

Inadequate assistance from health care providers

According to the majority of the respondents, the poor state of referral was attributed to inadequate psychological and emotional support from the health care providers. The four CHBC nurses agreed with the caregivers that the health team only did a minimal job in the care-giving process, as it was only in a few cases that they visited the caregivers and their clients. This normally happened with new clients who needed to be referred. However, such cases were usually rare. The health care providers' visit schedule was exacerbated by transport problems. The respondents reported not having access to counselling services for psychological support. This, according to the caregivers, left them not knowing when making progress or failing. Some said that some clients were dying because appropriate advice or counselling was not given to the caregivers in good time. The caregivers commented the following:

"We do not get counsellors to offer counselling in our caring duties".

"We do not see the health personnel coming to encourage us. We rarely get counselling".

Care giving, being psychologically draining and burdensome, calls for remedial services to caregivers to help invigorate and replenish their energy to maintain a state of well-being. Respondents, therefore, felt a dire need for counselling, debriefing, supervisory visits and incentives, among other things.

Attitudes of health service providers towards clients and their caregivers

Forty-two (50%) caregivers stated that most of the medical providers had poor public relations skills and a negative attitude towards the caregivers and their clients. For example, they indicated that most service providers were not adequately respectful and were rude to them. Respondents further indicated that, while the health personnel have gloves and masks for protection, these are not made available to the caregivers and their relatives who come to attend to their clients. The hospital authorities sometimes demanded that caregivers leave the hospital before finishing attending to their clients. This treatment made the clients and their caregivers reluctant to use the services rendered, which was affecting the referral process. These caregivers indicated that it was for that reason that some caregivers and their clients were looking for alternative treatment from traditional healers and opting for being attended to at home (NACP 31, 1996; UNAIDS, 2000a).

Stigma negatively influences referral

Sixty (73%) caregivers reported that even though the stigma was declining with time in Kanye and in Botswana generally, it was still affecting the treatment and therefore referral of clients to points of assistance. The caregivers revealed that some caregivers and family members were hiding their clients and therefore shutting the avenues of help for the clients. Caregivers reported having knowledge that some people were taking their clients to places further away such as the towns of Lobatse, Jwaneng or even Gaborone city. This is because of the stigma attached. However, since taking the clients to farther places was expensive, sometimes it was impossible, and this in turn usually affected the referral and treatment efficiency of such clients.

Transport challenge

Eighty (98%) caregivers admitted that the challenge of finding transport was seriously affecting the referral system. Though they admitted that the council had a vehicle that was supposed to help in the referral, it was not well managed and organised. They reported that in most of the cases when they telephoned the council officers for vehicle assistance, they hardly got assistance in time, or there was no assistance at all. This meant that caregivers were stressed to

a point of burnout as they struggle to get assistance, sometimes totally failing to take their clients in time. Sometimes they would fail to make referral and appointments dates, which was to the detriment of the health of the client.

Management of the CHBC programme

Forty primary caregivers (49%) caregivers indicated that the CHBC programme was not well managed. First they indicated that they were discriminated against in favour of the community caregivers (volunteers). For any knowledge package in the form of workshops, it was the community caregivers who were prioritised. They were also the ones who were given things like T-shirts, yet they felt that they were the ones who were on 24-hour duty for the clients. They also indicated that even the decline in the care package was a result of poor management. They noted that sometimes the clients are released to community home-based care programmes prematurely. This they said they understood was because of congestion in the referral hospital.

DISCUSSION OF THE FINDINGS

Demographics

The Kanye study findings confirmed that most caregivers are elderly women. Other studies in Botswana had found more or less the same condition. Atta and Fidzani (1996) found that over 50% of caregivers in most of the Botswana CHBC programmes are elderly women who may not adequately stand up to care-giving demands. This definitely impacts negatively on the quality of care giving. Leaving care giving to such elderly women is tantamount to threatening the traditional safety nets providing for care giving (McDonnel, Brennan, Burnham & Tarantola, 1994). Such elderly persons may not adequately understand the dynamics of care giving and seek referrals in time. Periodic training of these caregivers on care giving, especially on available avenues of referrals is critical (Abbat & Meija, 1988; Petit, 1994). The government and care managers need to increase community education and advocacy to attract especially the younger and the educated to share in the caring duties. Young and knowledgeable people are also in a position to understand the HIV/AIDS disease well and other avenues of assistance for the client referral.

As in the Kanye study, many caregivers of HIV/AIDS clients the world over are women (UNAIDS, 2001b). A study carried out in Botswana by Munodawafa (MOH/NACP 41, 1998) had all females as respondents, except one in Tutume, while in Molepolole, all caregivers were females. In this era of HIV/AIDS it is not fair to leave the caring tasks to women alone. They need to be assisted by their male counterparts. Due to the dynamics of HIV/AIDS, it is becoming very difficult to cope. According to Kelesetse (1998), a feminist, CHBC has shifted state responsibilities to women. This is therefore a case of gender exploitation and presents a human rights violation. This also contributes immensely to the feminisation of poverty (UNDP, 1995). Gender mainstreaming and socialisation intervention strategies should be carried out in all the institutions of the country, especially the schools. This will ensure that children embrace gender neutral norms, values and thinking from childhood. The boys as well as girls should grow up knowing that care-giving tasks are to be undertaken by all. Advocacy education by leaders and civil society bodies is necessary to show that care giving should be a task for all in society (MLHA, 1999; UNDP, 1995).

On the findings of the low educational status of many caregivers in Kanye, other studies in Botswana by Phorano, Nthumang and Ngwenya (2005) in Maun and Kweneng found that 33% of the caregivers studied had only lower primary education. To offset the impact of such low

literacy levels, there should be an emphasis in the programme on adult informal education and on-the-job training by care managers, in collaboration with the government, to ensure that there is adequate knowledge and that the coping capacities of the caregivers are improved (Abbat & Meija, 1988; Petit, 1994). As in the Kanye study, age has always been found to be a factor that negatively affects the quality of care giving. A study by Jacques and Stegling (2001) in Kweneng, Botswana, found three caregivers who were too old to adequately discharge their roles. Studies by Erikson (1959), and Wilkinson and Campbell (1997) indicate that the change towards senility is marked by a decline in cognitive, emotional and physical energies, affecting one's productivity holistically. This leaves doubt as to the capacity of these elderly caregivers in understanding referral and care giving generally. Research conducted in Thailand, Zimbabwe and Uganda found that over two thirds of elderly respondents were the main caregivers of ill adults or orphans whose parents died of HIV/AIDS, while further extensive research done in Thailand found that most of the caregivers taking care of HIV/AIDS sufferers were 50 years and over, with 40% being at least 60 years (Ntozi & Nakayiwa, 1999; UNAIDS, 2001a). This unexpected burden in their later years is a heavy one, particularly if they have no previous knowledge of HIV/AIDS or of basic home-care techniques such as universal precautions. On-the-job training and education in the avenues of help for referral are critical (Abbat & Meija, 1988). Socialising the young from childhood by inculcating non-gender-based values and education through educational institutions could ensure that boys as well as girls take care giving as the job for all.

The phenomenon of inadequate medical facilities is common in many resource-strained countries, especially in the developing world (WHO, 2002). Health care providers are frequently confronted with clinical challenges like infections and tumours that call for prompt and appropriate treatment. Treatment of these infections and tumours is of great importance, as it decreases suffering and prolongs life, especially in the absence of effective and non-toxic antiretroviral therapy against HIV (NACP 13, 1993). In the context of CHBC, the inadequate care package has resulted in conflicts between caregivers and their clients. In a study by Dant and Gully (1994), though conducted in a Western setting, clients demanding what was not available caused conflict between the clients and their caregivers. Inadequate medical supplies also caused some caregivers and their clients to look for alternative medication from traditional healers. However, use of both medication from modern medication and traditional medication has always presented a conflict, with the client likely to have his or her health decline (Kang'ethe, 2004, 2006; UNAIDS, 2000a). Research in Kanye by Kang'ethe (2004) indicates caregivers becoming frustrated because of the unreliability of the care package supplies, while another study by Kadzakumanja (2001) in Lilongwe, Malawi indicates that in clinics the care package supplies are irregular, late or not available at all. This seriously affects the referral process.

It is possible that widening the radius and scope of the referral system between the clinics and other private practitioners could possibly mitigate the challenge. This is because in his field research the researcher noted that, while some clinics lacked so many of the care packages as recommended by the government (NACP 30, 1996), some clinics had a substantial supply. While some caregivers would have to be buying gloves and incontinence sheets, other clinics may have them in stock. Therefore inter-clinic referral and communication should be strengthened to improve service delivery. The government needs to honour its policy obligation of providing especially the full care package as spelt out in NACP 30 policy document (NACP 30, 1996).

Various writers attribute the inadequate knowledge on disease progression to the fact that some caregivers are too old and have an inadequate educational background. In research by Mojapelo, Ditirafalo, Tau and Doehlie (2001) in Botswana, four clients did not have caregivers, and three clients were taken care of by very old caregivers who could not guarantee effective service delivery, while studies by Atta and Fidzani (1996) found that over 50% of caregivers in most of the Botswana CHBC programmes are elderly women who may not be able to meet care-giving demands adequately. According to Kang'ethe (2006), inadequate knowledge stems from lack of training. Lack of training is an indicator of the following:

- Likely low skills in care giving;
- Likely low capacity to handle prevention;
- Likely low coping skills and more prone to stress and burn out;
- Likely poor hygiene and poor medical protocol;
- Likely low capacity to handle conflicts with the client.

These factors are disenabling and likely to adversely affect the capacity of the caregivers' decision to refer the client to medical facilities.

In the same study by Atta and Fidzani (1996) it was found that only 10% of the caregivers had been exposed to training. Coupled with illiteracy and lack of training, 11% of the caregivers they studied found the instructions on the administration of the medicine too complicated and would not know the appropriate time to refer the clients to help systems or to take the clients to the referral hospital. Therefore the time to take the clients to the referral hospital would sometimes be delayed to the detriment of the client's health. Petit (1994) emphasises the need and importance of periodical training to the service provider (caregiver), if good care results are to be realised. The government should ensure through care managers that all caregivers are exposed to periodic training so that they can understand the progression of the disease of their clients and therefore afford them prompt and effective referral.

Poor conditions at hospitals occur in many countries and continents, especially in poor and resource-strapped countries (WHO, 2002). A study by Atta and Fidzani (1996) found the following flaws and shortcomings in the Botswana referral system: (a) improper counselling of the patients; (b) non-counselling of the patients; and (c) lack of communication between the hospitals and the clinics which receive the patients. Further literature in Botswana indicates that referral hospitals are usually overburdened by clients, especially in this era of HIV/AIDS (MOH, 1991; NACP 30, 31, 1996). This has made service delivery slow and sometimes led to neglect of the clients. The 1996 statistics from the two national referral hospitals of Nyangabgwe in Francistown and Princess Marina in Gaborone show that patients with HIV and related diseases occupied over 50% of hospital beds in the medical and paediatric wards, while information in 2002 revealed that the bed occupancy rate for most general medical wards was over 100%, while the occupancy rate for medical wards in general referral hospitals was over 133%. While the Average Length of Stay (ALOS) for all patients was five days, those with HIV/AIDS, was 9 to 14 days (NACA, 2002:ii; NACP 38, 1997). Since the biggest hurdle in the Kanye referral hospitals and others is inadequate staffing, the government needs to employ more doctors and nurses and improve remuneration to the already employed staff to reduce staff turnover.

Inadequate assistance from the health providers generally affects the service provision and referral process in many health care settings. Across the board in many care programmes in

Botswana the referral system is faced with the challenge of inadequate health care staff (Nurses Association of Botswana, 2004). Several studies in Botswana indicate that many caregivers and their clients, for instance, lack qualified counsellors to provide the needed psychosocial support to enable them to handle the challenges inherent in the HIV/AIDS situation successfully and be able to effect referral in time adequately (Jacques & Stegling, 2001; Kang'ethe, 2006; Mojapelo *et al.*, 2001). Generally across districts, the Department of Social and Community Development (S&CD) is especially understaffed, meaning that the services of the social workers to counsel and assess the economic circumstances of the HIV/AIDS clients and their caregivers for possible government assistance and referral hardly works well. This has implications of HIV/AIDS clients getting sick and sometimes dying while waiting for the government food basket, and possible referral advice (DMSAC Report, 2005; Kang'ethe, 2004, 2006).

Clear treatment guidelines are also lacking in many care settings of the world, especially in the developing world. Many health care workers have often not received training in the management of HIV/AIDS (Abbat & Meija, 1988; NACP 13, 1993; Nowlen, 1988; Petit, 1994; UNAIDS, 2001b), thus complicating and compounding the challenge of referral. In Botswana this negates the principles and aspiration of Botswana's vision 2016 of a safe, healthy and secure nation (Vision 2016, 1997). In a study by Atta and Fidzani (1996) in Botswana, 94,5% of the caregivers they studied indicated lack of support from health workers, and 57,8% of patients reported not having been visited by any health worker for a long time. Caregivers preferred health workers to visit the households in order to supervise them, to teach them and to encourage the patients to take their drugs. While the family welfare educators in Botswana are supposed to be at homes advising and directing the activities of the caregivers, Joy Phumaphi, former Minister of Health, observed that they remained in the clinics (*Botswana Daily News*, 2002) leaving the caregivers and their clients with inadequate support.

Subjective information in Kanye village of client neglect or clients being left in the hands of children is not uncommon (Kang'ethe, 2004). In a study by Mojapelo *et al.* (2001), it was found that two clients were taken care of by children. In such circumstances client disease progression and their referral cannot be guaranteed. The programme should ensure that all the clients are taken care of and their health and social needs addressed. In absence of caregivers, the programme should have a provision to allow such clients to go to hospitals and stay there. Though this would defeat the purpose of the CHBC programme, it would be ethically right to do so, if being at home means jeopardising the life of the client. The government needs to ensure that service delivery has enough drivers. The health staff should also adhere to their professional code of ethics enshrined in their job description, which requires them to deal with their tasks seriously and professionally (MOH, 1991).

The literature attributes negative attitudes by the health care providers towards clients and caregivers to their inadequate skills and exposure, and the heavy caseloads that sometimes make them suffer from burnout (Bennet, Ross & Kelaher 1993; Dant & Gully, 1994; MOH/NACP 41, 1998; NACP 31, 1996). Subjective information in the Kanye programme suggests that the community caregivers (volunteers) sometimes opt to go to the houses of the apparently well-to-do clients/primary caregivers, leaving behind those clients who were in abject poverty. There were also accusing fingers pointed at some of the nurses who broke the clients' confidentiality irresponsibly by disclosing the clients' status to the community. This created fear, inadequate confidence in the health facilities and affected the referral system and spirit. Health service providers should undergo a paradigm shift to treat all the clients equally

irrespective of their economic position. They should also stick to their professional code of ethics and the policy guidelines they accepted on their employment to serve all without discrimination and know that it is legally and ethically wrong to disclose the client's status (MOH, 1991). Training the community caregivers in service professionalism and ethics could help change their mindset.

Stigma remains a major obstacle in the HIV/AIDS campaign generally in many countries of the world (UNAIDS, 2000b, 2001). Some caregivers in the Kanye programme could not reveal their clients' status to help systems and therefore effect their referral and possible assistance as a result of the prevalent stigma, in Thailand neighbourhood communities were accused of stigmatising HIV/AIDS clients (UNAIDS, 2001a). Festus Mogae, President of Botswana, stated that the stigma and discrimination surrounding the HIV/AIDS disease remain one of the greatest barriers to the implementation of various care and prevention strategies (Botswana Millennium Development Goals Status Report, 2004), while Kalanke (2004), states that people living with HIV/AIDS (PLWHAs) resort to using and adopting alternative coping strategies such as avoidance, denial and secrecy because of the fear associated with stigma and discrimination of HIV/AIDS. This has had serious repercussions in negatively affecting the rate of consumption of services meant to help patients and to cushion the effect of the virus on those who are affected. It also affects the health of the clients and also the referral system, as clients fail to go to the health facility as a result of denial and avoidance (Fako & Linn, 2003).

In Kalanke's study the caregivers interviewed denied being HIV positive and thus did not utilise certain welfare services such as the food basket because of stigma attached to the programmes. This was a big drawback to care giving as most of the PLWHAs in the country happen to be poor and need help from their caregivers and other help systems. It shuts all avenues of assistance or any possible referral (Jacques & Stegling, 2001; Kang'ethe, 2006; Khan & Stegling, 2000; Mojapelo *et al.*, 2001). The government, organisations in the care field and civil society organisations should increase their anti-stigma campaign to normalise responses to HIV/AIDS. This would make client referral to health facilities and other sources of help easier (Tirisanyo Catholic Commission, 1993; UNAIDS, 2000b).

Lack of transport to effect referrals in good time is usually a common problem and critically affects the quality of service delivery and the whole spectrum of the referral system (MOH, 1991). While many CHBC programmes in Botswana are supposed to have ample transport to assist the clients to get to the hospital or the main referral hospital, the transport system is very poor and sometimes unavailable. Subjective evidence suggests that cases of clients being taken to the hospital by donkeys are not uncommon. This is usually done after efforts to contact the CHBC transport facility fails. Sometimes a vehicle could be available, but there is no driver. The CHBC programme should ensure adequate transport at all times to assist the clients in the referral. Communities should also contribute more and be ready to offer clients transport.

Inadequate care programme management also poses referral challenges in community home-based care programmes in Botswana. Under a normal and ideal CHBC situation, prior and robust arrangements need be in place before releasing the HIV/AIDS client to home-based care. For instance, it is necessary to know who will be taking care of the client, what the help system at his/her disposal is, and his/her suitability for the task. The economic and social environment of the home where the client is being discharged to needs to be assessed for possible help intervention. It is only after such an assessment by the home-based care team that a discharge sheet can be issued. However, subjective evidence of many CHBC discharge cases in Botswana

attests to the fact that clients are discharged without any such preparatory arrangements on the ground (Jackson, 2002; NACP, 30, 31, 1996).

CONCLUSION

The referral system is dynamic and complex, its success depending on how well the officers in the whole spectrum of health facilities communicate and cooperate. Proper communication, however, requires a spirit of cooperation and a commitment to the principle of doing what is best for the patients. Inadequate referral systems or networks pose huge challenges to the health of the clients, the effectiveness of care giving and the HIV/AIDS campaign generally. It kills the motivation and interest of the caregivers in using the health facilities, making them use other alternative assistance avenues, which may be detrimental to the clients' health. The government and other non-governmental organisations in the care field need to make sure that all the health facilities are well equipped with adequate staff as well as facilities to handle the clients satisfactorily. All the health facilities need to upgrade their communication systems with one another to be effective in the referral system. The government and organisations in the care field also need to do research and identify all the factors impeding the referral system and put in place measures to address the problems. This would also make caregivers aware of all possible avenues of assistance to their clients.

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