



INBORN ERRORS OF METABOLISM: HEARTACHE-SAVING TEST TO GO NATIONAL

Relatively cheap early testing of infants for inborn errors of metabolism, a condition of which the consequences can be tragic and traumatic for families, has become nationally available in terms of a university agreement with the National Pathology Group (NPG).

The University of Potchefstroom acquired laboratory equipment for carrying out Tandem Mass Spectrometry testing earlier this year and the NPG has now agreed to collect and transport blood specimens, significantly increasing the reach of screening programmes.

With early diagnosis crucial to successful treatment (diet and medication), the implementation of universal screening could reduce nearly all the complications and fatalities resulting from metabolic disorders.

According to the NPG the testing is fast, accurate, reliable, inexpensive (R140 per test) and easy to initiate. It can detect more than 30 of the 200 identified metabolic disorders.

Although relatively rare (a pilot programme to establish the South

African incidence revealed it to match the 1/1 000 births global norm), the disorder is inherited in an autosomal recessive manner, giving it a 25% chance of recurring in subsequent pregnancies. This makes it advisable to test an older child for metabolic disorders even if it is too late to help that particular child.

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According to the leading force behind the testing innovation, Dr Jennifer Cartwright, of the Department of Paediatrics, University of the Witwatersrand and Johannesburg General Hospital, many doctors believe testing to be 'expensive and pointless' and that babies born with these disorders will die anyway.

She led the charge to secure the equipment and co-operation of the NPG after witnessing many children, 'come through my doors with unexplained brain damage'.

'As a paediatrician I found this frustrating and alarming and when I investigated possible causes, I found that a frequently missed explanation was an inborn error of metabolism.'

She is aiming to expand the newborn screening programme in the public and private sectors with NPG laboratories having already agreed to collect and transport blood specimens for a minimal fee.

Scientists at Duke University adapted standard Tandem Mass Spectrometry to newborn screening, taking a single spot of blood from the heel of a baby and placing it on filter paper. The sample is analysed for a lack or excess of the by-products of metabolism resulting from the absence of the enzyme required in the metabolic process.

Chris Bateman

HEALTH CARERS CRACKING UNDER HIV/AIDS WORKLOAD

The biggest survey yet on the impact of the HIV/AIDS epidemic on public health workers in this country shows 16.3% of them to be HIV-positive and nearly half to be 'exhausted and stressed' from a four-fold increase in AIDS patients over the past five years.

At least 6 000 health workers could be dying every year from AIDS-related illnesses, if projections based on death notifications compiled by Statistics SA between 1997 and 2000 are accurate.

Prescribed precautions to lower the risk of blood-borne diseases are being flouted and only 43% of public hospital managers and just 7% of private hospital managers have seen the national AIDS plan.

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These are the major and alarming preliminary findings of a survey of a cluster of 222 mainly metropolitan health facilities across all sectors conducted by a Human Sciences Research Council team and led by Professor Olive Shisana last year. Shisana is the HSRC's Executive Director, Social Aspects of HIV/AIDS and Public Health.

Just under 2 000 health care workers and just over 2 000 patients in private and public facilities were interviewed.



Speaking after presenting her findings to a hushed audience at the national HIV/AIDS conference in Durban in August, Shisana told the *SAMJ* that one of the few comforting aspects of the research is that it was commissioned by the national Department of Health. 'I'm very pleased the department has taken up the challenge to find out what's going on and to see what they can do,' she said. The findings had far-reaching implications 'as far as the ability of the health care system to manage this pandemic'.



Professor Olive Shisana.

Public bed occupancy by patients suffering from AIDS-related illnesses stood at 89.3% while the total average length of stay in district, private and public health care facilities was 13.7 days for HIV-positive patients and 8.2 days for non-HIV-infected patients. District hospitals were taking the biggest strain at 91.8% of AIDS-related medical bed occupancies.

Non-HIV patients were being 'crowded out' by those infected with the virus and were becoming increasingly unlikely to get health care.

A conservative *SAMJ* survey of some major tertiary KwaZulu-Natal hospitals 2.5 years ago showed between 55% and

65% of medical beds to be occupied by patients suffering from AIDS-related diseases. Even then, doctors were complaining of non-HIV patients being 'crowded out' while those working in emergency rooms were openly flouting needle-stick protocols because the injury was so commonplace.

Shisana's team found HIV prevalence among health care workers to be highest in the North West (19.7%), Mpumalanga (19.6%) and KwaZulu-Natal (17.1%). Non-professional health care staff between the ages of 18 and 35 were the worst affected with an average HIV prevalence rate of 20%. The prevalence among professionals was 13.7%.

'This obviously has implications for the future supply of health staff as the younger group is worst affected overall,' said Shisana.

Contributing to the veil of silence surrounding the disease was the legal prohibition on informing relatives and partners and the human rights conflicts this produced, and patient volumes which precluded effective counselling and education.

The main reasons for exhaustion and stress among the workers were the disease itself not being notifiable (inability to distinguish infectious from non-infectious patients), the sheer volume of patients, lack of equipment, lack of patient support from relatives and the drop in the quality of care. 'They're racing against time and numbers,' said Shisana.

The survey projected 416 580 new AIDS cases this year, increasing to 486 120 in 2007 and predicts that half of all these patients over the 5-year period will seek care in the public health sector for HIV/AIDS-related illnesses.

Ironically, it was found that safety precautions taken by health care workers affected productivity and efficiency, while patients in denial further increased pressure on hospitals

by going from hospital to hospital trying to secure a negative HIV test.

Shisana said a number of respondents reported HIV-positive patients trying to bite them in what seemed like a deliberate attempt to infect.

A heavy workload was cited as the most debilitating environmental factor (73.4% of respondents), with 22.3% saying their workload had more than doubled in the previous year. Some 40% said they worked more than 'official' hours, 33% reported low morale and 16.3% said they had no job satisfaction.

When health care facility managers were asked whether they had an official workplace HIV policy, 54% replied that they had none. A full 36% of professional health care workers had no training in the understanding of how HIV was transmitted and only 40% had training in universal precautions around HIV/AIDS.

Shisana told the conference that this ignorance needed 'much closer' investigation.

The flouting of sterilisation requirements plus the discovery that only 65% of health facilities had sufficient sterilisation equipment between 75% and 100% of the time meant the distinct 'possibility of blood-borne viruses in our system,' she said.

Non-professional health care staff between the ages of 18 and 35 were the worst affected with an average HIV prevalence rate of 20%.

Some 30% of respondents said their facility had never stocked sterilisation equipment while 59% said they had never stocked HIV testing kits.

Drugs were available for opportunistic infections but not for prolonging life (ARVs). Only those drugs for prevention of transmission from mother to child or post-exposure prophylaxis were available while all



facilities were far better equipped to deal with tuberculosis than HIV/AIDS.

Shisana said she believed the Stats SA death notification figures were 'seriously under-reported', because stigma and insurance considerations contributed to the lack of AIDS-attributed deaths on certificates.

Two of the country's top health care union leaders, Nick Henwood and Fazeela Fayers, welcomed the HSRC

study. Henwood called for an urgent investigation into why health care workers did not have the confidence to report injuries like needle-sticks, in spite of supportive and enabling legislation. 'They tell us it's because of peer stigma, lack of medical confidence and the fear of losing their jobs,' he told conference delegates. He said the central issue was 'working towards a society where it is safe to declare your HIV status'. Fayers said she did not 'buy' the government's

argument of budgetary constraints.

A WHO study in the UK had shown that country to have a 10-year staffing plan and to spend 173 times more on staff than South Africa did.

Of those interviewed in the HSRC study 8.8% were medical practitioners and 48.3% nurses.

Chris Bateman

TELEMEDICINE BOOST FOR MATIE CAMPUS

A pioneering video-conferencing link between Tygerberg Campus and two rural health care hostels is enabling up to 30 University of Stellenbosch students at a time to enjoy top-quality on-site education while doing their primary health care rural rotations.

Jointly funded and equipped by the national Department of Health, the Medical Research Council and the private sector, the facility serves undergraduate and postgraduate students across all disciplines at the University's Faculty of Health Sciences.

According to Professor Helmuth Reuter, Director of the Ukwanda Centre for Rural Health that runs the project, it is the first time in South Africa that such facilities have been set up and made available to all health care disciplines on one campus.

The video-conferencing, set up in student hostels at Onrus near Hermanus (housing 9 students) and at Worcester (housing 20 students), aims to service 2 000 Matie health care undergraduates who'll spend between 1 and 5 weeks at a time there.

Reuter said it saved time, costs and reduced travel risks for both lecturers and students.

During their rotation, the students visit and work at municipal clinics, old-age homes, state hospitals and schools in the two districts and then jointly work-shop their experiences with one

another and anchor lecturers at Tygerberg.

All three sites could go 'on-line simultaneously', enabling a real-time learning environment.

Medical students spend 2 - 3 weeks at a time at either of these hostels and return there for a similar period for their late clinical rotation before completing their studies.



Professor Helmuth Reuter.

'To have a true community rotation backed up by high technology is totally new in this country. We've decided not to have a department of telemedicine (like the University of Natal). Instead we've formed the Ukwanda Centre for Rural Health and have chosen to have telemedicine drive its needs,' Reuter said.

Stellenbosch University Health Science schools that will be using the facilities will be Primary Public Health,

Pathology (Basic Sciences), Allied Health Sciences, Medicine and Oral Health.

Reuter said that the Ukwanda Centre was trying to develop something that could be extended and rolled out elsewhere.

He said the Ukwanda Centre was 'quite willing' to act as consultants to other campuses.

Asked why the facility was not being used in conjunction with other local universities, Reuter replied that he believed it was 'mainly a budgetary problem'.

However, he said some University of the Western Cape physiotherapy students were 'using some of our teaching tools', and this could in future include video-conferencing.

'This is all still relatively new (18 months in the development and setting up) — we'll probably only be fully functional from an IT and rotation point of view early next year,' he emphasised.

Accommodation for students was 'a major problem' and was being carefully addressed, he said.

'We're hoping to generate income by making the video-conferencing available to the private sector so that the entire project can be self-sustaining,' he added.

Chris Bateman