

supported by their communities (UNAIDS, 1999:24). The unfortunate dwindling of the black African altruistic spirit with time is a result of black Africans embracing Westernization and the Eurocentric values of individualism, thus abandoning the traditional communal or socialistic style of living that saw people doing work together for the good of all in the society. The concept of helping one another and sharing has always been at the core of African values (Makhubele, 2009:89). It is in this context that the notion of home-based care was envisaged.

INADEQUATE SUPERVISION BY HEALTH CARE PERSONNEL

Caregivers lamented that they are rarely supervised by health care professionals and they thus felt inadequate, as they often require professionals to guide them in what they have to do. Since most of them have a limited education, they are not always sure whether they are doing the right things or not, hence the relevance and importance to them of continued supervision by health care professionals. Health professionals, on the other hand, feel overwhelmed with the work load as a result of the shortage of staff in clinical areas (Atta & Fidzani, 1996:8). There was a general feeling amongst participants that clinics or health care centres are by and large understaffed and thus impose a burden on both health care workers and caregivers. The Nurses Association of Botswana (NAB, 2004:21) alluded to a general inadequacy of health personnel in many poor countries as a result of under-staffing. Jacques and Stegling (2001:8) concur that health care providers are failing to supervise community caregivers in their care-taking, whilst Atta and Fidzani (1996:6) indicate that 95% of the caregivers lacked supervision and support from health workers. It can thus be concluded that lack of professional supervision has a negative impact on the quality of care giving, thus posing a challenge to caregivers at grassroots level. It is therefore ethically unacceptable that this category of health care worker should be allowed to function independently. In the final instance it is the professional health care worker who is responsible for the assessment of the patient and for developing the care plan which the caregivers are involved in implementing. Consequently, the implementation process equally needs supervision, support and training of caregiver so that together they can provide holistic patient care and family support (Cameron *et al.*, 2009:9).

LACK OF PSYCHOLOGICAL SUPPORT

Care giving to the terminally ill was described by participants as being taxing, overwhelming and psychologically draining. Caregivers' repeatedly echoed lack of psychological support in the form of counselling or debriefing to ease the emotional strain as indicated above. They were of the view that lack of professional psychological support leads to stress, burnout and low morale. They emphasised this as the main reason for the high turnover of persons in care giving.

Debriefing and counselling are expected to help make caregivers come terms with the reality of the situation, instils hope and confidence, and consequently encourages caregivers to seek support and to share with others in order to reduce the psychological and emotional burden on them. As suggested by the NAB (2004), UNAIDS (2000) and Uys and Cameron (2003), it is the role of the government (Department of Health and Social Development) and organisations in the field of care giving to provide professional counsellors to caregivers to alleviate the psychological strains that can lead to feelings of isolation, stress, burnout and low morale amongst them. It is also the role of social workers to encourage caregivers to form support groups, because it is through support groups that caregivers' feelings and experiences are legitimised, and they are provided with a framework for coping (White & Madara, 1992:19). It is on the basis of this that caregivers expressed their need to be afforded the opportunity to share experiences and gain support from each other through the establishment of support

groups. Meeting others like them who have experienced a similar problem would, according to them, give a them sense of belonging, thus maximising emotional health. Since most of them are not educated or are illiterate, the involvement of professionals in facilitating support groups seemed the right thing for them. The participants expressed a strong need to see health professionals showing interest in their work and acknowledging the challenges they face in the world of care giving. Support groups are considered a valuable tool in the breakdown of secrecy and isolation, and in fostering an environment of psychological wellbeing (Want & Williams, 2000:14; Yalom, 1985).

Most groups lamented that though they do the work on a voluntary basis, and are sometimes forced to use their own limited resources, the CHBC programme provides no incentives, rewards or any strategies to motivate the caregivers. Huczynski (1987:251) explains the purpose of an incentive or reward as facilitating positive changes or behaviour that could result in increased productivity. Incentives, according to the participants, should include receiving stipends, bonuses, encouraging words, food packages, regular visits and supervision by health professionals. In other African countries the situation is different. For instance, in Zimbabwe caregivers receive as an incentive a year's pocket-money in a lump sum, whilst in Uganda the Aids Service Organisation (TASO) assists with the education of at least two children of each caregiver (UNAIDS, 1999:23).

IMPACT OF POVERTY ON CARE GIVING

The study revealed that most caregivers are from disadvantaged families, as 88% of them had no source of income. Most rely on welfare grants, food parcels and doing menial jobs within the community. Some get involved in doing care work because they feel it is better than staying at home without anything to do. This, according to respondents, moves the focus away from the "house" towards looking at their engagement as part of a community. A study by Mojapelo, Ditirafalo, Tau and Doehlie (2001:20) established that 85% of the caregivers were not employed and often cited poverty as a stumbling block in the provision of good care. Another study by Khan and Stegling (2000:23) found glaring poverty amongst the caregivers, as evidenced in a lack of the most basic necessities, with the lack of food being the gravest. The final element worth noting is this regard is that irrespective of how little they have, caregivers have an undying commitment to serve their families and communities. This, they indicated, gives them a purpose in life and they hope that the government will someday reward them in one way or another.

Caregivers felt they have social and cultural responsibility to take care of the sick. Mensah (1994:60) indicated that irrespective of poverty, communities especially in Africa have been helping each other in times of sorrow and distress.

LACK OF TRAINING

As indicated above, the study revealed that most of the caregivers were illiterate or had low levels of education, which calls for continuous in-service training. According to participants, training is offered only on an intermittent basis. They expressed their commitment and willingness to work for the community, but emphasised their lack of writing and language skills. This affirms the need for skills development. Atta and Fidzani (1996:8) confirmed that only 10% of caregivers receive appropriate training for their task. Because of illiteracy, 11% of the caregivers they studied found the instructions for the administration of the medicine that they were responsible for too complicated, making care giving a stressful task. Petit (1994:4)

emphasises the need for, and importance of, periodical training to the caregiver if good results are to be realised.

According to Cameron *et al.* (2009:10), community caregivers need training in home care, palliative care, infection control, psycho-social support as well as record keeping. Given the high rate of HIV and AIDS, it is imperative for caregivers to receive training in caring for HIV-positive people at home, and in understanding the implications of the HIV status of family members. It is also essential that caregivers be trained in pain management as, according to them, this is usually beyond the scope of what they can manage. This is mostly required when a person in their charge is dying. Losing a patient usually leaves carers with a sense of defeat, and a feeling that they have rendered a poor service or failed to save a patient's life.

CONCLUSION AND RECOMMENDATIONS

Given the fact that community caregivers are a key community resource in providing assistance and care to many who would otherwise have little access to any form of assistance, there is a critical need to support and acknowledge the work done by them. Caregivers have to deal with matters such as stigmatisation and discrimination, the emotional stress of repeated loss of clients, the physical strain of having to walk long distances to reach their patients or clients, lack of income, lack of adequate training, lack of psychological support and lack of recognition, all of which contribute to feelings of stress and fatigue. This indicates that they are a marginalised and uncared for category of workers, who should in fact be regarded as a key community resource. All this, coupled with the physical and emotional cost of providing care that is unpaid and undervalued, poses a serious challenge to willing community caregivers in rendering their valuable service. While the caregivers' contribution cannot be over-emphasised as a very important community resource, it is apparent that they face many challenges, which in turn makes their contribution lacking in many aspects necessary to make care giving a success and to ensure quality care.

Against the above background and in order to ensure that caregivers are enabled to render an effective service, the following recommendations are made:

- Social workers and professional health care workers should work together to assist community caregivers in their efforts to provide a valuable service to the community. This calls for a structured, formalised, and coordinated working relationship among the various health units within the Department of Health and Social Development and NGOs/CBOs responsible for caregivers. A structured, formalised and coordinated relationship is anticipated to encourage regular supervision, on-going training, care, and recognition of caregivers for the valuable service that they render.
- Legislation should be promulgated to regulate the functioning of community caregivers, if possible by placing them under the auspices of a particular statutory professional body. This will assist in developing standards or guidelines needed to streamline their functioning with a view to protecting clients and caregivers themselves.
- Stipends payable to caregivers to cover transport costs and meals are imperative. This will serve as an incentive to encourage commitment and security.
- Adequate provision of care-giving tools such as disposable diapers, gloves, antiseptics and protective clothing must be provided at regular intervals.
- Social workers as community brokers must be encouraged to provide a link between caregivers and health care professionals to facilitate provision of care giving tools or requirements.

In conclusion, it should be emphasised that, notwithstanding the fact that most community home-based caregivers do not have formal education, it is necessary to involve them in the decision-making processes of the CHBC programme. Since they are involved in the service at grassroots level, their suggestions may contribute to the quality of care of patients. This may also further improve their image and dignity within the community.

BIBLIOGRAPHY

- ADVANCING THE AGENDA. 2002. **Africans urge high level backing for volunteer action.** [Online] Available: http://www.unv.org/infobase/unv_news.
- ATTA, J.K. & FIDZANI, N.H. 1996. **Baseline study for Community Home Based Care Programme for Terminally ill HIV/AIDS patients in Botswana.** NACP 31. AIDS STD unit, Gaborone, Botswana.
- CAMERON, S., COETZEE, L. & NGIDI, N. 2009. **Legal aspects of palliative care.** Hospice Palliative Care Association of South Africa.
- DANT, T. & GULLY, V. 1994. **Coordinating care at home.** London: Collins.
- DONALEK, J.G. & SOLDWISCH, S. 2004. Demystifying nursing research: an introduction to qualitative research methods. **Urologic Nursing**, 24(4):354-356.
- FOSSEY, E., HARVEY, C., McDERMOTT, F. & DAVIDSON L. 2002. Understanding and evaluating qualitative research. **Australian and New Zealand Journal of Psychiatry**, 36:717-732.
- HUCZYNSKI, A. 1987. **Encyclopedia of organizational change methods.** Brookfield, VT, U.S: Gower.
- JACQUES, G. & STEGLING, C. 2001. **Panacea or perfidy?** Paper presented at the 3rd International Conference on Social Work in Health and Mental Health, July 1-5, 2001, Tampere, Finland.
- KELESETSE, N.M. 1998. **AIDS, home based care and the status of women in Botswana: a case study of Mogoditshane.** Gaborone: University of Botswana. (Unpublished dissertation)
- KHAN, B. & STEGLING, C. 2000. **An evaluation of the Kweneng district AIDS Home Based Care Programme,** Gaborone: SNV, Netherlands Development Organisation.
- MAKHUBELE, J.C. 2009. **Indeginising life skills education.** North West University. (Unpublished dissertation)
- MENSAH, M. 1994. Home based care for people with HIV/AIDS: Agomaya, Ghana. **Development in Practice**, 4(1):58-62.
- MOJAPELO, D., DITIRAFALO, T., TAU, M. & DOEHLIE, E. 2001. **Client satisfaction and providers perspectives of home based care in Kweneng District, Botswana.** Unpublished Report, Gaborone.
- MUCHIRU, S. & FROHLICH, J. 1999. **HIV/AIDS home based care.** Gaborone: MacMillan.
- NATIONAL AIDS CONTROL PROGRAMME (NACP) 30. 1996. **Community home based care for people living with AIDS in Botswana.** AIDS STD Unit, Gaborone.

- NATIONAL AIDS CONTROL PROGRAMME (NACP) 31. 1996. **Baseline study for the community home based care programmes for terminally ill HIV/AIDS patients in Botswana.** Gaborone, Botswana.
- NURSES ASSOCIATION OF BOTSWANA (NAB). 2004. **Caring for the caregivers.** Gaborone, Kgotla Designs.
- PETIT, P. 1994. Closing the performance gap. **Health Action**, (8):4.
- STATISTICS SOUTH AFRICA. 2009.
- UNAIDS. 1999. **Comfort and hope.** Six case studies on mobilizing family and community care for and by people with HIV/AIDS, June.
- UNAIDS. 2005. **AIDS epidemic.** December 2005.
- UNAIDS. 2008. **Caring for carers.** Managing stress in those who care for people with HIV and AIDS. UNAIDS Case study.
- URSULA, S. 1991. **Review of community based care programme in Uganda:** Kitovu mobile AIDS home care programme in the report of the regional workshop on HIV/AIDS community based care and control, 6-11 October. Entebe: Commonwealth Secretariat. and WHO
- UYS, L. & CAMERON, S. 2003. **Home based HIV/AIDS care.** Oxford: Oxford University Press.
- WANT, C. & WILLIAMS, P. 2000. Adventures in group work. **Dulwich Centre Journal**, 1&2:11-17.
- WHITE, B.J. & MADARA, E.D. 1992. **The self-help sourcebook.** American Self-Help Clearinghouse, Denville, New Jersey.
- YALOM, I.D. 1985. **The theory and practice of group psychotherapy.** New York: Basic Books.

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