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Human rights and ethics in the context of home-based care in Botswana

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The paper is based on two case studies on home-based care in Kweneng district, Botswana, in March-April 2000. Ethical and legal issues emerged that are in dire need of attention. Is home-based care an ethical solution in a country where almost fifty per cent of the population live below the poverty datum line? Is there adequate provision of food, shelter, physical and psychological support for the patients and families in home-based care? Do patients and carers have any choice about the care setting they prefer? The current stance on confidentiality may also be detrimental to breaking the silence surrounding the epidemic. Most of the carers are women living in cohabitation. Revision of property rights and inheritance laws is necessary to support those who are providing care for the terminally ill. Home-based care in Botswana should not be seen as a tool to de-congest hospitals, but as a way of providing quality care for AIDS patients at home.

Introduction

With the HIV epidemic becoming ever more visible in Botswana, the question of care for those who are falling ill with AIDS is more crucial today than it has ever been before. Addressing the care of AIDS patients is difficult in any country at the best of times but even harder in those countries that are characterised by a lack of resources in the health sector, Botswana being one of them. Despite the achievements Botswana has made since independence in 1966, the health sector is facing a growing number of problems related to the advancement of the pandemic. This trend is not made any better by the recent exodus of nurses from a health system that is characterised through under-staffing and de-motivated professionals due to unfavourable working conditions.

Botswana's answer to the growing number of AIDS patients in need of quality care has been the government led and supported introduction of community home-based care as a strategy that transfers some of the responsibilities of care from the health facilities to the community and ultimately to the family. As commendable as this idea may be in theory, it faces serious challenges in its practical implementation due to the social environment that forms the framework to the programme. Many of the social realities that have been evident for the past decades are more pronounced and visible in a situation in which government needs to rely heavily on the resources of its citizens. Poverty and gender inequality, for example, have been features of Botswana society despite the country's socio-economic successes in past decades but are now even more in need of addressing in the face of the worst health crisis the country has ever experienced.

The following paper seeks to address the concept of home-based care from a human rights perspective in the context of a developing country. The author makes an attempt to discuss the importance of adopting a rights framework when analysing the care of AIDS patients in Botswana. It is argued that protecting human rights of people living with HIV/AIDS is paramount to a public health response to the epidemic. However, HIV poses serious ethical dilemmas to Botswana society that need to be publicly debated in order to make a meaningful difference in the fight against a common enemy. The first part of the paper attempts to discuss human rights in relation to the epidemic, while the second part describes the concept of home-based care and its realities in Botswana. The arguments of the latter part of the paper are mainly based on two research studies that were undertaken in

Kweneng District in March-April 2000. The main focus of the argument is that in the current social and political environment of Botswana, home-based care may be an unethical solution to the care crisis, especially with reference to Vision 2016 and its notion of Botswana becoming a compassionate, just and caring nation.

Human rights and HIV/AIDS

Why, one may ask, do scholars develop a human rights framework when addressing HIV/AIDS when they do not do that in the case of any other disease, such as cancer or tuberculosis. The answer may be simple but should be convincing. AIDS is different because of its communicability through sexual contact, therefore, AIDS presents us with complex problems of stigma that we hardly find with any other disease. Such stigma often leads to the social marginalisation and persecution of those who live with the virus.

At a recent conference in Botswana,¹ findings of a study undertaken in 1999 in the Chobe District were revealed to a shocked audience of health practitioners, people living with the virus and members of the academia. According to the study, of the over 700 people interviewed, many displayed outrageous attitudes to people infected with HIV, such as suggesting that HIV positive people should be killed, possibly burned or simply killed by nurses in hospitals and clinics. It was also suggested that those infected should be marked with a sign on their body, such as a tattoo, in order for sexual partners to identify those who are sero-positive (Kaleeba 2001: 1). While these attitudes may not represent the feelings of a majority of Botswana, the example provides a good indication of the social environment many infected people face when they publicly announce their sero-positive status. It is against this background that a human rights approach to the epidemic becomes so important.

Botswana is a signatory to many of the international conventions safeguarding human rights and has accepted the Universal Declaration of Human Rights of 1948.² However, it is common that human rights are neglected in times of epidemics when people fear those infected in an attempt to protect themselves. It is in these times that the public and health authorities cry out for mandatory screening³ and the isolation of infected people. The history of HIV/AIDS is no exception to this and a reoccurring theme within the context of HIV/AIDS is whose right should be protected, that of the group or that of the individual (Stegling 2000: 10).

However, it has widely been argued that 'it has become increasingly clear that health and human rights cannot be separated from each other, if either is to be secured' (Piot & Timberlake 1998:1). It is with this understanding in mind that many international organisations such as the World Health Organisation (WHO) and United Nations agencies have argued that protecting human rights of people who are infected with the virus is essential for two reasons. Firstly, because every human being has the right to dignity and secondly, because the appreciation of these rights for individuals is not counter-productive to public health interests. It is argued that by recognising human rights fewer people get infected and it becomes easier for those infected and their families to cope with the disease.⁴ In the context of home-based care several rights issues emerge which have neither been debated adequately nor have they been addressed in the current programme. As I have argued elsewhere, the fundamental right to privacy and confidentiality is no longer protected in the context of home care for AIDS patients since the government has opted for a notion of 'shared confidentiality' (Stegling 2000:11). The reasons that informed the decision by government to enable 'health professionals'⁵ to share the HIV status with family members who are involved in the care of an AIDS patient are linked to a fear that caregivers may be at risk of infection due to their care activities.

While this fear is understandable in a situation in which contracts of care are not between an individual and a professional but between the individual, professional health workers and the family of the patient, the example of discriminating attitudes given above indicates that confidentiality should be paramount given the current social climate in Botswana.⁶ Arguments about the ability of 'shared confidentiality' empowering the community and the family and allowing for better quality care to be provided to AIDS patients should be taken into consideration but need to be seen within the context of discrimination and marginalisation.⁷

In an attempt to discuss issues of rights and ethics within the context of the epidemic, some scholars have suggested reference be made to the African Charter on Human and Peoples' Rights since it has been signed by many African countries and it provides an agreed set of ethical principles that could be referred to when designing and implementing HIV/AIDS policies. The Charter, for example, establishes the right to dignity, to life and health and the right to liberty and security (Turner 1995: 86). Taking these rights into account it becomes questionable whether the notion of 'shared confidentiality' would be in accordance with the Charter's declaration to the right to dignity. Since Botswana is a signatory to the Charter one needs to assess why government has not opted for a different approach when it comes to safeguarding the rights and health status of all citizens, such as the promotion of universal precautions. By promoting universal precautions everybody at all times would take steps to protect themselves against the possibility of infection, regardless of whether the HIV status of the patient is known. In order to understand the ethical and rights issues that emerge in the current situation in Botswana, the following paragraphs assess the formalised home-based care programme as it is currently implemented by government and the problems and challenges that emerge from it.

The adoption of home-based care in Botswana

Why home-based care? Community home-based care is characterised by a number of aspects that make it a suitable solution to responding to the epidemic in a developing country. Since resources are increasingly limited in the public health sector due to the growing number of people falling ill with AIDS related diseases, the state has to look for alternative ways to care for these clients. In Botswana, it is currently estimated that between 50% and 70% of hospital beds in the main referral hospitals in the country are occupied by AIDS patients, a fact that has forced health authorities to relocate such patients back into the community in order to be able to also provide care for patients with curable diseases (GoB & UNDP 1998: 41). This argument is obviously based on the idea that in Africa the extended family is traditionally the care giving unit on which in times of crisis the state can fall back on.

Community home-based care lies at the heart of Botswana's national response to the epidemic. At the end of June 2000 the cumulative figure for clients registered on home-based care stood at 7000, with 875 deaths having been registered on home-based care. While not all of these clients are suffering from AIDS related diseases, the great majority does. Additionally, there is a growing number of children that are living with an ill parent, currently the total number of children living with a sick parent or sick parents, stands at 6,823 (AIDS/STD Unit 2000: 12). However, it is obvious for all involved that many cases are not reported for fear of stigmatisation, and in many instances because people are not informed about services that are offered by government departments and non-governmental organisations to assist them in times of hardship due to chronic or terminal diseases.

In addition to being a cheaper and practical option of care, community home-based care has a great potential to unite aspects of care with prevention, which in the past have commonly been treated as two exclusive concepts. By including the family and the

community in the care of AIDS patients it becomes possible to discuss prevention within the community. Once AIDS patients are considered a reality within the local community it is easier for people within this community to accept their responsibility to prevent further transmission of the virus (AIDS Action 1995: 2). Through care in the community, it is thought that the discrimination and isolation of HIV positive people and their families is being prevented.⁸

A *continuum of care* is established, which connects the hospital with the community on the basis of care for people who are infected. In the case of a person infected with HIV, this continuum should start at the time the person is diagnosed with carrying the virus, followed by post-test counselling and advice on positive living, including emotional support and be carried through to the point when the client actually falls ill with AIDS. However, a holistic understanding of care for an AIDS patient should also include the care and support of the family of that patient and should, therefore, not end with the death of the patient but be continued through bereavement counselling of family members.

Furthermore, AIDS patients often need care for a very long time and by being cared for at home, carers may be able to pursue income generating strategies in their home environment which would be impossible if they had to stay with the patient in hospital or continuously visit the patient there. In some cases it also enables the patient to continue to earn a living or look after dependants at least for a limited time.

This said, care in the home is not supposed to delegate responsibility from the health authority to the family and the community. For community home-based care to operate effectively it needs to be planned as a strategy in which all players acknowledge their responsibility. Traditionally, the family may be the caring unit for ill people in Africa but this does not mean that there are unlimited resources within the family to deal with an increasing number of ill people. 'This source of care must not be taken for granted. As the number of ill people increases, communities may become overwhelmed and lacking support, abandon their traditional caring roles' (McDonnell et al., 1994: 429).

However, in Botswana, government perceives the family as

a cornerstone to support the process of self care at home. The multi-pronged approach adopted in our Community Home-based Care strategy aims at reducing the impact of the illness on the client, as well as reducing the burden of care on the family and the *home*. (AIDS/STD Unit 2000: 2).

This approach should be understood within the context of a government organised and formalised home-based care programme that has been in place for some time. According to the policy that is outlining the programme for Botswana, support given through government agencies should include counselling of the patients and the family at home, material support to assist the carer, continuous visits by health staff and a monitored system which co-ordinates the work between the hospital, the clinic, welfare officers, community organisations and the family. It also acknowledges that the carer will need to be trained so that the patient receives quality care and so that the carers know how to protect themselves.⁹

In order to understand the realities of the programme in Botswana, one needs to make an attempt to assess whether the support structures the home-based care policy envisages for the successful implementation of the programme are actually in place, that is, whether the family and the community have the resources and abilities to provide quality care for people with AIDS. Also, one needs to examine the actual implementation of the programme through government agencies and whether the assistance they offer is adequate for the needs of patients and their families. The following paragraphs will give a brief insight into the realities of home-based care in Botswana which will then be analysed within the earlier discussed rights framework.

The realities of home-based care in Botswana

In reality, home-based care in Botswana is faced with a number of serious challenges that prevent care providers from offering the best possible care to those who have fallen ill with AIDS. However, one needs to be aware that there is a serious lack of research that has been undertaken in this area, nevertheless, the few studies that are available seem to point out common trends and several sets of problems and weaknesses appear in all the studies currently available.

The following discussion is mainly based on two studies that were undertaken independently from each other in Kweneng District during March and April 2000.¹⁰ Findings of both studies identified poverty as the main barrier to the provision of quality care to AIDS patients. In one study, of the 29 patients interviewed, 24 had previously been employed and had contributed significantly to the household income before falling ill but at the time of the study only two patients had a paid job (Khan & Stegling 2000: 12). Clients in the same sample were asked about their main worries and a great majority voiced as their main concern the uncertain future of their parents and young children. Also, many patients felt uncomfortable about being cared for at home, in this way becoming a burden to their families. Furthermore, a majority of clients expressed their concern about the detrimental effect the disease has on the economic sustainability of the household.

Also, since almost all the patients interviewed in this sample denied the nature of the disease they were suffering from, they did not utilise certain welfare services, such as the food basket¹¹, because of the stigma attached to these. The argument brought forward by health and social service providers, being that once you receive the food basket, everybody in the community knows that you are an AIDS patient. Of the 29 patients in the sample, only five were assisted through the food basket programme. Additionally, many patients were unaware about the programmes that are available to them, e.g. only a small minority was registered as destitute and the researchers found that in many cases only the caregiver was registered destitute, often resulting in the entire family sharing a single destitute allowance¹². In general, carers interviewed in this sample were struggling to make ends meet, with none of them being formally employed and the majority either being registered destitute, doing small-scale farming or earning a small income through informal sector activities, such as running a shebeen or a tuck shop.

In terms of poverty, the other study does not indicate any difference in the research findings. Of the 30 patients interviewed in that study, none was holding a paid job at the time of the research and 85% of the carers were also unemployed (Mojapelo et al. 2001: 28). Another indication of the inadequacy of the home environment is the lack of appropriate shelter which is evident in this sample. Two of the patients lived in old derelict houses while one lived in a plastic shack, these are obviously not places where the wellness of the patient is supported. Additionally, of the 30 patients interviewed in this study, four did not even have a caregiver and two clients were cared for by children, while three had incapable caregivers due to old age or disability.

While poverty seems to be the main obstacle to caring for a patient at home, it is certainly not the only difficulty experienced by patients and their carers on home-based care. The assumption made by government and many scholars in the field that the extended family provides with support for those being cared for at home does not seem to hold up in reality. First of all, a clear gender balance exists when it comes to those who are looking after patients within the home environment with all the carers in the first study being female and 89% of the carers in the second study being women. Additionally, the great majority of volunteers participating in home-based care programmes are also female. This seems to clearly indicate that it is not the family and the community as such supporting the care of

AIDS patients but the female relative and community members who take on the responsibility of care.

Many of the participants in both studies also indicated that they receive very little assistance from the extended family and health service providers. In the first study most of the carers were single women (in some cases divorced or widowed) who were the sole caregivers to the patient and many complained that they were not receiving any assistance from the extended family. Only in some rare cases did male relatives occasionally assist by clearing the ground fetching medicines and home-based care materials from clinics or by organising transport to take the patient to the clinic or the hospital (Khan & Stegling 2000: 13). Similar problems were reported in the second study, with carers complaining that other members of the family were not assisting in any material way. Additionally, carers in the second study expressed their dissatisfaction with the services provided through volunteers and health professionals. As one carer pointed out:

Health workers give us medication only. No other support is provided. Even if the patient is in a bad condition the hospital staff refuse to admit the patient. (Mojapelo et al., 2001: 38)

The last part of the statement also points to another assumption that is commonly made in Botswana, referring to the attitude Batswana have in relation to hospitals. Many scholars and professionals believe that Batswana would rather have their patients being looked after at home than in the hospital. However, research indicates that this is not necessarily the case. One tends to forget the complex nature of AIDS related diseases, resulting in families to prefer for their patients to be taken care of within an institutional setting. Lack of information and knowledge concerning appropriate care and the sheer physical and psychological difficulties encountered by many caregivers often result in a feeling of hopelessness and inadequacy in terms of the care provided. As another carer pointed out: ‘

It's not good to take care of patients at home because I do not know how to take care of the patient. I was not told anything besides that I should use gloves’ (Mojapelo et al., 2001: 31)

All the above discussed weaknesses of the home-based care programme are not just featuring in recent studies but were already reported in the baseline study undertaken by government in 1996. In the 1996 study, carers reported difficulties with patient care due to a lack of training and because of limited economic resources within the household. Almost half the households then felt that they needed financial support and a large number reported the need for material support (Ministry of Health 1996b: 18). It seems that even though government has paid a lot of attention to home-based care and a large amount of financial resources has been allocated to the programme, the programme is still faced with a number of problems which are not necessarily inherent in the programme itself but in the surrounding social realities that form the background to care of AIDS patients at home.

Concluding remarks

Discussing the realities of home-based care in Botswana within an ethics and rights context leaves one with a strong notion that the current programme is not necessarily an ethical solution to the care crisis in Botswana. With HIV infected people and their families still experiencing discrimination on many different levels within society, one cannot force those infected to be open about their status. Currently, the great majority of AIDS patients are clinically suspected to be HIV positive rather than confirmed through a test and with the fear that the nature of their status may be communicated to others even less people may test in future. This argument indicates that the violation of the human right to dignity is detrimental to public health efforts rather than supporting them.

The article discusses many of the problems patients and their families on the programme are facing, the main ones being poverty and the lack of support by the extended family and health professionals. It seems, that government perceives home-based care as a convenient way to decongest hospitals rather than to unite aspects of prevention with care and as a way to provide the best possible care to those infected with HIV. With a considerable number of households in Botswana still living below the poverty datum and with the main burden of care being placed mainly with women who are often elderly, it becomes questionable whether home-based care is an equitable manner of providing for Botswana's AIDS patients. This article suggests that care provided at home does not only mean an often unbearable economic, physical and emotional burden for those who provide care but it also denies patients their right to choose the care setting they prefer. Rather than accepting home-based care as the only way to provide care for those infected with HIV, the author of this article suggests to adopt a rights approach and look for alternative solutions to the care crisis, taking into consideration the rights of patients *and* carers.

Notes

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1. First Regional Conference on Community Home-based Care in Botswana, March 5th to 8th 2001.
2. However, notwithstanding its signature not all of the principles contained in these treaties have been incorporated into domestic legislation or even made policy.
3. In Botswana, government agencies and the private sector are increasingly debating mandatory testing of students who apply for overseas scholarships, while one of the main providers of such scholarships, Debswana, is already undertaking pre-scholarship testing.
4. 'Resolution WHA 45.35 of 14 May 1992 recognised that there is no public health rationale for measures which arbitrarily limit individual rights, such as mandatory screening' (UN 1998:58).
5. One needs to bear in mind that the amendment of the act so far only allows doctors and dentists to disclose the HIV status of a person and, therefore, other health professionals such as nurses and midwives still have to adhere to strict rules of confidentiality. For reference please see *The Botswana Medical Council (Professional Conduct) (Amendment) Regulations, 1999*, Statutory Instrument Number 77 of 1999 as cited in Zuyderdiun and Melville 2000.
6. See for example the Botswana HIV / AIDS and Human Rights Charter that was published by Ditshwanelo, the Botswana Centre for Human Rights, in 1995 in collaboration with the Botswana Red Cross Society.
7. Lucas, for example, argues that 'confidentiality if rigidly pursued can stifle care initiatives which sources external resources and networks such as community based approaches' (Lucas 1998:3).
8. A view shared by the government of Botswana: 'Caring for patients with AIDS is probably the best way for families and communities to perceive AIDS as a reality in the community and for their own lives. A caring family will also be the best guarantee for prevention of ostracism of people with HIV/AIDS' (Ministry of Health, 1996a): 4).
9. Ministry of Health, AIDS/STD Unit, Botswana, 'Operational Guidelines—Community home-based care for people with AIDS in Botswana / NACP 30', (Gaborone, 1996).
10. Both studies are not yet published: B. Khan & C. Stegling 'Evaluation of the Kweneng District AIDS Home-based Care Programme', Report for SNV -The Netherlands Development Organisation, May 2000, Gaborone; D. Mojapelo et al., 'Client Satisfaction and Providers' Perspective with Home-based Care in Kweneng District, Botswana', Draft, February 2001.
11. Through the Ministry of Local Government, a food basket programme is available to clients with chronic and terminal diseases. The programme consists of food and material assistance, such as clothing and toiletry.
12. 'Since many of the carers were over 65 years old, they were receiving the government pension of Pula 110 and did not realise that they would still be entitled for the destitute allowance' (Khan & Stegling 2000: 14).

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