

The impact of HIV/AIDS on doctors - a report on 2 years experience of a balint group in Cape Town

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Abstract

Two years experience with a vocational trainee "Balint Group" is reported. A large proportion of the patients presented were HIV positive and some had active AIDS. These patients presented special difficulties for the young trainee doctors which are discussed. (Particularly the fact that most patients were similar in age to the doctors and that the illness involved sexuality and often violence). Illustrative case studies are described. It is concluded that trainee family physicians need special training to cope with the relationship issues that arise with such patients. It is suggested that Balint Groups are a suitable vehicle for such training.

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INTRODUCTION

The HIV/AIDS pandemic has currently affected an estimated 42 million victims worldwide, with Sub-Saharan Africa being the worst-hit area in the world (more than 10 million).¹ An estimated 1700 new cases are diagnosed daily in South Africa. The disease has devastating effects in terms of personal and family suffering, as well as being a severe drain on the nations health budget, and labour force. Of particular concern is the large number of young people (babies through mother to child transmission, adolescents and young adults) who contract the disease.

This paper attempts to draw attention to the affect that dealing with patients with this illness has on the attending doctors. It draws on the experience of a Balint Group in Cape Town over a 2-year period (1999-2000). "Balint Groups" are named after the founder Michael Balint, a Hungarian-born psycho-analyst, who, together with his wife Enid, began working with general practitioner groups at the Tavistock Clinic in London from 1950. The aim of the groups was *not* to "teach GP's about psycho-analysis" but rather to see if they could shed more light on the true

nature on the doctor - patient relationship in general practice with the aim of improving the therapeutic effectiveness of this relationship. The meetings, consisting of a group of 6 to 12 GP's under the leadership of one or two group facilitators, would take place \pm weekly and would take the form of "case presentations" by the presenting doctors. The work done in these groups resulted in some important publications including "The Doctor, his Patient and the Illness"² which has now been translated into \pm 25 languages) and "Six Minutes for the Patient - Interactions in General Practice Consultations"³. The work of the Balint groups soon spread to Europe and then the rest of the world. South Africa has had its own national Balint Society since 1977 and joined the International Balint Federation in 1978. Balint Groups have been actively used for post-graduate vocational training in family medicine in the Western Cape since the early 1990's. The group under discussion consisted of culturally diverse, mainly young, practitioners, most of whom were engaged in post-graduate training for family medicine in the Western Cape. The group met fortnightly, and like all Balint Groups, took the form of

"case presentations" with the presenting doctor presenting patients where s(he) was not comfortable with the nature of the **doctor-patient relationship**. After presentation the case would be discussed by the group members, facilitated by the group leaders, with a view to shedding light on the difficulties in the interaction, thus helping the presenting doctor to relate more effectively to his/her patient. There were no directives as to what kind of problems should be presented, but it was noteworthy that interactions with patients with HIV/AIDS (or related issues) featured very prominently amongst doctors who were seeing a significant number of these people. At the end of the 2-year period of the groups' meetings, members were asked to submit written reports on the patients they presented to the group. A few of these case reports are presented here, followed by discussion.

Dr A prefaced her reports with "all the patients that I presented to our group were HIV positive. Two of the people that I presented died during the time that we were meeting. Looking back at my cases, presenting them allowed me to face and acknowledge a spectrum of issues evoked by caring for HIV positive people".

Case 1 – Abigail – Frisky, feisty, and angry!

I met Abigail for the first time in casualty at Guguletu Community Health Centre, when I was working in the Trauma Unit. She was born in the same month of the same year as me. (Now I am 30 and she is dead). She was a frisky, feisty, highly intelligent woman.

When she presented, she was very ill, with meningitis. I referred her to Jooste Hospital where she was admitted and a diagnosis of cryptococcal meningitis was made. After discharge from Jooste, she came back to Guguletu CHC, and was my patient until her death about 8 months later.

Abigail and her life were chaotic. She never kept follow-up appointments and defaulted from the clinic at Groote Schuur repeatedly and so went off her maintenance fluconazole. She was very forgetful – perhaps due to a contribution of factors: her cryptococcal meningitis, possible HIV - dementia as well as her heavy drinking.

She was also ANGRY. About a month before her death, she stormed into the doctors office in the trauma unit, slammed her folder down on my desk, and said “Dr A, I am angry!” and stormed out of the room again. Hours later, she returned. We sat down to talk and she began to weep. She was very worried about her 2 children, and who would take care of them after her death. Beneath the confusion, anger and chaos, her sadness was huge.

Her family, who were just as chaotic as Abigail, ran a shebeen from their home. In the time that I took care of her, she was accompanied to the clinic by an assortment of sisters and cousins, all of whom would promise faithfully to get her to the appointment, supervise her medication etc. None of this ever happened of course! They lost every referral letter I wrote and never managed to bring me a letter back from any clinic that I referred her to.

In presenting Abigail to the group, her chaos became less infuriating and overwhelming. It became easier to accept her non-compliance and her disorganised family.

Her family brought her in on a stretcher to see me on the day before she died. She was very weak. She asked

me if I could send her back to Groote Schuur for the “medicine”, ie. fluconazole. When I told her that it was too late, she was very lucid and very sad.

The family were worried that she would deteriorate during the night and that she would be unable to cope. I explained to them that she was dying, and wrote them a letter for Jooste, so that they could take her there if she became very distressed and the morphine was not working. They lost the letter! The next day various family members came to the clinic trying to find me to get another letter. Finally they took her, without a letter, to hospital – and she died shortly after arrival.

Case 2 – Beatrice – “An exciting rare fungus”

Beatrice was a Sotho lady from Gauteng. She initially presented to me with a chronic cough and loss of weight. I diagnosed TB and she was started on treatment. She attended the TB clinic regularly, and came to see me regularly with a variety of HIV related complaints. I was very fond of her – she was a proud and dignified lady with great strength and courage.

She developed what looked like a gingivitis, which was treated with antibiotics by a dentist, but did not resolve. She then came to see me, in agony, and I treated her with different antibiotics. They didn't work. I sent her back to the dentist – who was also stumped. I then took her to see the “specialist” at the PM clinic at GSH. She was referred for a biopsy, which showed a deep fungal infection.

She presented to me again, in severe pain and extremely dehydrated. The lesion in her mouth had got worse – her mouth was slowly being eaten away by the fungus. I arranged for her to be admitted at GSH. She was started on anti-fungal treatment, and discharged soon after.

She came back to me a week later, still in terrible pain, with no improvement. I referred her back to Groote Schuur. Everybody got very excited about her rare fungus. She got no better.

She came back again and again. Her pain was never adequately controlled. While doctors got excited about her deep fungus, she slowly wasted away and died.

I still feel that I failed Beatrice. Presenting her to the Balint Group helped me to face the horror of her awful suffering which I was unable to take away.

Case 3 – Cindy – “Impenetrable denial”

Cindy is a 20 year old woman. She initially presented to Guguletu CHC after she had had a first trimester miscarriage – she wanted to find out **why** she had had a miscarriage. One of the medical officers did an HIV test on her for reasons that were not entirely clear from the records.

The first time I saw her she had come for the results of her “blood tests” – to find out why she had miscarried. When I told her that she was HIV positive she was horrified. She seemed not to have had any pre-test counselling at all. She was completely well and it was unclear to me why the test had been done – which made it a very difficult consultation where I felt that I was blundering around very elusively in the dark.

After counselling she agreed to have a second test and come back to me a week later for the result (positive). At this consultation we discussed condoms, “safe sex”, telling and testing her partner etc. She seemed overwhelmed by this information. A month later she presented to me complaining of lower abdominal pain. It emerged that her period was a week late, and she was hoping desperately that she was pregnant. She wasn't, on this occasion or on the several occasions following this one, where she presented with a variety of vague abdominal complaints that led on inexorably to yet another negative pregnancy test! On each occasion we discussed her HIV status, the prognosis, the consequences of a pregnancy, disclosure to her partner etc. On each occasion I felt as if our discussion was completely unreal to her. I became more and more frustrated with my inability to penetrate her denial. I also became more and more worried about the partner that I never met, with whom she was trying so desperately to conceive a child.

When I presented her to the group, I was feeling exasperated with her and with myself. Through presenting the case, I saw that I would have to acknowledge and sit out her denial with her

before we could move forward. (A number of people in the group expressed anger towards Cindy for having unprotected sex, putting her partner at risk, and wanting to fall pregnant when she had such a reduced life expectancy).

A week after we discussed her in the group, she presented to me again, requesting a repeat HIV test. When I explained to her that her blood had already had 3 separate Elisas done on it, and that there was no doubt that the result was correct, she started to cry. Something had shifted. One month later, she brought her partner to see me – a very gentle man who had the same air of innocence and bewilderment as Grace. He tested negative.

Case 4 – Doris – “Irrational guilt”

Doris was diagnosed HIV positive after developing Herpes Zoster. She is in her early 40's. The first time I saw her she was accompanied by her 8-month old daughter – her first and very wanted child – a beautiful chubby little child. I was struck by the warm and gentle interaction between mother and child.

After finding out her HIV status, Doris requested that her child be tested (the child had a chronic cough, but did not seem severely ill).

Her child tested positive. Thereafter, the child became seriously ill with disseminated tuberculosis, and was admitted to Red Cross Children's Hospital on several occasions.

I felt irrationally guilty about her child's HIV status – as if I had caused the HIV infection by doing the test. By the time the child was a year old, she was an emaciated, cruel caricature of her former healthy self. At 13 months of age, Doris brought the child into casualty with a severe pneumonia. She sat in the casualty with tears streaming down her face, clutching her emaciated pale-blue dying child in her arms. The child died later that day.

Case 5 (Dr B) – Peter – “Husband and pregnant wife”

Mr Peter, 30 years old, came from the Democratic Republic of the Congo via Angola. He consulted for persistent fever. Although he had been in South Africa for almost 3 years, he thought and

was convinced that he had malaria. I asked for a malaria smear and the laboratory recommended retroviral studies. He was recalled, counselled accordingly, and the blood was taken for an HIV test. It was positive and he was re-called for a confirmatory test. He disappeared after the second test and never came back for the final result yet he knew that he was HIV positive, and he accepted another HIV test in another clinic when he developed a papular rash all over this body. Denial for sure.

Our next interaction occurred a few months later when his wife who stayed in Angola (I never knew that he was married) arrived in South Africa. Knowing his condition, and not taking precautionary measures, he brought to the consultation his wife who had missed 2 periods. He never told her about his HIV status. As it is required for every pregnant woman to have blood taken for HIV and VDRL, she agreed to this. When the time came for both to receive the result, the husband came alone. He did not want to tell his wife his HIV status, because he feared that his wife would divorce him because he had been unfaithful during her absence. Her results came back negative and he persisted in his idea of not telling his wife the truth although I insisted that he do so.

When I presented the case to the group everybody insisted that I recall him for him to tell the truth to his wife and if he persisted in his refusal, it was my moral duty to tell the truth to his wife despite his refusal.

When I saw him, he agreed to tell the truth to his wife – unfortunately he never responded to my many calls after our last encounter – to date I do not have any news concerning this couple.

Case 6 (Dr C) – Eileen and Martin – “Accepting my limitations”

This doctor prefaced her case reports by saying: I think that through the group work I have learnt to be more accepting of my limitations and of the limitations of my patient interactions. I realise that if my patients approve of me, then my identity can stay intact and my vulnerabilities can stay deep down. When they can't or don't approve of me,

then I feel uncomfortable and the interactions become difficult for me. Sharing some of the pain of my patients' lives has made it more tolerable for me. I otherwise get to a stage where I feel overwhelmed with grief. Sharing this in a group makes me feel less alone and not so isolated.

Eileen presents first. Wants a baby. Tests HIV positive. Brings Martin in for testing. A young vibrant articulate man – he is obviously positive on clinical examination. He is deeply distressed at being told he may be positive. He is angry, and enraged and won't allow me to help him or get close to him in any way. He rejects me and this is very painful for me. Eileen tells me later that he is suicidal. I feel I have failed.

Case 7 (Dr D) – Francis – “Trying to take the pain and horror away”

This doctor commented that the group had made her aware that her interactions with patients were sometimes “inappropriately sunny and gay – trying to take away (their) fears and make it all okay”. “Also that it was hard for me to see that (people) so unable to cope could be affected with things so harsh”.

A 25 year old woman came to see me after she had been gang-raped while her boyfriend had been restrained. She feared that she had contracted AIDS. I felt I could not completely face the horror of the situation and that I gave her false comfort. The group helped me to acknowledge that it was a truly awful situation and to realise that I was scared to face it fully – and possibly could not. I realised I could not take the pain or horror away or make it better.

GROUP FACILITATORS PERSPECTIVE

From the cases presented above (and many others) it was clear that the task facing the (mostly young) doctors in this group was a particularly difficult one.

To begin with: while death and dying is always difficult for doctors to deal with, the fact that most of these patients were **in the same age group as the doctors themselves**, (coupled with the associated factors of sex and often violence), made it particularly trauma-

tic. This was further compounded by the close link between HIV/AIDS and sexual activity. The tragic nature of the cases often induced feelings of anger and despair in group members eg. "If there is a g-d, why does He inflict such suffering on innocent people?" and "why do people have to die for making love?" At times the anger was directed at the authorities for not doing more to combat HIV/AIDS and particularly at their support for "dissident" views, which denied the link between the HIV virus and AIDS. This came up repeatedly, and at one point the group facilitator invited them to speculate on the possible reasons why the government had adopted such an apparently irrational and potentially harmful position. Responses included "national pride", "there are members of the Cabinet who are HIV positive", "economics – they don't want to spend the money to combat the disease" etc. This discussion appeared to be therapeutic for the group not only because it gave them an opportunity to express their anger, but perhaps more importantly because it enabled them to counter-act the profound sense of chaos which these cases had induced in them.

An interesting "synchronistic" event occurred during the second year of the

group. The meeting, which always took place at the consulting rooms of one of the group facilitators (SL), was interrupted when he had to attend to a patient, who happened to be a black woman. When he returned to the meeting he had a bandage on a finger, the result of a needle-stick injury from an injection! This produced a near-panic reaction in the group and they insisted that he commence prophylactic AZT – treatment immediately (one of the members had samples at her rooms), until the HIV status of the patient was ascertained (which fortunately turned out to be negative).

With the passage of time, group members were more able to get in touch with and accept their deep feelings of **helplessness** in working with these patients.

This heralded a major shift in the groups' awareness, going against the prevailing medical ethos of active, interventive competence. Once this stage had been reached the doctors found themselves more able to empathise with their patients and come to terms with the painful feelings they were forced to experience.

The group facilitators were extremely impressed by the courage and commitment shown by the group members.

While at times complaining bitterly about what they went through, they never shirked from their tasks, and manifested great honesty and integrity in their work in the group. The cohesive nature of the group contributed greatly to the success of the groups' work.

DISCUSSION AND CONCLUSIONS

It is common knowledge that the HIV/AIDS pandemic presents a huge challenge to the political, social, educational, religious and health resources of society, particularly in Sub-Saharan Africa. However, there seems to have been insufficient emphasis on the strain that this condition has placed on our health professionals and young doctors in particular. There seems to be a clear need for better preparation and support for trainee doctors and other health workers working in this field. The experience of this Balint Group suggests that it is a suitable vehicle for providing this training. □

References

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Lilly and Bayer join forces to reduce the cost of diabetes care

It's no secret that the cost of private healthcare in South Africa is on a rapid upward spiral. Increased medical aid premiums are at least an annual occurrence with benefits often seeming to decline inversely and 2003 is looking to be no exception. The result is a growing dilemma for people suffering from chronic disease and disorders, such as diabetes.

The dilemma is even greater for patients of the public healthcare delivery system. Servicing approximately 84% of the population (statistics show that only 16% of the South African populace have access to private medical cover), state healthcare facilities are stressed both financially and physically and, in consequence, often cannot deliver the level of care necessary to manage diabetes effectively.

Thanks to the launch in July last year of an innovative patient care programme by a collaborative partnership of Eli Lilly and Bayer Pharmaceuticals, this scenario has changed for the better and has over the last six months proved both useful and cost-effective for thousands of diabetics countrywide. Designed to improve the level of care and effectiveness of diabetes management so as to enhance the overall quality of life, the Lilly/Bayer Diabetes Programme delivers extensive and proactive medical and emotional

support to all diabetics whose doctors enrol them for the programme.

Accredited Diabetes Advisers, by way of healthcare practitioners, co-ordinate and direct the Lilly/Bayer Diabetes Programme by delivering a consultative service to diabetic patients. These Diabetes Advisers pay personal visits to diabetic patients enrolled in the programme, to give dietary and lifestyle advice. They also ensure that patients understand the use of the Lilly pen device and offer useful tips on injecting and other aspects of managing their diabetes.

The efforts of the Diabetes Advisers will be complemented by the Lilly Outcomes Programme. Outsourced to a third party to ensure patient confidentiality, Lilly's Outcomes Programme aims to add meaningful value to diabetic patients. In addition to a welcome pack and file with personalised information, patients will be contacted regularly to ensure that they understand the disease and to assess their compliance with treatment.

Patients will also receive updated information on diabetes and sample packs of drugs.

For morning information contact The Lilly / Bayer Diabetes Helpline number at 0860 102 672