monitoring of the epidemic – when it should overcome confidentiality issues (value of reporting against the valie of confidentiality)
3. What is Lifeworks' practice in order to protect confidentiality? How data is stored?
4. In what set of data are employers interested in (what will be a maximum scope of data they would ask for) – any cases they ask for more identifiabke data in order to undertake more precise cost benefit analysis of the HIV/AIDS program?
5. Are there other measures companies implement to gather HIV/AIDS data about their employees? (What are the possibilities of collecting HIV/AIDS data through other methods of workplace surveillance)
6. What is the probability of disciplinary action against an employee for unauthorused disclosure of HIV/AIDS data? (in the workplace? In Lifeworks?)
7. What is better for HIV/AIDS data confidentiality – insourcing or outsourcing of HIV/AIDS management in the workplace?
8. What is your opinion on the role of trade unions in South Africa in HIV/AIDS policy?

It is difficult to assess the impact of outsourcing or insourcing of the workplace HIV/AIDS management on uptake of VCT or/and ARV. We as Lifeworks did try to assess whether perceptions of confidentiality of HIV/AIDS data in the workplace get

better if the company outsources the management of HIV/AIDS in the workplace. In other words, we tried to find out whether the VCT uptake be better if testing be organized by an outside provider. However, changes in uptake are always influenced by more than one condition. Even if we observe that more workers test after outsourcing of VCT by a company, it might be because other factors – for instance, incentives granted if someone tests for HIV – little gifts etc. We did have some discussion with BHP Billiton that outsourcing of VCT brings a significant increase of uptake among the employees but, in reality, it is usually a combination of factors, not outsourcing itself.

In Eskom, for instance, all workers are on medical scheme that covers medical management and VCT. Lifeworks recently did a pilot project in their head office, assessing the uptake of these benefits. The research was structured in the way to make it representative for greater population of employers. The outcomes showed that the employers are not very interested in using HIV/AIDS services provided. It seems obvious that in this country one needs to be proactive in providing HIV/AIDS testing or treatment. Even if HIV/AIDS facilities are in place people do not use them by themselves. There is a variety of reasons for that. Stigma, misinformation – many people think that if they feel well they are not HIVpositive. There is an urgent need for a multidisciplinary approach to the disease. And, especially, one needs to be proactive about VCT which should be combinesd with education.

Education is crucial in South Africa in managing HIV/AIDS. Lots of companies run information   activities, presentations on HIV/AIDS but they do not focus on the employees' state of mind. We as Lifeworks educate and create demand for VCT – immediately. In addressing HIV/AIDS we combine VCT with the disease management. Too often companies separate these two issues, creating a huge gap – in the consequence, they loose many potential patients, especially those who tested positive but still feel well. If the disease management is not provided immediately after testing a gap for denial is being created. This a lost opportunity from the perspective of the successful HIV/AIDS management and treatment.

Lifeworks runs a VCT programme in the enterprise where all employees willing to test sign the consent form. The programme consists not only of testing. People found HIVpositive are being contacted immediately and got on treatment. In this way Lifeworks provides with a post – post HIV/AIDS councelling which is urgently needed – the need to contact the patient after testing, to tell him/her why health management is needed. This stage is lacking in corporate HIV/AIDS management where companies rung huge VCT programs but afterwards the patients are not contacted proactively and the opportunity to get them on treatment immediately is lost.

We are trying to avoid this mistake. We provide with a comprehensive HIV/AIDS management where each patient is being dealt with individually. And we do implement a proactive approach. For instance, for many patients it is very difficult to manage administrative issues, set the appointments etc. We manage that. We plan the appointments of the patient and organize all administrative details which is an enourmous relief for people on scheme, who can then focus on their treatment.

Eskom begins to realize the importance of an integrated HIV/AIDS management. The used to have four disease management schemes. They used to run VCT. And people do know their status. But they are not managed continously. To some extend South Africa shares the characteristic of a Third World country – many people are naïve to manage a chronic disease and they need to be assisted. In treating HIV/AIDS assisstance is crucial. Unsupported patient is a not compliant patient. Lack of compliance after starting ARV treatment makes the patient resistant to drugs and treatment opportunity is lost. Lifeworks run a first pilot project in providing an integrated HIV/AIDS management in the workplace and it was very successful.

We see a change in workplace response to HIV/AIDS. On the one hand, the uptake of testing is bigger – it is observable even in the last 2 years. At the same time, there is a significant growth in corporate interest in VCT. Smaller companies realized that it is a business risk not to assess HIV/AIDS in the workplace. They did not see it like this before. For bigger companies this is now an important public relations issue. It also becomes a part of competition on the market to avoid the negative impact of HIV/AIDS on business by managing it. However, even if the companies run HIV/AIDS programs, the management of patients is poor as it is not their main focus. This is where companies like Lifeworks may have an important input.

When it comes to reporting the HIV/AIDS data back to the employer we have detailed procedures. We would never provide identifiable information back to the employer. We are fully aware that this would be a disaster for the testing and treatment programme as people would not uptake it anymore. Also, the trade unions would react and will have good grounds for it. We therefore carefully adjust our reporting. However, we have never had that case where a client requested an identifiable information. Perhaps service providers are more eager to give out such data in order to attract business to conract services with them. There might be cases in Swaziland that service providers disclosed identifiable HIV/AIDS data to their clients but I do not have more detailed information on this issue.

I do not remember cases where Lifeworks was asked by an employer to provide individualized information on workers' HIV/AIDS status. All we provide is data on HIV/AIDS prevelence in the workplace, with all the necessary safeguards to make it unidentifiable. Companies are interested in this kind of data in order to assess the impact of HIV/AIDS on business. Also, in my opinion, currently it is highly desired for the companies to show that they have a significant interest in HIV/AIDS, that they analyze the phenomenon and manage the risk HIV/AIDS creates for their bussiness. That is why they are paying for this data. We keep our data in a SQL database system[1] and we can easily provide our clients with the data they need.

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[1] SQL is a database computer language designed for the retrieval and management of data in relational database management systems (RDBMS), database schema creation and modification, and database object access control management. SQL is an acronym for Structured Query Language. SQL is a standard interactive and programming language for querying and modifying data and managing databases. Although

In organizing VCT in the workplace Lifeworks tries to bring its advanced experience. For instance, first we create the need, then we provide testing. Usually, we first give the presentation on HIV/AIDS and the need to check the status. It is like in a sales job – creating a demand for VCT. Then, immediately after the lecture, even without the audience leaving the room, we provide testing – one of these rapid saliva tests.

Secondly, we want every single group tested – employees, managers, office staff, workers. We try to make the CEO and/or Managing Director test first in order to build trust. This has a lot to do with confidentiality – we want to give the sign that testing is absolutely confidential – you see who is tested, but there is no way for the public to know results. By involving chief managerial staff – we want to create the feeling of „ubuntu". By providing testing immediately after the presentation we want to make it more difficult not to test then make difficult to test. The aim is to use this method in all companies we provide VCT for.

It seems that insourcing or outsourcing HIV/AIDS management in the workplace does have significant consequences for confidentiality and perceptions of confidantiality among workers. As far as Anglo American is concerned, the company that organizes its VCT through indepenedent but company-financed (?) research unit Aurum, I think that insourcing plays some role in the fact that they did not get the numbers they want of the workers tested. Also, outsourcing HIV/AIDS management may in some cases improve efficiency of the action (Rustenberg?). Outsourcing means better safeguards for confidentiality and observable improvement in uptake.

In Lifeworks we implemented the strictest safety arrangements for HIV/AIDS data. All employees that access it sign confidentiality clause. We have never had cases of unauthorised disclosure or data threft, but in such case the most severe discliplinary action would be undertaken. We are aware that treatment of data on HIV/AIDS is absolutely crucial for confidentiality. Not only in the office where data is processed and stored in a database. Also during transport. That is why our confidentiality saeguards include protocol for truck drivers who deliver data from the site (workplace) to our offices. For instance, they are even not allowed to stop at a petrol station. They have to drive straight to the office in order to secure safety of sensitive data.

It is enough to say one thing – our business is built on confidentiality. That is why independent providers are successful in getting employees tested in the workplace. They are interested solely in getting information on HIV/AIDS prevelence and in providing treatment. Their relation with the worklace is limited to that aim and therefore is not as complex as relationship between the employer and the worker.

SQL is both an ANSI and an ISO standard, many database products support SQL with proprietary extensions to the standard language. The core of SQL is formed by a command language that allows you to retrieve, insert, update, and delete data, and perform management and administrative functions. SQL also includes a call-level interface (SQL/CLI) for accessing and managing data and databases remotely. http://en.wikipedia.org/wiki/SQL [03.02.2008].

Trade unions may play a very important role in the success of the workplace HIV/AIDS action. We saw it for instance in BHP Billiton where we provided VCT programme. Trade unions were not properly consulted and involved and they did not support the campain which failed. Now we are aware that there is a need to involve trade unions in the VCT programme, all of trade unions present in a given workplace.

It is not always easy. Some employers are not eager to cooperate with trade unions. Also, some trade unions could be more active in the field of HIV/AIDS. There is still a gap. However, if it happens to have a proactive shopsteward in the workplace the VCT campaign can be very successful. For instance, in the same company BHP Billiton, but different site (Manganese division) where we provided VCT in 2005 trade unions strongly encouraged workers to get tested. They even packed people to buses to send them for test. But it is not frequent to have trade unions in the workplace active on HIV/AIDS and there is still a lot to be done.