Published in final edited form as:

AIDS Care. 2011 July ; 23(7): 839–845. doi:10.1080/09540121.2010.542122.

Stigma, burden, social support, and willingness to care among caregivers of PLWHA in home based care South Africa

Dinesh Singh¹, Stephenie R. Chaudoir², Maria Cabrera Escobar³, and Seth Kalichman⁴

¹Department of Psychiatry, University of Kwa-Zulu Natal, Durban, South Africa

²Department of Psychology, Bradley University, Peoria, IL, USA

³Health Economics and HIV/AIDS Research Division, University of Kwa-Zulu Natal, Durban, South Africa

⁴Department of Psychology, University of Connecticut, Storrs, CT, USA

Abstract

Despite its benefits for people living with HIV/AIDS (PLWHA), home based care (HBC) may have negative effects on caregivers. Caregivers experience high levels of burden and may be targets of HIV related prejudice and discrimination. In this cross-sectional survey of 358 caregivers from five hospices across KwaZulu-Natal, South Africa, 49 (13.7 %) caregivers personally experienced discrimination as a result of caring for PLWHA. One hundred and seventy (47.5%) marked one or more items on the HIV stigma scale. Eighty-eight percent had low to moderate levels of caregiver burden. People with higher level of burden and higher income were more likely to hold stigmatizing beliefs. Caregivers with the following characteristics: support from a nurse, support from community care-worker, HIV stigmatizing beliefs, and personal experience of discrimination as result of caring for PLWHA and low caregiver burden, had more than twice the odds of wanting to care for another PLWA in the future. Overall, caregivers in HBC experience low level of severe caregiver burden. The support offered to caregivers from the hospice and relatively low levels of discrimination encourage expansion of HBC programs for PLWHA.

Keywords

stigma; HIV/AIDS; home based care

Introduction

The aim of this study was to describe the prevalence of HIV stigma, personal experience of discrimination, caregiver burden, and predictors of willingness to care for another person living with HIV/AIDS. South Africa has a mature HIV epidemic with more than 5.7 million people living with HIV/AIDS (PLWHA) (WHO, 2008). By the middle of 2008, 568,000 adults in South Africa were receiving antiretroviral therapy (ART) treatment; however, an additional 760,000 to 1.8 million people were eligible, but not yet on ART (Adam & Johnson, 2009). Stigma, weak health systems, shortage of health-care personnel, and a lack of long-term sustained funding are some of the factors that have limited scale up of ART (Adam & Johnson, 2009; WHO, 2008). Without ART, people progress to AIDS quicker

which further overload the health care system and increase demand for palliative care. The health care system cannot provide long-term institutionalized care for these patients. Therefore, home-based care is an important complementary component of a health care model to address a mature HIV epidemic.

The integrated community and home-based care (IHC) model was first supported by USAID funds in a rural hospice in South Africa in mid-1997 and two years later the South African Department of Health provided further support to expand IHC model to seven sites across the country (Fox, Fawcett, Kelly, & Ntlabati, 2002). The IHC model provides a continuum of care between all health sectors with an emphasis on palliative care. This may include close relations with faith based organizations and non-governmental organizations. The professional nurse supervisor from the hospice is responsible for nursing care of a number of PLWHA in the community. The professional nurse is supported by the community care workers who support the caregiver. Caregivers are integral to the program because they provide the ongoing daily care. Caregivers are selected by the hospices and the following are considered: residence in the community, current unemployment, and good communication skills (Fox, et al., 2002). They are not excluded on the basis of gender, HIV status, or age. A systematic review concluded that palliative care, including home based care, improves a number of psychological and health outcomes (Harding, et al., 2005). Home based care (HBC) has other advantages, such as providing care for multiple family members, improving adherence when combined with tuberculosis and ARV programs, and being cost effective (Baingana, Choi, Barrett, Byansi, & Hearst, 1995; Ngamvithayapong, Yanai, Winkvist, Saisorn, & Diwan, 2001; Okello, Floyd, Adatu, Odeke, & Gargioni, 2003; Yaima, et al., 1995).

However, despite the demonstrated benefits of HBC for PLWHA, the impact of HBC on its caregivers has been much more mixed. On the one hand, several studies have demonstrated that HBC can be a rewarding and positive experience for its caregivers (Apondi, et al., 2007; Chimwaza & Watkins, 2004; Powell-Cope & Brown, 1992). On the other hand, some research has demonstrated that caregivers often experience negative consequences of HIV stigma, feel highly burdened, and experience mental and physical health problems because of the demands of their jobs (Bogart, et al., 2008; Holzemer, et al., 2007; Mwinituo & Mill, 2006; Pirraglia, et al., 2005; Wight, LeBlanc, & Aneshensel, 1998).

HIV is one of the most highly stigmatized medical conditions world-wide and HIV-related stigma is particularly severe in sub-Saharan African countries (Dlamini, et al., 2007; Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007; Lindsey, Hirschfeld, & Tlou, 2003). Although caregivers may not be HIV-infected themselves, they may incur the negative effects of “associative stigma” (Goffman, 1963) whereby caregivers may be targets of HIV-related prejudice and discrimination by virtue of the fact that they work with PLWHA.

Previous work substantiates this idea, indicating that caregivers may feel stigmatized because they work with PLWHA (Bogart, et al., 2008; Lindsey, et al., 2003; Uys, 2002). For example, in a qualitative analysis, caregivers in Ghana reported that they often felt the need to hide their care giving jobs from their friends and family members to avoid stigmatizing reactions from them (Uys, 2002). This secrecy often resulted in feelings of loneliness, isolation, and a lack of support from their social network.

Caregivers may also experience a great degree of burden due to the demands of their jobs. Caregivers frequently tend to patients’ wounds, bath and feed them, making care giving very physically demanding (Baker, Sudit, & Litwak, 1998; Chimwaza & Watkins, 2004; Choo, et al., 2003; Demmer, 1998; Engler, et al., 2006; Flaskerud & Tabora, 1998; Kipp, Matukala, Laing, & Jhangri, 2006; Kipp, et al., 2007; Lindsey, et al., 2003). Further, the emotional

burden of loss of loved ones to AIDS is often an unrecognized stressor for caregivers (Demmer, 2007). Consequently, caregivers of PLWHA suffer increased burnout (Demmer, 2004), depression (Flaskerud & Tabora, 1998; Land & Hudson, 2004; Pirraglia, et al., 2005), physical health problems, and stress symptoms (Wight, Beals, Miller-Martinez, Murphy, & Aneshensel, 2007).

Together, the negative effects of HIV stigma and the great degree of burden that caregivers experience may each be deterrents in caregivers' choice to care for additional PLWHA in the future. Given that the sustainability of HBC programs relies heavily on volunteers (Russel & Schneider, 2000), understanding how to minimize these negative effects of caregiving is essential to the success of HBC. Family, neighbours, volunteer workers, and faith based organizations have been identified as important sources of support that can mitigate the problems associated with care giving (Campbell, Nair, Maimane, & Sibiyi, 2008; Choo, et al., 2003). Thus, these sources of support are important resources that can help prevent loss of caregivers and increase caregivers' willingness to care for another PLWHA in the future.

Study Overview

In the current work, we examine the impact of the ongoing HBC program on its caregivers in KwaZulu-Natal, South Africa in four ways: 1) we document the prevalence of HIV-related discrimination experienced by the caregivers, 2) prevalence of HIV-stigma attitudes among caregivers, 3) degree of perceived burden of care giving work, and 4) factors predicting willingness to continue care-giving in the future.

Methods

Participants and Procedure

Our sample was made up of 402 randomly selected community caregivers from 5 hospices that adopted ICHC model in KwaZulu-Natal. Between 2003 and 2008, 15 hospices across KwaZulu-Natal were using the ICHC model and more than 16,000 PLWHA were supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria. Caregivers were responsible for one to three PLWHA and none of the caregivers were caring for a PLWHA for longer than two years. The hospices selected were a mix of rural, urban and peri-urban hospices from across the province. The caregivers were paid employees or volunteers; none were family members of the PLWHA. Data collection was done from December 2005 to March 2006. No incentive was given to participants. All participants provided written informed consent. The study protocol was approved by the University of KwaZulu-Natal bioethics committee.

Study instruments

A structured questionnaire was administered to collect socio-demographic and other outcome measures. The questionnaire took approximately 45 minutes to complete.

Demographics—We collected information regarding age, sex, level of education, and income. We categorized level of education into 3 categories representing no education, completed grade 1–7 (primary school only), and completed more than grade 7 (high school). We did not measure income as an absolute monetary amount because we felt it was more important to know what they could do with their income. We therefore asked them to report if they had enough for basics or some money for basics and important things or extras.

Discrimination and Willingness to Care—Participants indicated categorically (1 = yes; 0 = no) whether they experienced any discrimination as a result of caring for a PLWA and their willingness to care for another PLWA in the future.

HIV stigma—We assessed HIV stigma using The HIV Stigma Scale (Kalichman, et al., 2005). The HIV Stigma Scale is a 9-item scale that was developed and validated in South Africa. The scale includes items that capture constructs reflecting negative beliefs of PLWHA, shamefulness and endorsements of negative actions towards PLWHA. Sample items include “People who have HIV are dirty” and “It is safe for people with HIV to work with children.” Participants were asked to indicate their agreement or disagreement with each item (0 = *I disagree*; 1 = *I agree*). Items reflecting positive statements about PLWHA (e.g., *People who have HIV should be allowed to work*) were reverse-coded and a sum score was created indicating the total number of stigma items participants agreed with. There was, however, limited variability in these sum scores, so we created a final dichotomous variable that represented the presence or absence of any stigmatizing beliefs of HIV (0 = no agreement with any stigma items; 1 = agreement with one or more stigma items).

Burden—Caregiver burden was assessed with the Burden Interview (Zarit & Zarit, 1990). This 22-item measure assesses caregivers’ perceptions of and reactions to care giving demands based on the patient’s disabilities and level of reliance on the caregiver. Items were answered on a 5-point scale from 0 (*Never*) to 4 (*Nearly Always*). The items were summed to provide a nominal measure of burden, yielding a range of values from 0 to 88. Using these scores, the level of burden was categorized into little (0–20), mild to moderate (21–40), moderate to severe (41–60) burden or very severe (61–88) burden.

Perceived support—We used an instrument we piloted to measure support caregivers received from four sources: nurses, community care worker, other family members, and the church. Caregivers indicated the amount of support they received from each source on a 4-point scale (1 = a lot of support; 2 = some support; 3 = not very much support; 4 = no support). However, due to lack of variability, we dichotomized the responses “a lot of support and some support into support” into support and “not very much support and no support” into no support.

Data analysis

Forty-four caregivers were excluded from analyses due to missing data, leaving a final sample of 358 caregivers in the current analyses. Descriptive statistics are given to answer our first three questions. We examined personal experience of discrimination, HIV stigma, age, gender, burden, income, and support from nurse, community care worker, other family members, and church as predictors of willingness to care in the future. We first conducted univariate logistic regression analyses to explore the effect of each variable separately. From these models we selected variables to be included in the multivariate model if $p < .10$ (Sen & Srivastava, 1990). We present odds ratios (OR) at 95% Confidence Interval (CI) and effects were considered to be significant if $p < .05$.

Results

As can be seen in Table 1, caregivers in our sample were mostly, middle-aged females with limited income. More than half (54.4 %) reported having at least a grade seven education.

The experience of discrimination was uncommon in our sample. Only 13.7% ($n = 49$) of the caregivers reported ever being the target of discrimination. More than 47 % of our sample marked one or more of the items on the stigma scale.

The experience of severe burden was fairly low ($N = 2$). More than 60 % ($N = 217$) experienced mild to moderate burden. More than three quarters accessed support from the nurse and community care worker than less than half received support from the family and church (Table 1).

Finally, we examined willingness to care. A caregiver who received support from the nurse had more than three times the odds of being willing to care for another PLWA in the future. Caregivers with lower level of burden were more willing to care for another PLWHA. Surprisingly, people who had personal experience of discrimination or endorsed at least one item on the stigma scale were more willing to care for another PLWHA in the future (see Table 2). Even though seventy-five percent of the caregivers were volunteers, fifty-three percent of the caregivers were willing to care for another PLWHA in the future.

Discussion

In our study of home-based caregivers, we found that experiences of personal discrimination and severe caregiver burden were low but HIV/AIDS stigma was high. Caregivers in home based care reported receiving adequate support from nurses and community care workers but not from family and the church. Finally, caregivers who received support from nurses and community care workers and reported lower burden and personal experience of discrimination were more willing to care for another PLWHA in the future.

Our results correspond to those found in previous studies. The sociodemographic characteristics of our sample are typical of other studies conducted in Africa; the majority of our sample was comprised of older female volunteers (Andrén & Elmståhl, 2007; Kipp, et al., 2007; Lindsey, et al., 2003; Prachakul & Grant, 2003). Further, the prevalence of the experience of discrimination by caregivers was low and almost identical to what was reported from caregivers in Uganda. It has been hypothesized that personal experience of discrimination would contribute to increased stigma (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). The level of HIV stigma in our sample was high but lower than a report from other parts of the country. Using the same HIV Stigma Scale, Kalichman (2005) found that more than 56 % of the participants in a sexually transmitted infection clinic and 50 % of the participants from an African township in South Africa endorsed one stigmatizing item. Whilst the exact mechanism leading to reduced stigma cannot be established from our study, it does suggest the nature of the home based care program offers a model to build future interventions to reduce stigma. It may be a combination of accurate knowledge, skill building sessions, close personal contact with PLWHA and regular contact with nurses that may account for the reduced stigma. It may explain why caregivers with personal experience of discrimination endorsed fewer stigmatizing items. Our findings support the conclusions from Brown and colleagues' (2003) review of intervention research to reduce stigma. The body of evidence suggests that skills building and exposure to PLWHA is more effective than simple information on HIV. Self selection may account for the low levels of stigma in our sample i.e. people with low levels of stigma volunteer or seek jobs as caregivers.

There is high level of volunteerism in the ICHC. Even though three quarters were unpaid, more than half were prepared to care for another PLWHA in the future. These caregivers do the bulk of the work with little or no pay and consideration must be given to the sustainability of these programs. In a review of community based programs providing care for PLWHA in Southern Africa, Russel and Schneider (2000) found that programs that were underfunded and relied heavily on volunteers had a high turnover of staff. To make HBC sustainable, caregivers must be paid.

One important mitigating factor of willingness to care for PLWHA in the future was perceived social support. We found that feeling adequate support from other nurses and community care workers was related to greater willingness to care; however, perceived social support from family or the church did not affect this important outcome. The fact that support from nurses and community care workers was related to willingness to care provides additional evidence that the high levels of professional support offered by these individuals is a strength of the integrated HBC model (Choo, et al., 2003).

One reason why support from family or church did not relate to greater willingness to care in the future is that caregivers may not have been fully open with these individuals about working with PLWHA. Other research demonstrates that fear of AIDS stigma and discrimination may limit disclosure and hinder accessing support from family (Kalichman, et al., 2003). For example, Mwinto and Mill (2006) found that informal caregivers in Ghana kept their care giving secret from family and others and, therefore, also received little support from family. We cannot understand why people with higher levels of stigma were willing to care for another PLWA in the future. It is possible that stigma is not a necessary and sufficient cause in the willingness to care causal pie. Further research is needed to clarify this finding.

To the best of our knowledge this is the first study that examined the predictors of willingness to care for PLWA in the future. Further, we used a validated HIV stigma scale to quantify HIV stigma and this also allowed for us to compare the degree of stigmatizing beliefs among caregivers to those of a general community sample. This comparison provides new insight into the possibility of the ICHC model as a stigma-reduction strategy.

Despite the many strengths of our study, there are some limitations. First, social desirability concerns may have prevented our caregivers from reporting higher levels of HIV stigma or may have made our caregivers reluctant to report negative aspects of their work. We did try to limit this bias by using peer community care workers to collect study information and trained these individuals to develop rapport with the caregivers. Social desirability bias may have accounted for why caregivers indicated a willingness to care for another PLWHA. If this was true, then more people were not willing to care for another PLWHA. Relationship to the PLWHA would have influenced their willingness to care for another PLWHA in the future. The caregivers were recruited independently from the community according to a predetermined set of criteria therefore we assume most were unrelated. We used single items to measure of discrimination and willingness to care. These findings are also limited only to caregivers who were part of the ICHC program. Future studies should compare the ICHC model with other models of HBC. Finally, the cross-sectional nature of this study limits us from making any firm conclusions about causality.

Overall, our study adds to the growing body of evidence suggesting that the HBC can have positive social outcomes. Home-based care can help meet the challenges of up-scaling care to PLWHA especially in low and middle income countries. The caregivers' lower level of severe burden and discrimination from the community, high degree of volunteerism, and willingness to care for another PLWA in the future are encouraging. Given that the caregivers are a critical resource in the HBC and there is a lack of human resources in providing health care, every effort must be made to retain and recruit more caregivers. The support offered to caregivers in the ICHC model encouraged them to care for another PLWHA. However, more financial support must be given to home-based care programs to reduce the dependence on volunteers and retain more caregivers.

Acknowledgments

Dinesh Singh was supported by Fogarty International Centre, NIH, grant 5-D43-TW00231 (AIDS International Training and Research Program, Quarraisha Abdool Karim, Ph.D., Principal Investigator). The authors would like to thank the anonymous reviewers, Urvashi Vasant, Tanusha Raniga, Samantha Gengiah, Robert Pawinski, Umesh Lalloo, Barry McDaniel and South Coast Hospice for their assistance during various stages of this project.

References

- Adam MA, Johnson LF. Estimation of adult antiretroviral treatment coverage in South Africa. *S Afr Med J*. 2009; (99):661–667. [PubMed: 20073293]
- Andrén S, Elmståhl S. Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: A cross-sectional community-based study. *International Journal of Nursing Studies*. 2007; 44(3):435–446. [PubMed: 17078957]
- Apondi R, Bunnell R, Awor A, Wamai N, Bikaako-Kajura W, Solberg P, et al. Home-based antiretroviral care is associated with positive social outcomes in a prospective cohort in Uganda. *J Acquir Immune Defic Syndr*. 2007; 44(1):71–76. [PubMed: 17031319]
- Baingana G, Choi KH, Barrett DC, Byansi R, Hearst N. Female partners of AIDS patients in Uganda: reported knowledge, perceptions and plans. *AIDS*. 1995; 9 Suppl 1:S15–S19. [PubMed: 8561996]
- Baker S, Sudit M, Litwak E. Caregiver burden and coping strategies used by informal caregivers of minority women living with HIV/AIDS. *ABNF.J*. 1998; 9(3):56–60. [PubMed: 9677867]
- Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, et al. HIV-related stigma among people with HIV and their families: a qualitative analysis. *AIDS Behav*. 2008; 12(2):244–254. [PubMed: 17458691]
- Campbell C, Nair Y, Maimane S, Sibiyi Z. Supporting people with AIDS and their carers in rural South Africa: Possibilities and challenges. *Health & Place*. 2008; 14(3):507–518. [PubMed: 18023238]
- Chimwaza AF, Watkins SC. Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*. 2004; 16(7):795–807.
- Choo WY, Low WY, Karina R, Poi PJ, Ebenezer E, Prince MJ. Social support and burden among caregivers of patients with dementia in Malaysia. *Asia Pac.J Public Health*. 2003; 15(1):23–29. [PubMed: 14620494]
- Demmer C. Death anxiety, coping resources, and comfort with dying patients among nurses in AIDS care facilities. *Psychol.Rep*. 1998; 83:1051–1057. [PubMed: 9923185]
- Demmer C. Burnout: the health care worker as survivor. *AIDS Read*. 2004; 14(10):522–530. [PubMed: 15510388]
- Demmer C. Responding to AIDS-related bereavement in the South African context. *Death.Stud*. 2007; 31(9):821–843. [PubMed: 17886413]
- Dlamini PS, Kohi TW, Uys LR, Phetlhu RD, Chirwa ML, Naidoo JR, et al. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public Health Nurs*. 2007; 24(5):389–399. [PubMed: 17714223]
- Engler P, Anderson B, Herman D, Bishop D, Miller I, Pirraglia P, et al. Coping and burden among informal HIV caregivers. *Psychosom.Med*. 2006; 68(6):985–992. [PubMed: 17132844]
- Flaskerud JH, Tabora B. Health problems of low-income female caregivers of adults with HIV/AIDS. *Health Care Women Int*. 1998; 19(1):23–36. [PubMed: 9479092]
- Fox, S.; Fawcett, C.; Kelly, K.; Ntlabati, P. Integrated community-based home care (ICHC) in South Africa: a review of the model implemented by the Hospice Association of South Africa. Cape Town: Center for AIDS Development, Research and Evaluation (Cadre); 2002.
- Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect*. 2005; (81):5–14. [PubMed: 15681714]
- Holzemer WL, Uys L, Makoe L, Stewart A, Phetlhu R, Dlamini PS, et al. A conceptual model of HIV/AIDS stigma from five African countries. *J.Adv.Nurs*. 2007; 58(6):541–551. [PubMed: 17484748]

- Kalichman SC, DiMarco M, Austin J, Luke W, DiFonzo K. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *J Behav.Med.* 2003; 26(4): 315–332. [PubMed: 12921006]
- Kalichman SC, Simbayi LC, Jooste S, Toefy Y, Cain D, Cherry C, et al. Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS Behav.* 2005; 9(2):135–143. [PubMed: 15933833]
- Kipp W, Matukala NT, Laing L, Jhangri GS. Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care.* 2006; 18(7):694–697. [PubMed: 16971277]
- Kipp W, Tindyebwa D, Rubaale T, Karamagi E, Bajenja E. Family caregivers in rural Uganda: the hidden reality. *Health Care Women Int.* 2007; 28(10):856–871. [PubMed: 17987457]
- Land H, Hudson SM. Stress, coping, and depressive symptomatology in Latina and Anglo aids caregivers. *Psychology & Health.* 2004; 19(5):643–666.
- Lindsey E, Hirschfeld M, Tlou S. Home-based care in Botswana: experiences of older women and young girls. *Health Care Women Int.* 2003; 24(6):486–501. [PubMed: 12851169]
- Mwinituo PP, Mill JE. Stigma associated with Ghanaian caregivers of AIDS patients. *West J Nurs.Res.* 2006; 28(4):369–382. [PubMed: 16672629]
- Ngamvithayapong J, Yanai H, Winkvist A, Saisorn S, Diwan V. Feasibility of home-based and health centre-based DOT: perspectives of TB care providers and clients in an HIV-endemic area of Thailand. *Int.J Tuberc.Lung Dis.* 2001; 5(8):741–745. [PubMed: 11495265]
- Okello D, Floyd K, Adatu F, Odeke R, Gargioni G. Cost and cost-effectiveness of community-based care for tuberculosis patients in rural Uganda. *Int.J Tuberc.Lung Dis.* 2003; 7(9 Suppl 1):S72–S79. [PubMed: 12971657]
- Pirraglia PA, Bishop D, Herman DS, Trisvan E, Lopez RA, Torgersen CS, et al. Caregiver burden and depression among informal caregivers of HIV-infected individuals. *J.Gen.Intern.Med.* 2005; 20(6): 510–514. [PubMed: 15987325]
- Powell- Cope GM, Brown MA. Going public as an AIDS family caregiver. *Social Science and Medicine.* 1992; 34:571. [PubMed: 1604363]
- Prachakul W, Grant JS. Informal caregivers of persons with HIV/AIDS: a review and analysis. *J Assoc.Nurses AIDS Care.* 2003; 14(3):55–71. [PubMed: 12800812]
- Russel, M.; Schneider, H. A rapid appraisal of community based HIV/AIDS care and support programs in South Africa. Johannesburg: Center for Health Policy, University of Witwatersrand; 2000.
- Sen, S.; Srivastava, M. Regression Analysis: Theory, methods, and application. New York: Springer-Verlag; 1990.
- Uys LR. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *J.Clin.Nurs.* 2002; 11(1):99–108. [PubMed: 11845761]
- WHO. Towards Universal Access: Scaling up priority HIV/AIDS interventions in health sector, progress report; June 2008. Geneva, Switzerland: 2008.
- Wight RG, Beals KP, Miller-Martinez D, Murphy DA, Aneshensel CS. HIV-related traumatic stress symptoms in AIDS caregiving family dyads. *AIDS Care.* 2007; 19(7):901–909. [PubMed: 17712694]
- Wight RG, LeBlanc AJ, Aneshensel CS. AIDS caregiving and health among midlife and older women. *Health Psychol.* 1998; 17(2):130–137. [PubMed: 9548704]
- Yaima N, Ningthouja S, Sharma D, Bijaya L, Shyamkanhai K, Narendra P, et al. Lessons from home based care for persons affecting with HIV and AIDS. *Indian J Public Health.* 1995; 39(3):113–115. [PubMed: 8690490]
- Zarit, S.; Zarit, JM. The Memory and Behavior Problems Checklist and the Burden Interview. Pennsylvania, USA: 1990.

Table 1

Socio-demographic, burden index, HIV stigma, perceived support and willingness to care for another PLWHA amongst caregivers (N=358)

Characteristics	n	%
Age in years. mean (SD)	44	(8.1)
Gender		
Females	312	87.2
Males	46	12.8
Education		
<Grade 1	53	14.8
Grade 1–7	103	28.8
>Grade 7	202	56.4
Income		
Not enough for basics	114	31.8
Some money for basics and important things	166	46.4
Money for extras	78	21.8
Personal experience of discrimination: Yes	49	13.7
Willing to care for another PLWHA in the future: Yes	188	52.5
Volunteer caregiver:	268	74.9
Burden index (BI)		
Little or no burden (BI 0–20)	98	27.4
Mild to moderate burden (BI 21–40)	217	60.6
Moderate to severe burden (BI 41–61)	41	11.4
Severe burden (BI 61–88)	2	0.6
HIV stigma: Yes	170	47.5
Receive support from: *		
Nurse	316	88.3
Community care worker	267	74.6
Family	171	47.8
Church	172	48.1

* N >358 because some caregivers received multiple sources of support

Table 2

Logistic regression models of caregiver's willingness to care for another PLWHA in the future

Predictor	Univariate			Multivariate		
	OR	95% CI	p-value	OR	95% CI	p-value
Support from nurse						
No	1.0			1.0		
Yes	3.36	1.72 – 6.57	<0.000	3.17	1.16–8.74	0.025*
Support from community care worker						
No	1.0			1.0		
Yes	2.18	1.34 – 3.58	0.002	2.15	1.14 – 4.06	0.018*
Support from family						
No	1.0			1.0		
Yes	0.91	0.59 – 1.39	0.660	0.93	0.61–1.43	0.72
Support from church						
No	1.0			1.0		
Yes	1.23	0.79 – 1.91	0.345	1.09	0.6–1.8	0.41
Burden	0.96	0.94 – 0.98	0.001	0.97	0.94 – 0.99	0.049*
Stigma						
No	1.0			1.0		
Yes	2.18	1.41 – 3.37	<0.000	2.04	1.20 – 3.46	0.008*
Discrimination						
No	1.0			1.0		
Yes	1.66	0.89 – 3.09	0.113	2.34	1.09 – 5.05	0.030*

Notes. OR = Odds Ratio; CI = Confidence Interval

* =statistically significant