

PILOT COMMUNITY-BASED INTERVENTION TO ADDRESS THE NEEDS OF ELDERLY CAREGIVERS IN SOUTH AFRICA

The HIV epidemic in South Africa has placed a substantial burden on elderly caregivers, mainly women, who are often tasked with caring for their grandchildren who are orphaned and rendered vulnerable by the death or illness of their parents (Horizons Program 2004; Juma et al. 2004; WHO 2002; Nampanya-Serpell 2003). The Medical Research Council (MRC), Age-in-Action, and the Horizons Program conducted formative research to assess the needs of elderly caregivers in the Eastern Cape Province of South Africa in 2005 (Reddy et al. 2006, 2005a, 2005b). The investigation revealed that elderly caregivers faced a number of challenges including fears and a sense of hopelessness around matters regarding youth; difficulty communicating with youth; barriers to accessing health care; insufficient funds to cover basic needs; and difficulty accessing social service grants. Based on these findings, Horizons, MRC, and Age-in-Action developed an intervention study to explore and test whether a health education program would effectively lead to (1) improved care and support provided by elderly caregivers, (2) improved psychosocial outcomes for the caregivers themselves, and (3) increased capacity on the part of health service providers to enhance the care they provide to the elderly.



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Elderly women caregivers face a number of challenges meeting the needs of their dependents as a result of the HIV epidemic.

Methodology

The quasi-experimental study included a community-based health education intervention with cross-sectional pre- and post-surveys to test for effectiveness with a convenience sample of elderly caregivers. The intervention was conducted in the Eastern Cape of South Africa in Motherwell; Uitenhage served as the comparison arm.

Community health workers (CHWs) from Age-in-Action and data collectors from the community recruited 409 Xhosa-speaking elderly caregivers ages 60 years and older who fulfilled the following selection criteria: 1) caring for adult children, grandchildren, or other dependents, 2) willing to participate in the

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four-week intervention program, and 3) consented to being interviewed at three time points. Researchers at the MRC developed and pre-tested questionnaires that were administered to caregivers prior to any intervention activities (n = 209 in Motherwell, n = 200 in Uitenhage), immediately after the intervention activities (n = 176 in Motherwell, n = 190 in Uitenhage), and again after 3 months (n = 185 in Motherwell, n = 178 in Uitenhage). The surveys measured changes in the group's responses over time, as additional participants joined the intervention after baseline data collection (see intervention section below).

Scales were used to measure theoretical constructs such as knowledge, attitudes, self-efficacy, social norms, and beliefs. The frequency of depressive symptoms was measured by the 15-item Hopkins Symptom Checklist (Kaaya et al. 2002). Coping was assessed with a 17-item Ways of Coping scale (Folkman et al. 1986), in which six subscales were measured. The subscales included negative as well as positive ways of coping. Negative ways of coping were categorized as self-controlling, escape-avoidance, and distancing. Positive ways of coping consisted of planned problem solving, seeking social support, and positive reappraisal.

At the end of the intervention, elderly caregivers who participated in all sessions were invited to participate in a focus group discussion (FGD) to share their impressions of the program and the content of the intervention. FGDs were also conducted with Age-in-Action service providers who worked with the elderly caregivers and conducted the intervention workshops. The FGDs elicited information on the changes CHWs observed in the elderly caregivers after the workshops, with a focus on their abilities to cope, access services, and communicate with their dependents.

Quantitative data were analyzed using SPSS 14.0. The results were compared between intervention and comparison groups as well as pre- and post-intervention. Pearson's Chi Square tests were used to determine statistically significant differences between the control and the intervention group within each round of data collection. A p-value of 0.05 was used as a cut-off for statistical significance in most cases. However, since these scales were new to researchers and no other study had used them, a cut off of 0.10 was used in some cases.

Horizons conducts global operations research to improve HIV/AIDS prevention, care, and support programs. Horizons is implemented by the Population Council in partnership with the International Center for Research on Women (ICRW), PATH, the International HIV/AIDS Alliance, Tulane University, Family Health International, and Johns Hopkins University.

Effect analysis was conducted using the univariate general linear model. Effects at endline and at 3-month follow up were controlled for possible differences between the control and intervention groups at baseline. Age and total number of duties were included as covariates. Gender, marital status and whether the elderly caregivers received formal education were included as factors one by one. This provided insight into possible interactions between certain variables and the outcome.

To test for internal consistency of the scales, reliability analysis was used. A Cronbach's alpha of more than .70 indicated that individual variables shared a commonality and were adequate to describe the concept captured by the scale. In the case where the scale reliability measured below .70, factor analysis was used to test if the variables were related to each other. The variables with a high loading of > 0.4 were grouped to form a factor.

Atlas.t, a qualitative statistical package, was used to analyze the qualitative data. The transcribed and translated data from the focus groups were divided into meaningful analytic units or segments.

Intervention

Based on information collected during the formative research and subsequent interviews with senior staff at Age-in-Action, possible topics for the intervention workshops were brainstormed and finalized. An intervention package consisting of weekly training workshops for elderly caregivers was developed which included four workshops of about three hours each that focused on:

- Providing accurate information about HIV.
- Building skills to bridge the communication gap between elderly caregivers and their dependents.
- Building skills to provide basic home-based nursing care.
- Providing up-to-date information on available social support services.
- Fostering an appreciation for the need to do relaxation exercises and the skills required to do them.

The intervention manual, entitled "Parenting a second time around: Grandparents as HIV/AIDS Caregivers," was translated into IsiXhosa.

With the help of Age-in-Action, nine initial CHWs (six in Motherwell; three in Uitenhage) and a further nine new CHWs (three in Motherwell; six in Uitenhage) were recruited for the study. The CHWs were trained in recruiting elderly caregivers, obtaining consent, conducting the survey, and implementing the intervention. Ten of the CHWs received intensive and interactive four-day training on the intervention. The training covered how to facilitate the four workshops, keep records, and record the sessions. Four teams were set up with the CHWs serving as facilitators and the new staff as co-facilitators.

All 209 elderly caregivers in the intervention as well as 200 in the comparison arm were visited in their homes by one of the trained Xhosa-speaking team members and were fully informed about the study. After informed consent was obtained, the baseline questionnaire was conducted. Participants in the intervention arm were invited to the workshops, which were intended to take place over four weeks. Elderly caregivers in the comparison arm were encouraged to continue with their usual participation in Age-in-Action club activities which included engaging in relaxation exercises, a choir, and doing sewing, beadwork, plays, and skits that were organized by the CHWs.

The workshops in the intervention arm were based on participatory discussions and practical exercises, and information was provided through talks and handouts. The groups consisted of 10 to 12 participants each. Of the 154 elderly caregivers recruited initially, only 60 completed all four sessions in the four intervention weeks. Reasons for non-attendance were mostly related to health problems or death in their families. To make it possible for everyone to finish all four workshops, three additional weeks of make-up sessions were scheduled and the elderly caregivers who were unable to attend initially were contacted and invited to attend the scheduled make-up sessions. In total, 146 elderly caregivers completed all four workshops.

An additional 69 elderly caregivers who did not complete the baseline questionnaire but had heard about the workshops from their friends or their communities showed up at the workshops. They were all facing the same problems and were desperately seeking training, information, and advice. Fifty-one of these individuals completed the four workshops. All participants were provided transport, tea, and lunch, and upon completion of the training, they were given a gift package comprising of soap, washing powder, disinfectant, paracetamol tablets, and a face-cloth.

Sociodemographic Profile of Elderly Caregivers

At baseline, the mean age of the participants was 71.6 years (see Table 1, page 4). The majority of the respondents were female (86 percent), and more than half were widowed. Half of the elderly caregivers had formal schooling and a majority received an income (63 percent). On average, the elderly caregivers cared for 4.6 dependents (an average of three grandchildren and one adult).

The intervention and control groups were significantly different on most of the demographic variables. It is possible that elderly caregivers in Motherwell did not perceive of the old age pension as a source of income, and therefore did not indicate that they received an income.

Key Findings

Intervention led to improvements in caregivers' HIV knowledge

An encouraging finding of the study was the increase in HIV-related knowledge among the intervention group (see Table 2, page 5). The number of correct answers provided by elderly caregivers in the intervention group improved significantly at endline and was maintained at 3-month follow-up. A significant difference was also found between the intervention and control groups. At endline, elderly caregivers in the intervention arm answered 5.64 questions correctly, while the elderly caregivers in the control condition answered 4.68 questions correctly ($F(1, 303) = 22.07, p < 0.001$). Improvements in knowledge related to HIV were maintained at 3-month follow-up.

Elderly caregivers demonstrated improvements for several psychosocial variables

Elderly caregivers in the intervention arm were less likely to report depressive symptoms than those in the control group ($p < .04$) at endline. At 3-month follow-up, the differences between control and intervention groups remained significant ($p < .001$) for depressive symptoms. Elderly caregivers in the intervention group were also less likely to report feeling helpless regarding carrying out tasks for their dependents at endline ($p <$

Table 1 Sociodemographic profile of elderly caregivers at baseline

	Intervention (n = 209)	Control (n = 200)	p-value
Mean age (sd)	73.1 (8.52)	70.0 (7.39)	0.02
Gender			0.04
Female	172 (82.3%)	180 (90%)	
Male	34 (16.3%)	19 (9.5%)	
Unknown	3 (1.4%)	1 (0.5%)	
Ethnic background			0.5
African	208 (99.5%)	199 (99.5%)	
Colored		1 (0.5%)	
Unknown	1 (0.5%)		
Marital status			0.01
Married	47 (22.5%)	62 (31%)	
Single	25 (12%)	37 (18.5%)	
Divorced	16 (7.6%)	6 (3%)	
Widowed	119 (56.9%)	95 (47.5%)	
Unknown	2 (1%)		
Received formal education	88 (42.1%)	120 (60%)	0.000
Highest education level	121 (57.9%)	80 (40%)	
No formal education	35 (16.7%)	30 (15%)	
Lower primary	33 (15.8%)	53 (26.5%)	
Higher primary	15 (7.2%)	27 (13.5%)	
Junior secondary	5 (2.4%)	10 (5%)	
Senior secondary			
Receive income	70 (33.5%)	187 (93.5%)	0.000
Income*	1 (0.9%)		
Paid job	109 (96.5%)	189 (95.9%)	
Old age pension	4 (3.5%)		
Unemployment benefits	2 (1.8%)	5 (2.5%)	
Disability grant	17 (15%)	15 (7.6%)	
Child support grant		3 (1.5%)	
Foster care grant		2 (1%)	
Private pension		5 (2.5%)	
From spouse/family/friend			
Monthly income			
Less than R500	4 (1.9%)	1 (0.5%)	
Between R500–1000	87 (41.6%)	182 (91%)	
Between R2000–5000	4 (1.9%)	15 (7.5%)	
Unknown	114 (54.6%)	2 (1%)	
Caregiving responsibilities			
Average number of dependents (mean, sd)	4.85 (2.78)	4.30 (2.74)	0.89
Number of sick dependents (mean, sd)	0.86 (1.07)	0.76 (0.85)	0.17
Number of school going children (mean, sd)	2.11 (1.40)	1.99 (1.47)	0.30
Only caregiver	155 (74.2%)	175 (87.5%)	0.72
Number of caregiving duties (mean, sd)	16.85 (7.51)	18.46 (8.92)	0.044

*some elderly have more than 1 income source

Table 2 Changes in intervention group’s knowledge responses

Question	Baseline % correct	Endline % correct	3-month follow up % correct
1 HIV damages the cells that protect against sicknesses	36	72	78
2 A healthy looking person can be infected with HIV	27	67	68
3 A person can get infected with HIV when hugging someone who has HIV	41	65	68
4 Only young people can get infected with HIV	42	60	66
5 HIV infection can be prevented by using condoms correctly when having sex	41	61	76
6 HIV can be passed on to an unborn child when the mother is infected with HIV	42	60	57
7 HIV is present in blood, semen and vaginal fluid	38	74	79

.001) and at 3-month follow-up ($p < .001$). Significantly fewer elderly caregivers reported that they sometimes felt like abusing their dependents in the intervention group compared with the control group at endline (intervention: 11 percent, control: 51 percent, $p < .01$) and 3-month follow-up (intervention: 8 percent, control: 42 percent, $p < .001$) (see Figure 1, page 6).

Intervention had limited impact on attitude and self-efficacy variables

Study results found that the intervention did not impact on elderly caregivers’ attitudes. There were no significant changes in the attitudes of elderly caregivers in the intervention group towards HIV, nursing care, communication, and providing an income. Similarly, the intervention did not result in changes in intervention group in the areas of elderly caregivers’ confidence about their ability to carry out tasks (i.e. self-efficacy) related to caring for their dependents.

For several attitude and self-efficacy variables, the intervention groups scored lower than the control group, which highlights the fact that behaviors, once taught, are not always easy to implement. At the same time, it is possible that the intervention group reported from a more realistic perspective of trying to engage in the behaviors and experienced the difficulties associated with their actual implementation in the home environment.

Elderly caregivers felt confident sharing information after the intervention

More than eight out of ten (88 percent) of the elderly caregivers were confident sharing information about HIV after the workshops and nine out of ten actually did so. They shared the information with their grandchildren, children, spouses, other elderly, and other people.

Other people would ask “What do you learn over there?” and I would tell them everything we are learning, and explain.

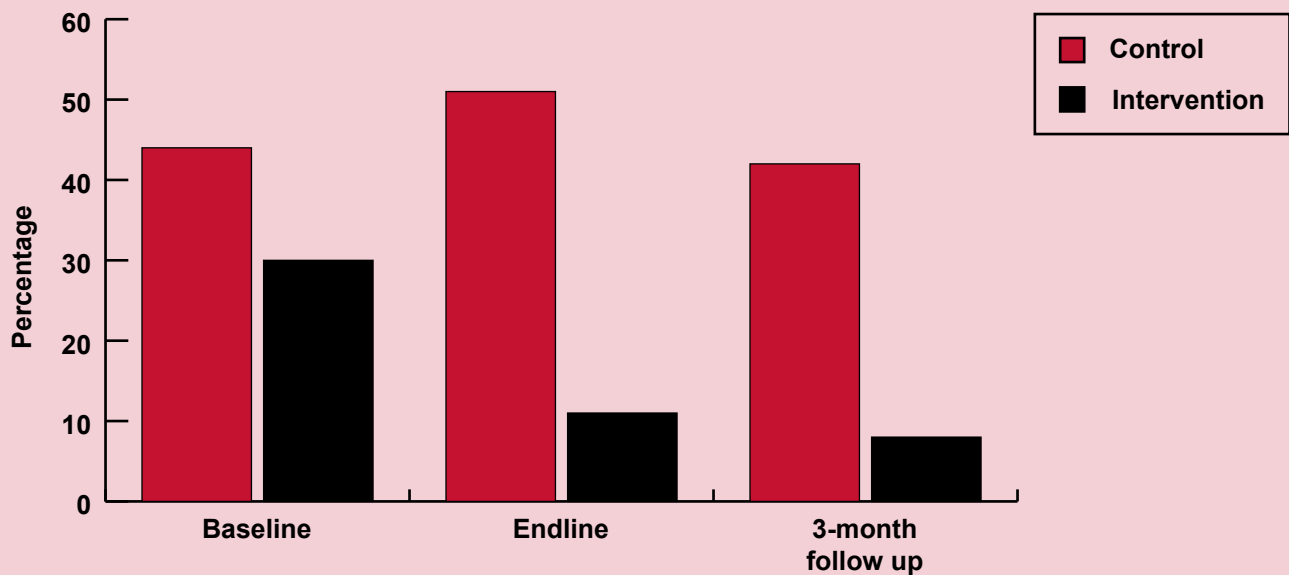
Female elderly caregiver

The majority of the participants (56 percent) indicated that they were five times more likely to talk to their children or grandchildren about HIV after the workshops. Many reported finding the workshop on intergenerational communication helpful and the skills gained practical.

I take the condoms for my children...and I tell them you must use those condoms. I have a grandchild that died, because I was struggling. I don't want you to be bones.... I do not want grandchildren from my grandchildren.... You must use condoms, go for injections and go for testing, that is what I said to this last born.

Female elderly caregiver

Figure 1 Elderly that sometimes feel like abusing their dependents



I liked that one on how to teach children and how to talk to them, that we must not push them but talk calm and nicely.

Female elderly caregiver

Elderly caregivers practiced home-based basic nursing care post-intervention

Following the workshops about half (55 percent) of the elderly practiced the basic nursing skills they learned at home. Skills that were seen as most useful were mostly related to giving a bath to someone in bed.

We loved it when you showed us how to bed bath a person who is sick. We understood all those things because it has been a while since we have been nursing.

Female elderly caregiver

Many elderly caregivers showed other members of the family how to do bed washes correctly.

...I told her that we were taught how to give a bed bath and that we should have two towels. You must put one under the head and the other to wipe with and start from top to down.

Female elderly caregiver

However, one out of five of the elderly caregivers experienced problems when practicing the nursing care skills at home. These problems mostly consisted of not having nursing equipment available such as gloves, towels, soap, or disinfectant.

Workshops increased elderly caregivers' knowledge of social grants

Many elderly caregivers were previously unaware of the number of different grants available for assistance with their children and grandchildren apart from the old age pension, and they were unfamiliar with the procedures to apply for these grants. About 60 percent of elderly caregivers felt confident with the process of applying for the additional grants after they received the information at the workshops.

After the workshops, five participants applied for grants for themselves, 18 applied for grants for their grandchildren, one applied for her child, and three applied for someone else. Six of the elderly caregivers experienced difficulties with their applications, where they did not have all the required documents or their application was returned unsuccessfully. Several applications were still in process at the time of the writing of this summary, but after completing the workshop, 11 participants had received the grant they applied for.

Health workers observed several changes in elderly caregivers

CHWs reported several changes in the behaviors of elderly caregivers after the intervention. Participants showed an increase in their skills and knowledge, especially recognizing symptoms of HIV.

The fact is that the children would make an excuse of having TB, while they know that they are HIV-positive, but the elderly caregivers after the workshops, are now aware of the symptoms and are able to encourage them to go to the hospitals for tests.

Community health worker

CHWs stated that elderly caregivers improved their communication skills with their children and grandchildren.

Some grandchildren are actually happy because there is a change in their homes...there is also a change in the grannies because they are not talking to their children the same way they used to.

Community health worker

Through the workshops, the elderly caregivers became more open to sharing their experiences related to HIV and receiving support from each other.

...the group thing worked well because a lot of them were trying to hide the AIDS fact, but they finally got the confidence and they talked to one another about it, so it was not a secret anymore, because of the way they were talking to each other and the teaching we gave them.

Community health worker

Health workers gained new skills themselves through workshops

Community health workers expressed that they learned new skills from the workshops, or refreshed existing skills used in their daily work.

I personally think the topics are very important, especially to us health workers because we come across these problems a lot, like for instance giving a bed bath. We were never taught properly before.... I learnt something else now.

Community health worker

...there is a problem that people always tell us about, when it comes to the social grant. I learnt that if someone wants to apply for a grant, I know which days that person must go there and what to bring for a grant for a child. Instead of the elderly wasting her last cents by going there without knowing anything.

Community health worker

Health workers also gained confidence as they went through the sessions.

I used to be scared but as the workshops went on, I just told myself that I can do this and felt confident. More especially because we were hosting one topic a week...then I thought to myself, if I know this, I have got to be confident and speak to people, tell them about what they don't know. So I gained a lot in that way.

Community health worker

...I also liked all of them because they were so important and I have gained a lot of knowledge from the workshops.


Community health worker

Conclusion

The intervention, which aimed to improve the ability of the elderly to cope with their caregiving roles and responsibilities, had mixed success. The study reflected positive findings on several psychosocial variables, such as a reduction in reported depressive symptoms. Overall, the elderly caregivers reported using skills they learned such as bed bathing as well as communication techniques despite some barriers such as the lack of resources. The elderly caregivers demonstrated a perseverance and desire to change their situation by using the skills taught to them, as confirmed by the FGDs held with them and CHWs.

Impacting on attitudes and self-efficacy proved to be more challenging, and the intervention had limited success in this area, as discussed above. These findings suggest that future interventions would benefit from spending more time exposing elderly caregivers to activities that allow them to practice strategies that address attitudes, enhance self-efficacy, and build confidence. This will also require additional training of CHWs to facilitate hands-on role modeling and experiential teaching.

The biggest challenge in implementing the intervention was getting all of the elderly caregivers to the training sessions. Personal reasons related to illnesses and deaths in the family resulted in some of the participants dropping out of the training and requiring the creation of make-up sessions, which should be built into future interventions. Lack of economic means to purchase equipment and material needed by the elderly caregivers to practice the nursing skills that they had learnt during the intervention was a challenge for many of the participants. Community structures and resources need to be mobilized to improve the accessibility of nursing equipment.

This study demonstrates the possibility of working with a vulnerable population, the elderly, and addressing areas where they need support. For this experimental process to transcend the realms of research into practice, different stakeholders such as health, social development, and community organizations should be encouraged to collaborate to address the problems that the elderly caregivers are facing, and to devise interventions to improve their capacity to care for themselves and for their dependents. 

February 2009

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The authors would like to acknowledge the contributions made by Professor B. van den Borne and Dr. R. Ruiter, Maastricht University, The Netherlands for their scientific guidance, statistical support, and interpretation of data analysis. Many thanks to the Age-in-Action staff, community health workers, volunteers, and elderly caregivers of Uitenhage and Motherwell, Port Elizabeth, Eastern Cape for their support of the study.

Principal study investigators included Professor P. Reddy, Dr. S. James, and Ms. H. Mutumba Bilay-Boon of the Health Promotion Research and Development Unit, Medical Research Council, Cape Town and Dr. E. Williams formerly of Horizons/Population Council.

Suggested citation: Reddy, P., S. James, H. Mutumba Bilay-Boon, E. Williams, and H. Khan. 2009. "Pilot community-based intervention to address the needs of elderly caregivers in the Eastern Cape Province, South Africa," *Horizons Research Summary*. Washington, DC: Population Council.



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This research summary is made possible by the generous support of the American people through the United States Agency for International Development (USAID) and the President's Emergency Plan for AIDS Relief under the terms of HRN-A-00-97-00012-00. The contents are the responsibility of the Horizons Program and do not necessarily reflect the views of USAID or the United States Government.

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