

Older-Age People Supporting HIV/AIDS Children and Household Relatives on Antiretroviral Treatment.

Case Study of Six Communes of Banteay Meanchey Province, Cambodia.

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> Analyzing Development Issues Trainees and Team

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Executive Summary

Introduction

In Cambodia access to antiretroviral therapy (ART) accelerated rapidly in the past decade and came to restructure in large part the circumstances and experience of those dealing intimately with the AIDS epidemic. Until very recently HIV infected persons living in Cambodia who had contracted opportunistic infections (OI) associated with AIDS were destined to endure debilitating illnesses terminating inexorably in death. Beyond those infected, the epidemic extended to family members including older-age parents who often bore the emotional, economic, and social consequences of intensive care giving and the premature deaths of their children and relatives. Expanded availability of ART in Cambodia drastically reconfigured the prevailing situations of those affected by the disease. With ART the onslaught of AIDS related infections could now be effectively treated and the health of the AIDS patient could be noticeably restored. Meanwhile increased testing for HIV enabled ART treatment to begin before OI became symptomatic and started to take their toll. As persons living with HIV/AIDS (PHLA) experienced improved health on ART, family members including parents similarly benefited as the adverse effects of the disease were mitigated or at least substantially delayed.

This Analyzing Development Issues (ADI) study focuses on older-age people supporting HIV/AIDS positive children and household relatives on ART in six communes of Banteay Meanchey province in northwest Cambodia. More specifically, the study seeks to examine the background characteristics of the older-age people and their ART recipient children and household relatives, to understand the involvement of the elders in care giving and assistance with treatment adherence, to assess the financial and health impacts of care giving on the older age people, to identify the consequence of ART use for the elders and their children and household relatives, and to explore the support services provided to the elderly caregivers. The study also gauges the scope of parental and family support from information supplied by ART recipients or their caregivers in the study communes. Older persons are largely ignored in the discourse concerning the AIDS epidemic despite the fact that they are intimately involved.

The study employs quantitative and qualitative methods. In May 2008 a one page questionnaire was used to gather information on 382 ART recipients in six purposively selected communes of Banteay Meanchey province. In the same month and in the same communes a total 108 people 50 years and older with ART recipient children living in the same or different households or with ART recipient relatives living in the same household were purposively selected and interviewed about their care giving experiences. In July 2008, 10 of the 108 survey respondents were approached again and interviewed in qualitative in-depth interviews. In Phnom Penh and Banteay Meanchey province the study also interviewed government officials involved in the provision of ART and NGOs involved in home based care support.

ART Recipient Survey

The ART recipient survey reveals that three-fifths of the 382 respondents had at least one living parent and that nearly three-fourths of those with a surviving parent lived in the same household or location as their parents. This placed parents in an advantageous situation to monitor and support ART use. More than two-fifths of the ART recipient parents, and almost two-thirds of the co-resident parents, often or daily reminded their children to take their ART medicines. Compared to older parents, younger parents and especially co-resident younger parents reminded their children often or daily to take ART. Moreover, among ART recipients who had a living parent, more than three-fifths had a parent who reminded them to get their medicines from the hospital or health center. Similarly almost one-third had a parent who had actually taken or accompanied them to get medicines.

Older-Age People's Survey

The older-age people's survey reveals that elderly respondents and/or their spouses in 101 (94 percent) of the 108 households interviewed provided care to HIV/AIDS positive children and household relatives. Moreover in these households elderly women comprised 82 percent of the primary care givers. The pronounced role of elderly women in care giving was striking considering their demographic and social characteristics. A majority were separated, divorced or widowed without partners to rely on, nearly half had never attended school, two-thirds were still working to support their households, and just over half were 60 years of age or over. Despite these constraints elderly women generally assumed primary responsibility for the care of HIV/AIDS positive children and household relatives.

While older persons' and especially older women's commitment to caring for HIV/AIDS positive children and household relatives was strongly evidenced in the research, the care giving of elders came at a cost. Slightly more than 90 percent of the elderly respondents incurred expenses for the care and treatment of their HIV/AIDS positive children and household relatives apparently before receiving the ART medicines for free. Most elders making these payments had depleted their savings and/or borrowed money. Many had sold land, gold or jewelry. Elderly respondents likewise incurred financial burdens for medical and/or funeral expenses as a result of HIV/AIDS deaths in their families. While more than 40 percent of the elderly respondents complained of poor or very poor health, the elders generally did not associate specific health complaints with the consequences of care giving.

The use of ART resulted in improved health for almost all of the elders' children/household relatives and enabled them to care for themselves. Nearly three-fourths of the elderly respondents reported that ART recipient children/household relatives were able to return to work and more than half had ART recipient children/household relatives who were able to contribute to the income of their households. While the time spent by the elders in care giving dropped sharply after ART

use, the elderly respondents remained actively involved in reminding the ART recipients to take their medicines

To provide effective assistance with ART treatment adherence, elders must have sufficient understanding of the treatment regimen. The study examined the association of ART knowledge and the extent to which older persons received instruction from the ART treatment program. The result indicated a strong association between the extent of instruction received and ART knowledge. This suggests that receiving advice from program sources considerably improves older persons' knowledge.

In the study communes home based care teams led by NGOs assisted respondents' children/household relatives on ART. Three-fourths of the households' surveyed acknowledged their PLHA's involvement in such programs. According to respondents in these households, the teams encouraged the ART users to take their medicine on time, to eat nutritious foods, and to practice good hygiene. The teams also provided the ART recipients with counseling and made referrals for them to health centers and hospitals. In some instances the teams provided ART beneficiaries with material goods such as sleeping mats, mosquito nets, and blankets.

Elders and their AIDS infected children/household relatives likewise participated in PLHA group meetings and this participation was highly valued. A large majority (87 percent) of the 108 respondents reported that their children/household relatives on ART had attended PLHA group meetings. By comparison, elders in about half (49 percent) of the 108 households surveyed had participated themselves in PLHA group meetings. Nearly all the respondents reporting either type of involvement acknowledged that the meetings were helpful for their PLHA children/household relatives and/or for themselves.

While some discrimination towards HIV/AIDS positive children and household relatives existed before they came to be on ART, the prejudice was not particularly severe. A high incidence of respondents reported that neighbors had visited even before the start of ART treatment. During this time some neighbors even bought food or medicine. This noted, ART use had beneficial effects on community reactions. After ART treatment began the incidence of respondents reporting visits by neighbors increased while the incidence of respondents noting avoidance and gossip by neighbors decreased.

Policy Implications

Cambodia's response to its AIDS epidemic has been remarkably effective albeit highly dependent on donor funding. Rigorous life long treatment adherence to ART regimens is crucial to sustain the health benefits achieved and lessen drug resistance associated with treatment failure. The ongoing success of Cambodia's response to the disease relies on developing culturally appropriate, pragmatic and cost effective approaches to long-term ART adherence. This entails not only continued provision of drugs and medical personnel to dispense them, it requires persons to supply social and psychological support as well. The formation of PLHA support groups and home based care teams to augment treatment adherence constitutes the prevailing strategy in Cambodia to address this

challenge. The results of this study which empirically document the contributions made by elders in response to HIV/AIDS suggest opportunities for expanding this strategy to include older-age persons and other family members.

Compelling arguments emerge from the research for involving older-age persons and other family members more inclusively in ART adherence programs. Elderly persons often live with or nearby ART patients and have deep emotional reasons for wanting the patient to achieve and maintain restored health. They are highly committed to caring and are often present at the specific times that medicines need to be taken. Moreover, they neither ask nor expect to be paid for their assistance. In short, older-age persons represent a largely untapped resource in Cambodia's organized response to the AIDS epidemic.

The underutilization of older-age persons in Cambodia's ART adherence programs is perhaps due to health professionals' perceptions that their advanced ages and general lack of formal education render them incapable of providing useful assistance. But as evidenced in this study neither their older ages nor their low levels of education and literacy prevented the elders from understanding the basic requirements of treatment adherence. Indeed ART knowledge was strongly associated with the extent of instruction received suggesting that training from program sources substantially improved older persons' knowledge. This has implications for involving PLHA support groups more proactively in the education of older-age persons and other family members. Working in tandem PLHA support groups and older-age persons could generate greater synergy and contribute significantly to Cambodia's response to the AIDS epidemic which will likely confront the country for years to come.

Introduction

In Cambodia access to antiretroviral therapy (ART) accelerated rapidly in the past decade and came to restructure in large part the circumstances and experience of those dealing intimately with the AIDS epidemic. Until very recently HIV infected persons living in Cambodia who had contracted opportunistic infections (OI) associated with AIDS were destined to endure debilitating illnesses terminating inexorably in death. Beyond those infected, the epidemic extended to family members including older age parents who often bore the emotional, economic, and social consequences of intensive care giving and the premature deaths of their children and relatives. Expanded availability of ART in Cambodia drastically reconfigured the prevailing situations of those affected by the disease. With ART the onslaught of AIDS related infections could now be effectively treated and the health of the AIDS patient could be noticeably restored. Meanwhile increased testing for HIV enabled ART treatment to begin before OI became symptomatic and started to take their toll. As persons living with HIV/AIDS (PHLA) experience improved health on ART, family members including parents similarly benefited as the adverse effects of the disease were mitigated or at least substantially delayed.1

This section explores how the widespread provision of ART in Cambodia transformed the role of older persons in HIV/AIDS care giving and treatment assistance. It begins by tracing the trajectory of the AIDS epidemic in Cambodia from 1991 to the present. It then examines how older age persons were affected by the deteriorating illnesses and consequent deaths of family members infected with AIDS. It likewise assesses the changes taking place in the role of older persons in the era of ART. Finally it considers older-age persons as a resource in the rigorous and long-term treatment adherence regimen required by the effective use of ART.

The AIDS Epidemic in Cambodia

The HIV virus was first identified in Cambodia in the blood supply in 1991.² From its initial detection the epidemic spread rapidly with adult prevalence rates reaching their peak at 3 percent in 1997. By 2003 it was estimated that 94,000 people had died of AIDS related illnesses and that 123,000 people were living with HIV or AIDS. At the same time the initial response proved effective. This revolved around government and NGO collaboration and aggressively targeted high-risk groups. By 2003 the adult prevalence rate had dropped significantly to 1.2 percent and by 2006 had further declined to 0.9 percent.³

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¹ See Knodel, John, Jiraporn Kespichayawattana, Chanpen Saengtienchai, and Suvinee Wiwatwanich, Older-age Parents and the AIDS Epidemic in Thailand: Changing Impacts in the Era of Antiretroviral Therapy, Bangkok: United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), 2009.

² This sections draws heavily on Markus Buhler, David Wilkinson, Jenne Roberts, and TAP Catalla Jr., *Turning the Tide: Cambodia's Response to HIV & Aids 1991-2005*, Phnom Penh: UNAIDS, 2006.

National Aids Authority (NAA), UNGASS Country Progress Report Cambodia, 2008.

In the early and mid 1990s the majority of new HIV infections were the male clients of female sex workers. Focusing scare resources on preventing transmission among these high-risk populations helped stem the onset of the epidemic. However by 1998 the principal mode of transmission had shifted from husband to wife and increasingly from mother to child. By then the epidemic was already generalized and PHLA, estimated at 154,000, were found in every province of the country. The strategy of targeting prevention interventions at specific groups was becoming increasingly difficult and expensive, particularly given the absence of a viable public health system in Cambodia. Similarly, as the epidemic matured it was necessary to go beyond prevention and awareness raising activities to the provision of care and treatment programs for affected individuals and families.

A key feature of Cambodia's successful response to the AIDS epidemic was the government's adoption of the "Continuum of Care" (CoC) framework in 2003. The CoC concept provided the rationale for the home based care program and its outreach services to PLHA and their families. A pilot home based care program was launched in 1998 in Phnom Penh under a partnership of the Ministry of Health (MoH) and NGOs. In 1999 at the end of the pilot phase the National Centre for HIV, AIDS, Dermatology and STI (NCHADS) began to implement the program with the Khmer HIV/AIDS NGO Alliance (KHANA) channeling technical and financial support to implementing NGOs. Although the public health system in Cambodia remained weak, the establishment of the NCHADS within the MoH in 1998 provided the government with a dedicated national health agency and a much needed vertical structure to combat HIV throughout the country.

Under the management of NCHADS the home based care program was scaled up considerably with NGOs such as KHANA, World Vision, and Care supporting home based care teams. In 2005 NCHADS reported that 261 home based care teams were providing services to PLHA in 56 operational districts in 17 provinces. By the third quarter of 2009, NCHADS announced that 323 home based care teams covered 689 health centers in 68 operational districts in 18 provinces. These home based care teams supported 27,431 PLHA with 9,440 receiving treatment for opportunistic infections and 17,991 receiving ART. This coverage represented 73 percent of the total health centers and 48 percent of the total ART recipients. 5

Under the CoC framework NCHADS similarly developed a strong Voluntary Confidential Counseling and Testing (VCCT) program and encouraged the formation of PLHA support groups. In 1995 the Institut Pasteur was the only provider of HIV testing and counseling services in Cambodia. In 2000, a full five years later, the number of VCCT sites had only increased to 12. However the VCCT program expanded rapidly in the new millennium once treatment services followed positive testing and were provided largely free of charge. By year end 2005, 109 VCCT sites, operated mainly by the government, had been established and by the third quarter of 2009 229 VCCT sites, again

⁴ National Centre for HIV, AIDS, Dermatology and STI (NCHADS), Comprehensive Report on HIV/AIDS Year 2005, 2005.

NCHADS, Third Quarter Comprehensive Report, 2009, 2009

operated primarily by the government, were in use. The number of PLHA support groups likewise grew rapidly in the new century from 24 in 2002 to 415 in 2005. By the third quarter of 2009 NCHADS reported that 919 PHLA support groups actively involved 36,983 PLHA. These groups enabled PLHA to share experiences, receive training and adherence assistance, and provide emotional support to one another.

ART was piloted in Cambodia in 2001 by the NGOs Medecins Sans Frontieres, Medecins Du Monde, and the Centre for Hope. Although government and donors were initially reluctant to support ART provision the early outcomes convinced the MoH that the ART program could be viable. NCHADS assumed management of the program and achieved rapid scale-up with generous donor support. The number of PHLA on ART increased sharply from 71 in 2001 to 12,355 in 2005 to 37,315 in 2009 (Figure 1). According to the NCHAD director the 2009 estimate represented about 95 percent of the PLHA in need of ART.⁶ With Cambodia still in the process of developing a viable public health system this was truly a remarkable accomplishment.

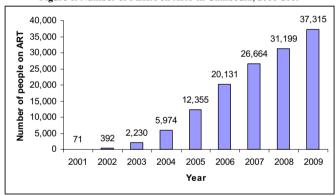


Figure 1. Number of PLHA on ART in Cambodia, 2001-2009

Sources: NCHADS, Treatment Care for PLHA in the World and Cambodia, 2009; NCHADS, Facility ART Report from All Sites, 2009, 2010.

Cambodia response to the AIDS epidemic relies almost entirely on donor support. Initially the funds available were minimal but generally perceived as adequate. Major increases in financial resources occurred from 2001 with the scale up of prevention programs and the emerging emphasis on treatment. While retaining existing donors Cambodia in 2003 secured the first of several rounds of funds from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM). In 2005 Cambodia obtained US\$ 48 million to fight the AIDS epidemic up from US\$ 10 million received in 2000. While resource constraints were not an immediate concern, some observers felt that raising

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⁶ Dr. Mean Chhi Vun presentation of Cambodia's Experience on Linked Response for Prevention, Care, and Treatment of HIV/AIDS, 2009 cited in NCHADS, Treatment Care for PLHA in the World and Cambodia, 2009.

funds could become more difficult as the HIV prevalence rate continued to fall. They argued that cost effective approaches, pragmatic interventions, and greater synergy among programs should be made a priority.⁷

The Impact of AIDS on Older Age Persons

In 2004 a broad-based representative survey of the elderly was conducted in Cambodia. Data from this original survey plus a supplementary study conducted in 2005 revealed significant insights into the impact of AIDS on older age parents in Cambodia. Older adults who had experienced the death of a child due to AIDS virtually always played an important role during the child's illness. Nearly 80 per cent of the households interviewed in the original survey reported that an older age parent was a main personal caregiver to the deceased child. Personal care refers to assistance with activities such as eating, bathing, dressing, cleaning wounds, and going to the toilet. Similarly almost 65 per cent of the same sample reported that a parent was a primary instrumental caregiver to the deceased child. Instrumental care involves tasks outside the home such as providing transportation, visiting health care facilities, and buying medicines. The average duration of the care giving period was over seven months.

Results from the original survey also showed that just over three-fifths of the elderly respondents lived with their AIDS infected child before the child's death. This was higher than cases involving a child's death unrelated to AIDS. Apparently many of the AIDS infected children moved back from other locations to be with their parents and to receive care in the terminal stages of their illness. Based on the combined surveys 30 per cent of the children who had died of AIDS in the locality of their parents had returned from other locations. This compares to 14 per cent of returning children who had died of other causes. The survey data on care giving and co-residency at the time of death underscore the high levels of involvement of older age parents in Cambodia with children who die of AIDS.

Elderly parents also assumed responsibility for paying medical and funeral expenses of their child who had died of AIDS. The combined surveys indicate that a parent paid some medical expenses in 77 percent, and was the primary source of payments in 55 percent, of the households interviewed. The same sample further reveals that a parent had net funeral expenses in 78 percent of the households interviewed. Parental payment for medical and funeral expenses was higher in cases of child deaths resulting from AIDS than in those related to other causes. At the same time the incidence of parental payment for medical and funeral expenses was high regardless of the cause of death, underlying the lack of alternatives to family and parental assistance. At the time of the surveys only 25 percent of the elderly respondents reported that their sick child or family had received assistance

⁸ Knodel, John, Sovan Kiry Kim, Zachary Zimmer, and Sina Puch, Older Persons in Cambodia: A Profile from the 2004 Survey of the Elderly, Ann Arbor: University of Michigan, Population Studies Center, May 2005

⁷ Buhler et al, *Turning the Tide*.

⁹ Knodel, John, Sovan Kiry Kim, Zachary Zimmer, and Sina Puch, The Impact of AIDS on Older-age Parents in Cambodia, Phnom Penh: UNFPA and Royal University of Phnom Penh, 2006.

from formal sources, mostly from NGOs and much less frequently from the government or local community. Tellingly, respondents in the poorer half of the sample were the least likely to receive any formal assistance.

Expenses related to an AIDS illness and death generally strained the financial resources of the elderly. Among the respondents in the combined surveys who paid medical and/or funeral expenses, 75 percent found it to be a serious burden. Two-thirds of respondents who had paid expenses had borrowed money for the costs of their child's illness and AIDS related death and two-fifths still owed most of what was borrowed. Moreover, one-half of respondents making payments sold land, livestock or household possessions, and one-fourth sold gold or jewelry, to meet their child's expenses.

The illness and death of a child with AIDS not only added emotional and financial burdens to the elderly, the child's incapacitation and demise also resulted in the loss of assistance to the parents. More than half of the respondents in the combined surveys reported that the deceased child had provided material support for the parental household. Even more importantly, two-fifths of the respondents indicated that the deceased child had been a main source of material support. Poorer parents were especially likely to have been receiving material support from the deceased child and fully half of them mentioned that the deceased child was a main source of their support. Almost two-thirds of the respondents who reported receiving support from their deceased child maintained that the loss of material support created much difficulty. Poorer parents were more likely to report that the loss of material support created severe difficulty.

A major finding that emerged from a multivariate analysis of the combined surveys was that the loss of a child due to AIDS resulted in a weakening of the parents' overall economic well-being. Parents experiencing the death of a child to AIDS were more likely to report that their economic condition had worsened during the prior three years compared to those who lost a child to other causes or those who did not experience the recent death of a child. In Cambodia the poor are particularly vulnerable to the economic effects of the AIDS epidemic and the death of an adult child to AIDS led some parents to fall deeper into poverty. ¹⁰

The Changing Role of Older Persons in the Era of ART

By end year 2006 ART provision in Cambodia had already reached 20,131 PLHA and ushered in a new era of HIV/AIDS treatment. In late 2006 a study conducted in Cambodia based on 25 semi-structured open-end interviews provided insight into the changing role of older-age parents in this transition. ¹¹ The study included 10 cases whose child was currently receiving ART and 15 cases whose adult child died of AIDS. The

¹⁰ See also Knodel, John, "Poverty and the Impact of AIDS on Older Persons: Evidence from Cambodia and Thailand," *Economic Development and Cultural Change*, Volume 56, Number 2, 2008; and Knodel, John, Zachary Zimmer, Kiry Sovan Kim, and Sina Puch, "The Effect on Elderly Parents in Cambodia of Losing an Adult Child to AIDS, *Population and Development Review*, Volume 33, Number 3, 2007.

¹¹ Williams, Nathalie, John Knodel, Sovan Kiry Kim, Sina Puch, and Chanpen Saengtienchai, "Overlooked Potential: Older-Age Parents in the Era of ART," *AIDS Care*, Volume 20, Number 10, 2008.

qualitative research supported several of the key findings of the combined surveys discussed above and importantly indicated new directions in parental care giving and treatment assistance resulting from the availability and use of ART.

In almost half of the 25 cases documented the PLHA was already living with or nearby their parents prior to illness. In other instances the PLHA lived in another location before becoming ill and returned home only when their health deteriorated. Most HIV-infected children returned in desperation, having nowhere else to go, and sometimes before their parents' had knowledge of their AIDS illness. In other cases parents urged their children to return or personally brought them back once they learned the child had AIDS. In some instances, a married child returned to the home of their parents with their spouse and their children when the couple, and often even their children, were afflicted with AIDS. Of note, adult children on ART remained co-resident with their parents for some time after their health improved. This meant that parents extended their care giving and were well placed to monitor adherence to treatment regimens.

Older-age parents not only supplied living quarters for their HIV-infected children they were also actively involved in care giving. Parents narrated that they boiled water for bathing and drinking. They bathed their children, carried them to the toilet, washed their clothes and bed sheets, and washed and dressed wounds with soap or salt water. In the terminal stages of their disease some children were too sick to perform these basic tasks for themselves. At the same time most parents understood that good hygiene helps to prevent further infections and thus contributes to the efficacy of ART and opportunistic infection treatments. Care taking likewise entailed the provision of good nutrition. Parents generally prepared nutritious food to their sick children when they were able to do so.

Many of the older-age parents interviewed in the qualitative study encouraged their adult children to get tested for HIV/AIDS and to seek treatment. Usually the parent noticed that their child exhibited symptoms of HIV infection. Some parents personally went with their adult children to the testing center and some even received the results for them. Several of the elderly respondents took their grandchildren to be tested.

Older parents with children on ART all reported that they helped to remind them to take their medicines at the appointed times. The parents nonetheless conceded that the PLHA normally remembered to take the drugs themselves as prescribed. Parents too reminded the PLHA to keep monthly appointments with medical personnel and to attend PLHA support group meetings. Older age persons played an even more important role in dispensing ART and opportunistic infection (OI) drugs to their grandchildren and in taking them to their medical appointments. According to several respondents their grandchildren did not like or understand the reasons to take the drugs and regularly forgot to take them. Grandparents taking care of orphaned grandchildren often assumed total responsibility for the grandchild's care and treatment.

A key finding of the case study research was that older parents had an extraordinarily good understanding of complicated treatment regimens and the rationale behind them.

Many uneducated parents were able to speak knowledgeably about treatment courses and specific drugs their low education levels notwithstanding. Home based care teams and health personnel were instrumental in providing training to the elderly respondents at home and at health centers respectively with regards specifically to dispensing ART and OI drugs and monitoring the PLHA's treatment adherence. Attendance of older-age parents at PLHA support groups was less useful in providing information to them.

Older-Age Persons as a Resource in Cambodia's Response against the AIDS Epidemic

The research cited above cogently describes the consequences of the AIDS epidemic for older-age persons in Cambodia. At the same time it draws attention to the contributions made by elderly people in response to the disease. Older-age persons have contributed considerably to Cambodia's ability to cope with the epidemic by supplying personal care, emotional help and material assistance to their infected sons and daughters. This support continues as access to ART becomes virtually universal throughout Cambodia and HIV/AIDS becomes more and more a chronic though manageable condition albeit one highly dependent on donor funding for the requisite supplies of ART medicines. Widespread provision and use of ART have important implications for treatment strategies that include a more prominent recognition of the contributions that older-age people can make.

Effective use of ART demands rigorous life-long adherence to drug regimens, eating nutritious foods and exercising, and coping with occasional severe side effects. This presents a major challenge to countries like Cambodia where the public health system is still underdeveloped. The formation of PLHA support groups serves to augment treatment adherence and constitutes the prevailing strategy in Cambodia to address this challenge. Acknowledging the contributions made by elders in response to HIV/AIDS suggests opportunities for expanding this strategy to include older-age persons and other family members. Elderly persons often live with or nearby ART patients and have deep emotional reasons for wanting the patient to achieve and maintain restored health. Moreover, they are often present at the specific times that medicines need to be taken. In light of the literature reviewed older-age persons appear to represent a largely unrecognized resource in Cambodia's organized response to the AIDS epidemic.

Research Objectives

This Analyzing Development Issues (ADI) study focuses on older-age people supporting HIV/AIDS positive children and household relatives on ART in six communes of Banteay Meanchey province in northwest Cambodia. More specifically, the study seeks to examine the background characteristics of the older-age people and their ART recipient children and household relatives, to understand the involvement of the elders in care giving and assistance with treatment adherence, to assess the financial and health impacts of care giving on the older age people, to identify the consequence of ART use for the elders and their children and household relatives, and to explore the support

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¹² Knodel et al, Older-age Parents and the AIDS Epidemic in Thailand.

services provided to the elderly caregivers. The study also gauges the scope of parental and family support from information supplied by ART recipients or their caregivers in the study communes. Older persons are largely ignored in the discourse concerning the AIDS epidemic despite the fact that they are intimately involved.

Methods

The study employs quantitative and qualitative methods. In May 2008 a one page questionnaire was used to gather information on ART recipients in six purposively selected communes of Banteay Meanchey province. In the same month and in the same communes a total 108 people 50 years and older with ART recipient children living in the same or different households or with ART recipient relatives living in the same household were purposively surveyed about their care giving experiences. In July 2008, 10 of the 108 survey respondents were approached again and interviewed in qualitative in-depth interviews. In Phnom Penh and Banteay Meanchey province the study also interviewed government officials involved in the provision of ART and NGOs involved in home based care programs.

ART Recipient Survey

In April 2008 Analyzing Development Issues (ADI) team members approached four NGOs working in ART home based care programs in Banteay Meanchey province to assist in administering a one-page questionnaire that was developed for a comparable study in Thailand. The survey was designed to assess family, and especially parental, assistance in ART adherence. The four NGOs selected visited ART recipients in home based care programs in the six communes purposively chosen for the survey and each had detailed lists of the ART recipients in their coverage areas.

The Social, Environment, Agricultural Development Organization (SEADO) was responsible for following up ART recipients in O'Ambel commune in Serey Sophorn district and O Bei Chorn commune in O'Chrov district. The Khmer Youth Association (KYA) was responsible for visiting ART users in Teouk Thla and Kampong Svay communes in Serey Sophorn district. The Cambodian Socio-economic Development and Democracy Association (CSDA) was responsible for providing support to ART recipients in Preah Ponlea commune in Serey Sophorn district. Finally the Center for Hope Organization (CHO) was responsible for visiting ART recipients in Poipet commune in O'Chrov district.

The ADI team members instructed home based care team members on how to administer the one-page questionnaire. In most cases NGO home based team staff conducted the interviews themselves. In some instances, e.g. in O'Ambel commune, the ADI team enlisted the help of village home based care team volunteers to administer the questionnaire and in one case, O Bei Chorn commune, they sought assistance from

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¹³ See Knodel, John, Jiraporn Kespichayawattana, Chanpen Saengtienchai, and Suvinee Wiwatwanich, 'The Role of Parents and Family Members in ART Treatment Adherence: Evidence from Thailand," Research on Aging, Volume 32, Number 1, 2010.

government health center staff who are likewise members of the home based care teams. The survey was conducted in May 2008. In situations were the ART recipients were very young the home based care team members interviewed their parents or grandparents. However, in the large majority of cases the home based care team members interviewed the ART recipients themselves. ¹⁴ Each interview took on average about 5 minutes to complete. To ensure strict confidentiality names were not placed on the questionnaires only checked off on the master lists. In all 382 ART recipients were interviewed, 340 of whom were 18 years of age and above.

Older Age Persons Survey and In-depth Interviews

In April 2008 the ADI team drafted the older age persons survey questionnaire based on semi-structured guide questions developed by Professor John Knodel of the University of Michigan and his colleagues for a study in Thailand. The research was conducted as part of an ADI advanced course and participants in the course had an opportunity to comment on the draft instrument and suggest their own revisions. The survey was then pre-tested in Battambang province with members of older-age associations formed with assistance from HelpAge International. After incorporating insights from the pre-test, and with email comments from Professor John Knodel, the survey questionnaire was revised and finalized in Khmer and English.

In May 2008 the ADI team members and the course participants were divided into small teams and assigned to administer the older persons survey in the six communes purposively chosen for the study in Banteay Meachey province. Again these were the same communes where the one-page ART recipient survey had been conducted: O'Ambel, Teouk Thla, Kompong Svay, and Preah Ponlea communes in Serey Sophorn district and Poipet and O Bei Chorn communes in O'Chrov district. Starting with the lists of ART recipients in the respective NGO coverage areas, the research teams enlisted the help of home based care team members such as NGO staff and village volunteers to help them identify cases of ART recipients with older age people in their households as well as older persons who had a child on ART that lived elsewhere. ¹⁵

This method of recruitment was skewed in a way that would include older persons who lived with or near the ART recipient child while it served to omit most instances in which the older person had a child on ART not living in the locality. Thus the older persons interviewed in the survey are not typical of those who have a child on ART but selective mainly of those who live with or very near the ART recipient child. The results of the

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¹⁴ In Thailand the questionnaire focused on ART recipients 18 years and above and was self-administered. This study covered all ART recipients including those less than 18 years. It also involved persons with low literacy levels hence the decision to have home based care team members conduct the questionnaire.

¹⁵ It should be noted that although the selection of respondents was contingent on their having a child and/or household relative on ART, many of the respondents interviewed also had experiences with HIV/AIDS positive children and/or households relatives who had died before receiving ART. The study was able to generate some information on these experiences as well.

survey are thus likely reflective of this large subset of older persons with a child or relative on ART living in the same household but not of all older persons with a child or relative on ART.

The survey teams thus conducted the survey with respondents 50 years and over who had HIV/AIDS positive children living in the same or different households and/or relatives in the same household on ART. Only one elder from each household was interviewed. On average the survey questionnaire took one hour and 15 minutes to complete. During the five days of fieldwork the research teams with strong support from home care team members were able to locate nearly all of the older age persons in the six communes with HIV/AIDS positive children or household relatives on ART. In all 108 older age persons were interviewed.

In July 2008 ADI team members returned to Banteay Meanchey province to tape record in-depth conversations with informants previously interviewed in the older persons survey that had particularly interesting or compelling stories to tell about their care giving experiences. On average these interviews took two hours to complete. In all 10 in-depth interviews were tape recorded, transcribed into Khmer, and translated into English. The excerpts that appear in this report from these interviews have been edited for conciseness.

ART Recipient Survey

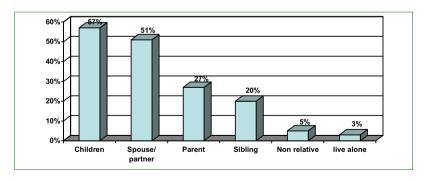
The ART recipient survey helps to place the more comprehensive results of the older persons' interviews in context. The survey provides information on family members who live with the ART recipients and the extent to which family members are involved in reminding them to take their medicines. More particularly, the survey examines whether the ART recipients have surviving parents and where they live in relation to their parents. The survey likewise inquires into the role of parents and others in treatment assistance.

Basic Characteristics of ART Recipients

The ART recipient survey gathered information in May 2008 on 382 ART recipients living in six communes of Banteay Meanchey province. Females composed 56 percent of the sample and males the remaining 44 percent. The mean age of the 382 ART recipients was 34.6 years. Eleven percent of the total was less than 18 years old.

More than half of ART recipients lived with children and with spouses and more than one fourth lived with a parent. The high level of co-residence with children reflected high fertility rates in Cambodia. Less commonly ART recipients shared households with siblings. Few lived with non relatives or lived alone (Figure 2). This had important implications for augmenting adherence to ART regimens. Family members who live with ART recipients are potentially available to assist them in treatment.

Figure 2. Percent of ART Recipients Living with Persons of Specified Relationships, Banteay Meanchey Province, May 2008



Location of ART Recipient Parents

Most ART recipients had a living parent and the majority of living parents resided with or near them. In all more than three-fifths (61 percent) of the ART recipients had at least one living parent and more than one-fourth (27 percent) had both parents still surviving. More of the sample had mothers alive (56 percent) than those that had fathers alive (31 percent). Men tend to marry women younger than themselves, and thus fathers reach advanced ages of higher mortality rates sooner than mothers do. ¹⁶ In Cambodia more men than women were also killed during the Pol Pot regime.

Of the ART recipients with a living parent and location of parents known, 72 percent lived in the same household as their parents or in the same location, i.e. next to the ART recipient or in the same village or community. Considered alone co-residence of ART recipients with parents reached a high 46 percent (Figure 3). These residence patterns were important as proximity increases the opportunity for parent involvement in treatment adherence support.

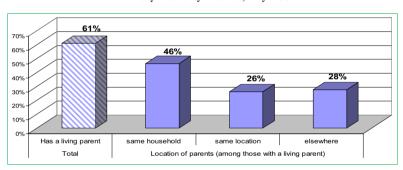


Figure 3. ART Recipients with a Living Parent and Location of Parents, Banteay Meanchey Province, May 2008

The percent of parents living elsewhere was far greater in the two communes of O'Chrov district along the Thai border (41 percent) than in the four communes in the interior district of Serey Sophorn (23 percent). ART recipients living along the Thai border in Poipet and O Bei Chorn communes were more likely to be migrants than those living in the interior communes. Poipet in particular has been designated as a special economic development zone and attracts labor migrants from across the country. Generally parents knew that their children were on ART although this was less so for parents living elsewhere

¹⁶ Knodel et al., "The Role of Parents and Family Members in ART Treatment Adherence."

Treatment Assistance

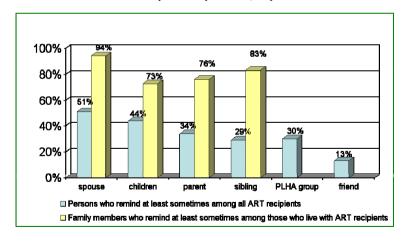
The ART recipient survey inquired into the role of family members and especially parents in assisting with treatment adherence. The survey gathered information on the various types of persons who helped remind ART recipients to take their medicines. Specific questions focused on assistance from parents: how often parents reminded ART recipients to take medicines, whether or not parents reminded them to replenish supplies, took them to replenish supplies, or helped them to prepare medicines.

Assistance from Family Members

Among all ART recipients the types of persons most frequently mentioned who reminded them to take their medicines were spouses (51 percent), children (44 percent), and parents (34 percent). Less frequently mentioned were siblings (29 percent), PLHA group members (30 percent), and friends (13 percent) (Figure 4). Co-residence greatly enhances the ability of family members and others to remind the ART users to take their medicines. Not surprising the percentages of all types of family members who remind the ART recipient to take their medicines increase sharply when responses are cross referenced with co-residence in the same household (Figure 4). This indicates concern on the part of all co-resident family members for the well-being of the ART recipients.¹⁷

Figure 4. Percent of Those Who Currently Remind ART Recipients to Take Medicines at Least Sometimes (among all ART recipients and among ART recipients who co-reside with family members),

Banteav Meanchey Province, May 2008



¹⁷ Knodel et al, 'The Role of Parents and Family Members in ART Treatment Adherence.'

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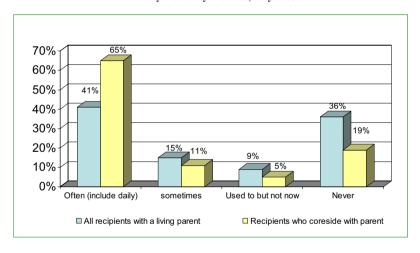
Co-resident spouses and siblings are the most common persons to remind ART recipients to take their medicines although co-resident parents and children are mentioned frequently as well (Figure 4). ¹⁸ Thus regardless of their specific relationship to the ART users most family members who live with ART recipients play an important role in reminding them to take their medicines.

Assistance from Parents

Parents frequently supported ART recipients with treatment adherence assistance. Among all ART recipients with a living parent, a majority 64 percent of parents had reminded them to take their medicines and 41 percent still reminded them either daily or often to do so. Again not unexpectedly, levels of parental adherence support increased among ART recipients with co-resident parents. Among this group 81 percent of parents helped ART users remember to take their medicines and 65 percent still helped them to remember either daily or often to do so (Figure 5).

Figure 5. Frequency that Parents Remind ART Recipients to Take Medicines (among those with a living parent and among those who co-reside with a living parent),

Banteay Meanchey Province, May 2008

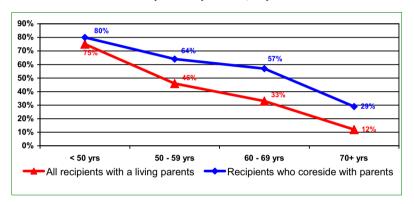


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¹⁸ Note that the frequency of reminding may only be very occasional in some instances as the frequency of reminding was only asked in relation to parents.

Compared to older parents, younger parents and especially co-resident younger parents reminded their children often to take ART medicines. Figure 6 graphically depicts the active involvement of all parents under 50 and how this progressively declines as parents get older. The decline is noticeably steeper for all parents compared to co-resident parents until the age of 70. Once parents reach 70 years their advanced age perceptibly reduces their involvement in reminding their children to take ART. At the same time even within this age group co-resident parents are more involved than all parents considered together.

Figure 6. Percent of ART Recipients Whose Parents Remind Them Often to Take ART Medicines by Age of Younger Parent, Banteay Meanchey Province, May 2008



ART adherence centers upon remembering to take medicines on time. But likewise important are the efforts involved in replenishing supplies and preparing the medicines for use. Among recipients who had a living parent, more than three-fifth had a parent who reminded them to get their medicines from the government hospital or health center. Moreover, almost one-third had a parent who had taken or accompanied them to get the medicines. By contrast, only one-fifth had a parent that helped to prepare the medicines. The low level of help in preparing medicines was quite possibly because the preparation of ART alone had become simple or unnecessary. In total 72 percent of the living parents had helped ART recipients in at least one of the three tasks of reminding them to get medicines, of taking them to get medicines, and of helping them to prepare medicines. Similar to the trend of being reminded to take medicines, incidence of such assistance was generally higher among younger than older parents (Table 1).

Table 1. Percent of ART Recipients with a Living Parent Who Ever Helped with Getting and Preparing Medicines by Age of Youngest Parent, Banteay Meanchey Province, May 2008

	Age of youngest parent			
	< 60 yrs	60 – 69 yrs	70+ yrs	Total
	Percent	Percent	Percent	Percent
Parent reminded to get medicines	60	70	42	61
Parent helped to get medicines	44	25	6	32
Parent helped to prepare medicines	34	13	3	22
Parent helped with any of these tasks	78	72	49	72
	N=113	N=79	N=33	N=225

Older-Age Persons Interviews

Background Characteristics of Respondents

The older person's survey was conducted in May 2008 with 108 respondents, 50 years and older, with HIV/AIDS positive children/household relatives on antiretroviral therapy (ART) in Banteay Meanchey province. Specifically, 84 (78 percent) of the 108 respondents resided in the four communes of O'Ambel, Teouk Thla, Kompong Svay, and Preah Ponlea of Serey Sophorn district while 24 (22 percent) of the 108 respondents lived in the two communes of Poipet and O Bei Chorn of O'Chrov district. A rather high 83 (77 percent) of the 108 respondents had lived in their current villages for more than 10 years although most were not originally from these villages.

Overall 93 (86 percent) of the 108 respondents were female and 15 (14 percent) were male. The mean age of all respondents was 61.5 years with the mean age of the females slightly lower and the mean age of the males just higher than this. Of the 108 respondents 47 (45 percent) ranged from age 50 to 59, 41 (38 percent) ranged from age 60 to 69, and 18 (17 percent) ranged from age 70 and over. Of note, 56 (60 percent) of the 93 female respondents were separated/divorced or widowed compared to 14 (93 percent) of the 15 male respondents who were currently married. A high level of widowhood among older women in Cambodia was also found in the 2004 Survey of the Elderly. ¹⁹

Of the 93 female respondents, 46 (49 percent) had ever attended school and only 19 (20 percent) had completed more than 5 grades. Still 55 (59 percent) of the 93 elderly female respondents maintained that they were able to read and write. By contrast, 13 (87 percent) of the 15 male respondents had ever attended school and only 4 (27 percent) had completed more than 5 grades. All but one of the elderly male respondents reported that they were able to read and write. In Cambodia boys traditionally have had far more opportunities than girls to attend school and this translates into much higher literacy rates among older men than women.²⁰

Despite their advanced ages more than two-thirds (75 or 69 percent) of the 108 respondents said that they worked to support the household. These included 61 (66 percent) of the 93 female respondents and 14 (93 percent) of the 15 male respondents.

¹⁹ The 2004 Survey of the Elderly in Cambodia recorded that 64 percent of the female respondents were widowed, while 82 percent of the male respondents were currently married. This was attributed at least in part to the historical legacy of political violence and turmoil during the Pol Pot regime. See Knodel et al, *Older Persons in Cambodia.*

²⁰ The 2004 Survey of the Elderly in Cambodia reports than 76 percent of the men ever attended school and that 72 percent were literate. This compares to 21 percent of the women who ever attended school and 20 percent who were literate. See Knodel et al, *Older Persons in Cambodia*.

The main type of work of the 61 female respondents contributing to the support of the household was predominantly small business or petty trade (38 percent) followed by wage labor (20 percent), cultivating vegetables (15 percent), and cultivating paddy rice (11 percent). The main type of work of the 14 male respondents was also spread out among these same activities. A large majority (92 percent) of the 75 working respondents reported that their main work did not take them out of the village for more than one week at a time. ²¹

Of note, the respondents engaged in productive work that required little formal education or capital investment and permitted them to earn income in their own villages. The informal nature of the work also allowed the elders some flexibility in their work hours. These factors served them well when they were encumbered upon to adjust their livelihood pursuits to the demands of care giving for HIV/AIDS positive children and household relatives

Background Characteristics of HIV/AIDS Positive Children and Household Relatives on ART

In total the 108 respondents surveyed had 487 living children with 237 living in the same household and 250 living outside the household. Among the total number of living children 85 were on ART with 60 ART recipient children living in the same household and 25 ART recipient children living outside the household.

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Comparing data from the 93 female respondents to data from the 107 female respondents/spouses differences in only one background characteristics stands out prominently. Perhaps not unexpectedly only 52 percent of the 107 female respondents/spouses were separated/divorced or widowed compared to 60 percent of the 93 female respondents. At the same time comparable percentages of the 107 women respondents/spouses had lived in their villages for more than 10 years (77 percent), had ever attended school (52 percent), and still worked to support their household (67 percent). The mean age of the 107 women respondents/spouses at 61.0 years was also comparable to the mean age of the 93 female respondents at 61.4 years.

Comparing data from the 15 male respondents to the 52 male respondents/spouses reveals greater variation perhaps due somewhat to the smaller sample sizes. Among the 15 male respondents 93 percent were currently married, 73 percent had lived in the their villages for more than 10 years, 87 percent had ever attended school, 93 percent still worked to support their household, and their mean age was 62.3 years. By comparison among the 52 male respondents/spouses, 98 percent were currently married, 81 percent had lived in the their villages for more than 10 years, 81 percent had ever attended school, 77 percent still worked to support their household, and their mean age was 61.6 years.

²¹ The older person's survey purposively interviewed any person that was at home 50 years or older with ART recipient children or household relatives. As a result the survey is biased towards older age women respondents who were more likely to be at home and willing to talk. Considered alone, the percentage of female respondents to total respondents is 86 percent. Considered as part of the total number of respondents and spouses, the percentage of females is 67 percent. Thus the viewpoints of women in the survey predominate disproportionally over the viewpoints of men. Specifically out of the 159 respondents and spouses 107 were female and 52 were male. Keep in mind also that 9 (6 males and 3 females) of these 159 persons were under 50 years old.

Other than the children that lived with the respondents, an additional 343 relatives likewise lived in the same household. The average household size of the respondents at a rather high 6.4 persons also revealed that family members had moved in with the respondents. Among the relatives living in same household, 52 were on ART. This relatively large number included 31 grandchildren and 16 children-in-law and exposed the presence of a sizeable group of ART recipients often overlooked within older-age households.

My daughter was always sick and the blood tests showed that she was HIV positive. About six months later rashes and blisters appeared all over her body. Her condition deteriorated fast. She became seriously ill and moved in with me. When she improved she went back to live with her husband in his village. Two months later she died. Since then I have been caring for her daughter who is also HIV positive. The father of the child remarried and does not visit anymore. I don't think that he will come back. He will leave his daughter to her fate. Talking about it, I can hardly hold back the tears. [66 year-old mother of daughter deceased with AIDS and with granddaughter on ART, Teouk Thla commune]

The total number of living children and household relatives on ART was 137. Of these, 71 (52 percent) were male and 66 (48 percent) were female. Data available for 134 of these ART recipients reveal that their mean age was 28.6 years with 29 (22 percent) under 15 years of age. Not unexpectedly, all the ART recipients under 15 years of age were single and all, but one, were grandchildren. Of the 134 ART recipients of school age (6 years and above), 113 (84 percent) had attended school and 44 (39 percent) had completed five grades or more.

Of the 108 ART recipient children/household relatives 15 years and older, 54 (50 percent) were currently married, 49 (45 percent) were divorced/separated/widowed, and 5 (5 percent) were still single. The high incidence of divorce, separation, and widowhood among the ART recipients may partially be explained by the nature of the disease itself. HIV/AIDS is often transmitted from sex workers to spouses leading to marital breakups. Before the advent of ART, HIV/AIDS was a terminal disease resulting in high rates of widowhood among spouses.

I know that my daughter got infected with HIV from her husband. After their marriage in 1997, her husband went to work in Thailand because he had no job here. In Thailand he had sex outside of marriage although he denied it. At that time we did not know what HIV/AIDS was. We just heard people talking about it, saying that it was a killer disease. Two weeks after her husband died, my daughter started to have headaches and to break out in skin rashes. She was seriously ill when I brought her home to my house from her in-laws. I took her to a private clinic and they gave her intravenous fluid and tested her blood. My daughter could hardly believe that she tested HIV positive since she was fat and, until then, in good health. Her young child also tested HIV positive. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

My story is too sad to tell. After my daughter was abandoned by her husband she left her child with me and went to Thailand to buy fruits for sale in Cambodia. I noticed that the child had skin rashes and blisters on his body so I took him for a blood test. The result was HIV/AIDS positive. I cried a lot. I had my daughter take the blood test herself and she too was HIV/AIDS positive. She got infected from her husband who had worked in Thailand. [57 year-old divorced mother of daughter on ART and with grandson on ART, Kompong Svay commune]

Of the 89 ART recipients with children, 66 (74 percent) had children that were now living with the elderly respondents. Indeed 142 (67 percent) of the 212 children of the ART recipients were now living with the older-age respondents. Meanwhile spouses of 34 (63 percent) of the 54 currently married ART recipients were now also living with the elderly respondents. These trends no doubt contribute to the high mean size of the respondents' households.

Location of ART Recipient before Respondent Knew S/He Had HIV/AIDS

More than two-thirds of the ART recipients were living in the same house or the same village as the respondent before the respondent knew s/he had HIV/AIDS (Table 2). More critically, a majority 59 (81 percent) of the 73 ART recipients who had not always lived with the respondent had moved into the house of the respondent after contracting HIV/AIDS. The main reasons why these ART recipients moved in with the respondents were that they were too sick to care for themselves, not able to work anymore, or too sick to care for their children.

Table 2. Location of ART Recipient before Respondent Knew S/He had HIV/AIDS,
Banteav Meanchey Province, May 2008

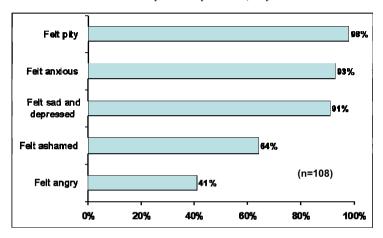
Location	Number	Percent
Same house as respondent	64	47
Same village (different house as respondent)	30	22
Same commune, district or province	27	20
Phnom Penh	3	2
Elsewhere in Cambodia (aside from Banteay Meanchey or Phnon Penh)	4	3
Thailand	9	7
N= 137		

With respect to 62 ART recipients who had always lived in the respondent's house, the respondents knew that they had HIV/AIDS for an average 4 years and five months and that 61 had been on ART for an average 2 years and 8 months. With regard to the 59 ART recipients who had moved into the respondent's house after contracting HIV/AIDS, the respondents knew that they had HIV/AIDS for an average 3 years and 6 months. On average, these 59 ART recipients had lived with the respondent for 2 years and 10 months and 57 had been on ART for an average 2 years and 5 months. With regard to the 14 ART recipients who had not lived in the respondent's house at any time since contracting HIV/AIDS the respondent knew that they had HIV/AIDS for 3 years and 8

months and that 13 had been on ART for an average 2 years and 6 months. Close proximity appears to be a factor in the elders knowing sooner about HIV/AIDS infection although it also appears to be unrelated to the length of time recipients were on ART. When the respondents first learned that their children/household relatives had contracted HIV/AIDS a large majority felt pity and anxiety although a sizable minority felt anger for their HIV/AIDS children or household relatives (Figure 7).

Figure 7. Percentages of Respondents Experiencing Various Feelings Upon Learning that their Children/Household Relatives had Contracted HIV/AIDS,

Banteay Meanchey Province, May 2008



When we learned that my daughter was HIV positive the ART medicines were not yet available. I had the monks pray for her at home. I also bought her Khmer traditional medicine that looks like rabbit feces. She did not get better so I bought her back to the hospital. They checked her sputum and found that she had tuberculosis. She stayed at the hospital for three months and took medicines everyday. She got better but not for long. She could not walk and had to be carried up and down the stairs of the house. Listening to her talk, I was overwhelmed with pity and knew that she had no hope of living very long. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

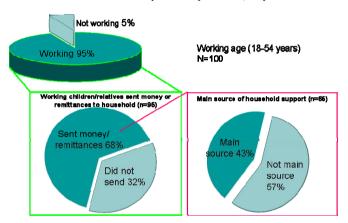
When my daughter learned that she was HIV positive, she was depressed and had had no hope that she would live long. She cried a lot. If I had not consoled her, she would have died soon. She had been to many doctors including Khmer traditional healers but her condition had not improved. She had abscesses all over her body that did not respond to treatment. Knowing she was HIV positive I was both angry with her and had pity for her. I was angry with her for her irresponsible life of indulgence working as a singer and going out with so many

men. Some children listen to their parents. Others do not. But she is my daughter. I had no choice but to take care of her. [64 year-old widowed mother of daughter on ART and with grandson on ART, Kompong Svay commune.]

Children/Household Relatives Working Before and After ART

Most of the ART recipients were working before they contracted HIV/AIDS. Many were sending money or remittances to the respondents and some were the main source of support (Figure 8). In total 95 (95 percent) of the 100 ART recipients of working age (18 to 54) at the time were working before they contracted HIV/AIDS. The main type of work for many centered on small business or petty trade (33 percent) and wage labor (25 percent). For elders who relied partially or fully on these persons for financial support the loss of income due to the debilitating effects of HIV/AIDS was a burden that had to be endured.

Figure 8. Percentages of ART Children and Household Relatives Working, Sending Money to Respondent's Household, and Main Source of Household's Support before They Contracted HIV/AIDS, Banteay Meanchey Province, May 2008



Once they were on ART most of the HIV/AIDS positive children/household relatives were able to continue or resume working. In all 79 (77 percent) of the 103 ART recipients now of working age (18 to 54) were working after taking ART. As before the main type of work for many centered on small business or petty trade (38 percent) and wage labor (25 percent). A majority (58 percent) of the 79 ART recipients worked in the

same villages where the respondents resided.²² Others worked in the same commune, district, or province. Some even worked in Thailand.

Involvement of Older Persons as Caregivers

Elderly respondents and their spouses were actively engaged in care giving. In 101 (94 percent) of 108 households surveyed the elderly respondents and/or their spouses provided care to their HIV/AIDS positive children/household relatives. Moreover, in the 101 households where elderly respondents and/or their spouses provided care, elderly women comprised 82 percent of the primary care givers.

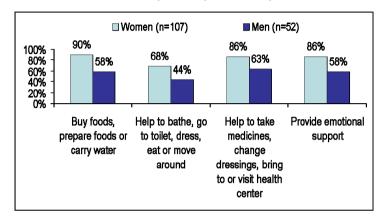
The paramount role of elderly women in care giving was truly amazing considering their demographic and social economic characteristics (see footnote 20). A majority of the 107 female respondents/spouses were separated, divorced or widowed without partners to rely on. Nearly half of the 107 female respondents/spouses had never attended school. Two-thirds of the 107 female respondents/spouses were still working to support their households. And just over half of the 107 female respondents/spouses were 60 years of age or over. Despite these constraints elderly women generally assumed primary responsibility for the care of their HIV/AIDS positive children and household relatives.

I thought that my life would be easier when my children grew up. But it has turned out to be the opposite of my expectations. This is my fate. For more than 10 years now, since the death of my husband, I have sold Khmer noodles to support my children and to pay for the medical expenses of my daughter who has been ill with HIV/AIDS. We live from day to day on what I earn from selling Khmer noodles. Everyday I have to sell Khmer noodles even on days when I am not feeling so well. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

Considering the total number of 159 respondents and spouses, women were more involved than men as care givers in both absolute and proportional terms. Overall 97 (91 percent) of the 107 women, and 35 (67 percent) of the 52 men, provided some care to their HIV/AIDS positive children/household relatives. Figure 9 depicts the involvement of older age women and men in four care giving areas: 1) Buying food, preparing food or carrying water; 2) Helping to bathe, go to the toilet, dress, eat or move around; 3) Helping to take medicines, change dressings, bring to or visit health center; and 4) Providing emotional support. Reasons given for older persons not providing care were commonly that their spouse did so or that the ART recipient's spouse or children did so.

²² This high percentage of ART recipients working in the same villages where the respondents resided reflects the selectivity of the sample of older people which was drawn from lists of ART recipients living in their households. A random sample of older people with a child on ART would likely produce different results.

Figure 9. Percentages of Elderly Respondents and their Spouses Engaged in Four Areas of Care Giving, Banteay Meanchey Province, May 2008



My daughter had HIV/AIDS. She was sickly for about two years. Rashes and blisters appeared on her face. She had pain but could not tell me where it was. She cried. I stayed awake at night and dropped water into her mouth. She was all skin and bone. I bought medicines for her. The rashes and blisters disappeared for awhile but then came back and spread over half her body. I took care of her. I was very thin. Before she died she was seriously ill. [55 year-old stepmother of stepdaughter deceased with AIDS and with step grandson on ART, O'Ambel commune]

My son had fever and chills that did not respond to treatment. The NGO workers took him for a blood test and found out that he was HIV positive. He went to the hospital but his fever got much worse. His condition was serious. I pitted him. I stayed up until midnight to attend to him. I wiped his body with a wet cloth. I helped him go to the toilet. I cooked food at home and brought it to him at the hospital. He tested positive for tuberculosis and was given medicines for this. He started to get better. Later he was given the ART medicines. I was at the hospital with him for two months. [63 year-old mother of son on ART, Kompong Svay commune]

Most respondents practiced good hygiene and encouraged their HIV/AIDS positive children/household relatives to eat good food. Overall 92 percent of the 108 respondents practiced good hygiene in caring for their HIV/AIDS positive children/household relatives such as regular bathing the patients, washing their clothes and bed sheets and cleaning their wounds. Similarly, 96 percent of the 108 respondents encouraged their

HIV/AIDS positive children/household relatives to eat nutritious foods such as rice, soup, vegetable, fruits, meat and fish.

About one month after he tested HIV positive, my grandson had diarrhea from morning until night. I took him to the Children's Hospital in Siem Reap province. In the hospital I stayed awake by his bedside to care for him, even though I am old and have no strength. I washed his body and clothes of the waste. My other children told me to take the child to an orphanage but I would rather keep him and take care of him. He started to get better after taking ART. Now I worry that someday his condition will worsen and he will die. [57 year-old divorced mother of daughter on ART and with grandson on ART, Kompong Svay commune]

Older age involvement in caretaking nonetheless had its consequences. In the 101 households providing care, 87 percent of the respondents and/or their spouses had to stop or reduce work because of caretaking responsibilities. In the same 101 households, 61 percent of the respondents and/or their spouses had to stop or reduce going to the pagoda or participating in religious ceremonies because of caretaking responsibilities.

My HIV positive granddaughter has been on ART for three years. She is better. But when her condition worsens, I have to stay with her and take care of her. I cannot go to the pagoda regularly. I cannot work in the rice field or around the house. Taking care of my granddaughter takes a lot of our time. We are very poor and have to work to support our family. Although I am hungry, I make sure she has good meals because I am afraid that she will die. In times of sickness I am the one that bears the cost. [66 year-old mother of daughter deceased with AIDS and with granddaughter on ART, Teouk Thla commune]

Nearly three-fourths of the elderly respondents and/or their spouses encouraged children/household relatives to get tested for HIV/AIDS. Once ART medicines became available free of charge through government hospitals and health centers, about two-thirds of the elders encouraged them to seek ART treatment (Table 3). Provincial health department staff in Banteay Meanchey province explained that there were three stages involved in securing ART treatment. Initially the health department staff assessed the health condition of the PLHA applicant and provided counseling. Then the staff provided training in the use of ART, the strict regimen of its application, and its side effects. Finally the staff checked the CD4 count of the PLHA and in principle started the patient on ART if her/his CD4 count was less than 250 with symptoms or less than 200 without symptoms. The health department staff remarked that patients usually came to them when they were very sick often with CD4 counts below 100.

Once HIV/AIDS children/household relatives began ART treatment, a large majority of the respondents and/or spouses reminded them to take the ART medicines. To a lesser extent, the elders normally paid the transportation costs for children/household relatives to get ART from the government hospitals or health clinics (Table 3).

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Table 3. Respondents or their Spouse Provided Support to HIV/AIDS Positive Children/ Household Relatives on Antiretroviral Therapy,

Banteav Meanchev Province, May 2008

	Number	Percent
Encouraged their children/household relatives to get tested for		
HIV/AIDS ^(a)	80	74
Accompanied their children/household relatives to the testing center ^(a)	45	42
Encouraged their children/household relatives to seek ART		
treatment ^(a)	71	66
Reminded their children/household relatives to take ART medicines ^(a)	95	88
Normally paid for the transportation costs for children or household		
relatives to receive ART ^(a)	30	28
Reminded their children/household relatives to take medicines for		
opportunistic infections ^(b)	50	81
Paid for medicines to treat opportunistic infections of		
children/household relatives resulting from HIV/AIDS ^(b)	14	23
(a) N=108		
(b) N=62		

(b) N=62

All but one of the 108 respondents reported that their child or household relative usually remembered to take ART as prescribed. Similarly 95 (88 percent) likewise knew that their child/household relative was supposed to take ART once in the morning and once in the evening. Moreover, 90 (83 percent) of the 108 respondents knew that all persons infected with HIV/AIDS were eligible to receive ART free of change from the government health center. However the elderly respondents were less knowledgeable about the conditions required by the government for their child or household relative to receive ART.

I go to Siem Reap province every two months to get the medicines for my grandson. I am old and it is not easy for me to travel there too often. I pity my grandson because both of his parents are dead. I care more about his life than my own. I arrive at the hospital early in the morning to receive the medicines ahead of the others. Hundreds of people come to the hospital to receive medicines and if I am late I might have to stay overnight in Siem Reap. [81 year-old widowed mother of daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

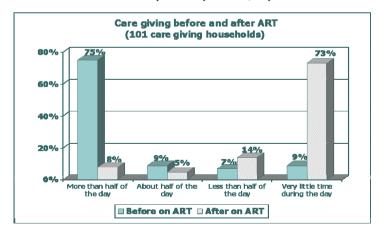
HIV is a retrovirus that infects cells of the human immune system destroying or impairing their function. In the early stages of HIV infection the person shows no symptoms. However, as the infection progresses the immune system becomes weaker and the person becomes more susceptible to what are called opportunistic infections. In all, 62 (57 percent) of the 108 respondents reported that in addition to taking ART their HIV/AIDS positive children/household relatives took medicines for opportunistic infections. Of these, 82 percent got their medicines for these infections from government health centers or hospitals, 19 percent from private clinics or hospitals, and 11 percent from other sources. A large majority of the 62 respondents with children/household

relatives on treatment for opportunistic infections reminded these persons to take their medicines. A smaller number paid for these treatments (Table 3).

My son and his wife had blood tests and the results were HIV positive. At first their son tested negative but later he also tested positive. The parents left their son with me and gave me 100 Thai Baht each month for his support. I bought food and used the savings for his medical care. Under the care of his mother, this child would have died. I have taken good care of him. My grandson takes almost 100 tablets of medicine a month. The medicines have to be taken at the exact time and in the exact amounts as prescribed by the doctor. The ART medicine has to be taken twice a day at six o'clock in the morning and at six o'clock in the evening. The medicines are received at the health center and I put them into a plastic box with partitions to make it easier for me to give him the right medicines each day. I will not let his mother take him from me since she will not be able to give him the medicines at the exact times. His father now lives and eats with us. His mother lives far away with her own mother and seldom visits. [52 year-old widowed mother of son on ART and with grandson on ART, Preah Ponlea commune]

Time spent in care giving by respondents and spouses in the 101 care giving households dropped sharply between the periods before and after ART use. Before children/household relatives started to take ART, respondents and/or spouses in three-fourths of the care giving households spent more than half of the day in providing care. Since children/household relatives started to take ART the pattern was reversed with respondents and/or spouses in nearly three-fourths of the care giving households spending very little time during the day to provide care (Figure 10).

Figure 10. Percentage of Time Spent in Care Giving Before and After Taking Antiretroviral Therapy, by Care Giving Households, Banteay Meanchey Province, May 2008



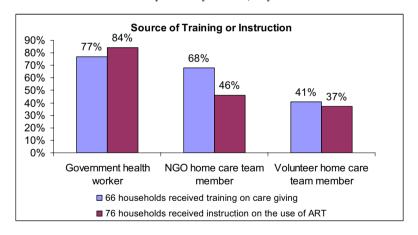
Older-Age Caregivers and Training

While older-age respondents and/or their spouses provided personal care to HIV/AIDS positive children and household relatives in 101 (94 percent) of the 108 households surveyed, elders were not specifically singled out to receive advice or training on how to care for PLHA. Indeed respondents and/or their spouses in only 66 (61 percent) of the 108 households interviewed received advice or training on this pertinent topic. Caretakers in these 66 households received training mostly from government health workers and NGO home care team members and less so from volunteer home care members (Figure 11).

By contrast, slightly more elders received training on how to care for ART recipients. Respondents and/or their spouses in 76 (70 percent) of the 108 households surveyed received instruction on the use of ART. Caretakers in these 76 households received instruction predominantly from government health workers and less so from NGO and volunteer home based care team members (Figure 11).

Figure 11. Percentages of Respondents Reporting Source of Training or Instruction on HIV/AIDS Care Giving and the Use of Antiretroviral Therapy,

Banteay Meanchey Province, May 2008



Association of ART Knowledge and Instruction

The study examined the association of ART knowledge and the extent to which older persons received instruction from the ART treatment program. An ART knowledge score for the older persons was computed on the number of correct responses to eight questions

concerning whether ART was available free of charge, how often ART medicines needed to be taken, how often supplies needed to be obtained, and awareness of five specific requirements of the ART program. The extent of ART instruction received was measured by the number of six possible sources from which respondents indicated having received advice on how ART medicines should be taken. Results indicate a strong association between the extent of instruction received and ART knowledge, and respondents' education levels and ART knowledge (Table 4). Adjusting for education only slightly weakens the association between ART knowledge and instruction. This suggests that receiving advice from program sources considerably improves older persons' knowledge.²³

Table 4. Mean ART Knowledge Score of Older Age Persons by Number of Sources of Instruction and by Years of Education,
Banteay Meanchey Province, May 2008

	Number of Cases	Mean ART Knowledge Score
Number of Sources of Instruction		
None	32	3.19
1-2	56	4.89
3-4	20	5.65
Education		
None	49	3.86
1-5 years	36	4.75
6 plus years	23	5.61
N=108 for each set of cases		

At the hospital the staff instructed me on how and when to give the medicines to my daughter. Then they asked me several questions about what the medicines were for and when they should be taken. I had to answer the questions correctly or I would not have received the medicines. They wanted to make sure that I knew everything well. The role of caregiver is very important. The hospital staff gave me the medicines only when they were satisfied that I knew how to use them. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

At the hospital in Siem Reap province I was given a watch and told to give the ART medicine to my granddaughter at six o'clock in the morning and six o'clock in the evening. I strictly follow the instructions of the doctors about the amounts, the hours, and the durations for giving my granddaughter the medicines. [66 year-old mother of daughter deceased with AIDS and with granddaughter on ART, Teouk Thla commune]

²³ Knodel, John, Sochanny Hak, Chandore Khuon, Dane So, and John McAndrew, A Comparative Study of Antiretroviral Therapy Assistance from Parents and Family Members in Cambodia and Thailand, Ann Arbor: University of Michigan, Population Studies Center, June 2010.

I am not able to read and write and could not read the labels on the medicines. I spent one week learning about the medicines from the hospital staff in Siem Reap province. At the end of the training, they tested me. What medicines should I give? At what times and in what amounts should I give them? After I gave the correct answers they gave me the medicines for my grandson. They also gave me a plastic box divided into seven parts for the days of the week and for the morning and evening medicines. At the end of the week I put the medicines in the box for the next week. I make sure to follow all the instructions of the hospital staff. They also gave me a watch to remember the times for him to take the medicines. [81 year-old widowed mother of daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

Consequences of Antiretroviral Use

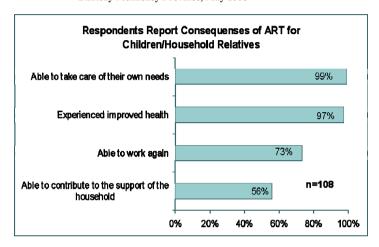
'ART is a sacred medicine provided by God.' These words spoken by one of the 108 respondents captured the sentiments of many of the older age persons interviewed. Many of the elders who had experienced their children and household relatives literally dying before their eyes now witnessed miraculous recoveries once the patients had started to take ART.

My grandson's health got better after taking the ART medicines. Before he was very thin and had rashes on his skin. He was not able to eat and always had diarrhea. After three or four months of taking the medicines his health improved. He gained weight, ate more, and had fewer rashes on his skin. I am happy that these medicines restored his health. He goes to school and can read and write. At night when I put him to sleep, I think that ART is a sacred medicine provided by God. [81 year-old widowed mother of daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

My daughter had treatment for tuberculosis for eight months before receiving ART. She had lost a lot of weight from 48 kilograms to about 30 kilograms. She was all skin and bones. She was in the hospital when they told me she had gotten worse. I rushed back to the hospital and saw her motionless on the bed just like a dead body. I prayed for her to live. The doctors gave her intravenous fluids. I begged them to help her. Now after taking ART for a long time her condition has improved. She is working again, doing some light work. [57 year-old divorced mother of daughter on ART and with grandson on ART, Kompong Svay commune]

All but one of the 108 household surveyed maintained that taking ART had helped children/household relatives suffering from HIV/AIDS. For the most part ART recipients were able to take care of their own needs and experienced improved health. High percentages were able to work again and contribute to the support of the household (Figure 12).

Figure 12. Percentages of Respondents Reporting How Antiretroviral Therapy Has Helped HIV/AIDS Positive Children/Household Relatives, Banteay Meanchey Province, May 2008



Last year my daughter who is HIV positive was so weak. She could not take care of her child. I helped her. She went to the hospital and was given ART. One month after taking the medicine she was much better and had no more fatigue. She was able to walk around, clean dishes and look after her child. Now she looks healthy and works like other people. She wears jewelry and good dresses. I am thankful to the people who made the medicine to cure this disease. [68 year-old widowed mother of daughter on ART, Teouk Thla commune]

Taking ART has helped save my son's life. He has gained weight, sleeps better, and has more strength. He takes the ART two times a day, at seven o'clock in the morning and at seven o'clock in the evening. He remembers to take the medicines himself and goes to the hospital regularly to get more supplies. Soon after he left the hospital he began to teach school again. Last year he remarried. His wife is a widow with three children. I did not know that they were in love. She says that she has pity for him and does not mind that he has HIV/AIDS. Having a companion makes his life easier. [63 year-old mother of son on ART, Kompong Svay commune]

My eight year old grandson is the only one that survived. His mother, father and elder brother all died of HIV/AIDS. He also has HIV/AIDS. He was very thin before and not able to eat much. Rashes, blisters and abscesses appeared on his

skin. The NGO told me to take him to the hospital in Siem Reap. At first the hospital staff gave him medicines for opportunistic diseases and then ART. After taking the drugs his health improved. He looks fine and has put on weight. I am thankful and happy that he has gotten better. He goes to school and rides his bicycle because he gets tired easily when he walks. He will probably live a long life. [55 year-old stepmother of stepdaughter deceased with AIDS and with step grandson on ART, O'Ambel commune]

My son-in-law tested HIV positive but hid it from his employer for fear that he would that lose his work in Thailand. He also hid it from his wife. He didn't tell me until after my daughter had died of AIDS and rashes had appeared on his body. He became weak and could not work much. He thought he would not live long. The village health workers took him to get the ART medicines. He got better after taking the medicine every day as instructed. He says that he now has hope. He was born in Siem Reap province but his parents are dead and he prefers to stay here with me and his two children. He helps with the farm work and just started a small business. [51 year-old widowed mother of daughter deceased with AIDS and with son-in-law on ART, Teouk Thla commune]

At the same time three-fourths (81 or 75 percent) of the 108 respondents reported that their children or household relatives had experienced side effects in taking the ART medications. The most common ailments experienced by ART recipients in these 81 households were trembling (62 percent), headache (59 percent), feeling weak (57 percent), vomiting (44 percent), and skin rashes (30 percent).

The ART medicine was very effective. Before using the medicine my daughter had lost a lot of hair, had blotches on her skin, and could not get up from bed. After taking the ART medicine, her condition improved and her hair started to grow back. At first she vomited and felt miserable but the doctor said that this was normal and that she should continue to take the ART medicine regularly as instructed. We were careful to remind her to take the medicine on time. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

Financial Impact of Care Giving on the Elderly

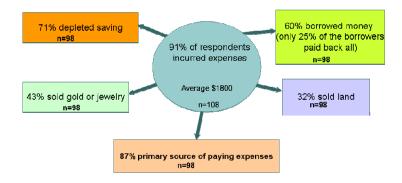
Elderly respondents incurred financial burdens, borrowed money, sold assets, and depleted savings to pay for the care and treatment of their HIV/AIDS positive children and household relatives. Overall 98 (91 percent) of the 108 respondents incurred expenses associated with the care and treatment of their HIV/AIDS positive children and household relatives. For 96 of these respondents the average total expenses for care and treatment of HIV/AIDS positive children and household relatives was US\$ 1,800. However, this figure is skewed to the upper end of the financial outlays for only 23 (24 percent) of the 96 households spent US\$ 1,800 or more. By comparison, 48 (50 percent)

of the 96 households spent US\$ 750 or less and 30 (31 percent) spent US\$ 375 or less. A large majority (90 percent) of the 98 respondents who incurred expenses said that these costs caused hardship for them and their households.²⁴ Anecdotal evidence indicates that some households were cheated by persons promising cures.

In all, 71 percent of the 98 respondents who had incurred expenses for the care and treatment of HIV/AIDS positive children and household relatives had to deplete savings to help pay these expenses. Similarly, 62 percent of these 98 respondents had to borrow money to cover such costs. Only 25 percent of these borrowers had paid back all of their loans. Moreover, 32 percent of the 98 respondents who had incurred expenses for care and treatment of HIV/AIDS positive children and household relatives had sold land, 14 percent had sold livestock, and 43 percent had sold gold or jewellery to help pay these costs or debt arising from these costs. While 54 percent of the 98 respondents acknowledged that other family members had contributed to expenses for HIV/AIDS treatment, 87 percent maintained that they or their spouse was the primary source of payment (Figure 13).

Figure 13. Percentage of Respondents Incurring Expenses, Depleting Savings, Borrowing Money, and Selling Assets, for Care and Treatment of HIV/AIDS

Children and Household Relatives,
Banteay Meanchey Province, May 2008



I have sold all of our cows and pigs and borrowed money for the medical care of my daughter who has HIV/AIDS. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

²⁴ While the survey did not differentiate between expenses incurred for care and treatment of PLHA before and after ART, most expenses presumably occurred before ART as the ART medication is provided free through donor grants to the government.

My son who has HIV/AIDS has been hospitalized nine times. He stayed at the private clinic not at the public hospital. He sold his motorbike and even his house for medical treatment. We also sold the motorbike of his younger brother for his medical care. Now we have run out of resources. My son continues to need treatment and intravenous infusions. He started to receive ART when he was hospitalized for the third or fourth time. His CD4 count was less than 100 and his condition was serious. He has not been hospitalized for nearly one year now. If his condition gets worse I will take him to the public hospital. We can no longer afford to go to the private clinic. [52 year-old widowed mother of son on ART and with grandson on ART, Preah Ponlea commune]

My daughter gave birth in Thailand. The doctor told her not to breastfeed the baby because she was HIV positive. She could not believe it since she still felt strong. When she came home she was careless about her health. She smoked, drank beer, and ate dog meat. Her condition deteriorated. We went to a local doctor who promised to cure her AIDS for 9,000 Thai Baht. I felt so relieved. I was desperate for her recovery and sold my gold. That was all that I had. But after three days the doctor escaped. My daughter cursed her and said that she would haunt her after she died. I took her to the district hospital and she vomited blood all night. Thinking that she would not live long, I bought her home and her husband carried her up the stairs into the house. I asked her to recite a prayer but she would not. I said the prayer myself. When I woke up, I found her dead. [51 year-old widowed mother of daughter deceased with AIDS and with son-in-law on ART. Teouk Thla communel

Medical and Funeral Expenses Associated with HIV/AIDS Deaths in the Family

Elderly respondents likewise incurred financial burdens as a result of HIV/AIDS deaths in their families. In all 41 (38 percent) of the 108 respondents reported a total 56 family members had died as a result of HIV/AIDS. The 56 deaths occurred mainly among children-in-law (31), children (14), and grandchildren (8).

Notably 28 of the 41 respondents who had experienced the death of a family member to HIV/AIDS had helped to pay some of their medical expenses. Of the 28, 18 had depleted their savings to do so. Similarly, 20 of the 28 respondents had to borrow money to cover the medical expenses or debt arising from these expenses. Only 13 of the 20 borrowers had paid back all of their loans. Moreover, 17 of the 28 respondents who had helped to pay medical expenses for family members now dead of HIV/AIDS had sold assets, 7 had sold land, 3 had sold livestock, and 9 had sold gold or jewellery. While 11 of the 28 respondents acknowledged that other family members had contributed to the medical expenses of those who had died of HIV/AIDS, 21 maintained that they or their spouse was the primary source of payment.

In all, 25 of the 41 respondents who had experienced the death of a family member to HIV/AIDS had helped to pay some of their funeral expenses. Of the 25, 13 had depleted

their savings to do so. Similarly, 13 of the 25 respondents had to borrow money to cover the funeral expenses or debt arising from these expenses. Only 7 of the 13 borrowers had paid back all of their loans. Moreover, 11 of the 25 respondents who had helped to pay funeral expenses for family members now dead of HIV/AIDS had sold assets, 3 had sold land, 7 had sold gold or jewelry, and 2 had sold other assets. While 13 of the 25 respondents admitted that other family members had contributed to the funeral expenses of those who had died of HIV/AIDS, 16 contended that they or their spouse was the primary source of payment.

My husband is disabled and my daughter and her son had HIV/AIDS. I had to sell some land to pay for their medical treatments. I bought nothing for myself, not even one sarong. My clothes are old and second hand. I cannot afford to buy new clothes. When my daughter died I sold another plot of land for her funeral. Now I have no land. I am living on land that belongs to my brother-in-law. I also borrowed money to start a small business. People lend me money because they know that I am a good person and will repay them. But I am worried that I may fall ill. Who will repay them? Who will support my grandson? Who will go to Siem Reap to get medicines for him? My grandson is too young to take care of himself. He would die. I try to stay healthy to help him. [55 year-old stepmother of stepdaughter deceased with AIDS and with step grandson on ART, O'Ambel commune]

My daughter and her husband had been sick for a long time. My daughter had rashes all over her body. Her husband had headaches, fever, chills, and stomach pain. He was not able to eat much and always had diarrhea. We did not know that it was HIV/AIDS. The condition of my son-in-law continued to deteriorate until he died. My daughter died one month later. I had no money to pay for their funerals. I relied on rice and contributions from neighbors. Before my daughter died she asked me to care of her three month old child who was also seriously ill. The child died soon after. I felt so sad and alone. I had the two young sons, one HIV/AIDS positive, of my daughter to care for and no one to support me. [81 year-old widowed mother of daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

Physical and Emotional Health of Respondent

Among the 108 respondents, 15 percent rated their health as good or very good, 43 percent rated their health as fair, and 43 percent rated their health as poor or very poor. However, 54 percent of the 108 respondents acknowledged that their health had improved since their children/household relatives had been on ART. Another 27 percent reported that their health had remained unchanged and 19 percent said that it had gotten worse.

Similarly, 51 respondents rated the health of their spouses. The health of 25 percent of the spouses was rated as good or very good, the health of 33 percent of the spouses was rated as fair, and the health of 41 percent of the spouses was rated as poor or very poor. Moreover, 49 respondents reported on changes in their spouses' health since their children/household relatives had been on ART. The health of 39 percent of the spouses was said to have improved, the health of 45 percent of the spouses was said to have gotten worse.

While rather large numbers of the respondents had suffered ailments in the last month, these afflictions for most respondents had generally not started or become worse since caring for HIV/AIDS positive children/household relatives. In all but one instance the incidence of ailments that had started or worsened as a consequence of care giving was less than 50 percent (Table 5).

Table 5. Ailments Respondents Suffered in Last Month and Whether Started or Became Worse during HIV/AIDS Caring, Banteay Meanchey Province, May 2008					
	In last month		Ailment started or became worse		
	respondent has ailment		since HIV/AIDS caring		
	Number	Percent of	Number	Percent of those with	
		total		ailment that started or	
		respondents		worsened since HIV/AIDS	
				caring	
Felt weak	86	80	42	49	
Headache	75	69	33	44	
Pain in joints	72	67	27	38	
Dizziness	72	67	27	38	
Fever	57	53	12	21	
Back pain	57	53	20	35	
Trembling hands	47	43	19	40	
Stomach ache	46	43	21	46	
Chest pain	42	39	18	43	
Problems breathing	41	38	21	51	
N=108	*				

For the past seven days I have been sick. It started with dysentery. Now I have chills and am fatigued. The doctor says that I have heart disease. I work hard. He gave me an injection. Now I feel better. When I took care of my son in the hospital I was in good health. [63 year-old mother of son on ART, Kompong Svay commune]

I am eighty one years old and my health is not so good. Sometimes I get tired and dizzy and my hands tremble. I have ringing in my ears. My eyes fill up with tears. When I am tired I buy medicine to sleep. Even though I am tired I still work for the sake of my grandson who has HIV/AIDS. His elder brother is working now. He will get married soon and be able to look after him. [81 year-old widowed]

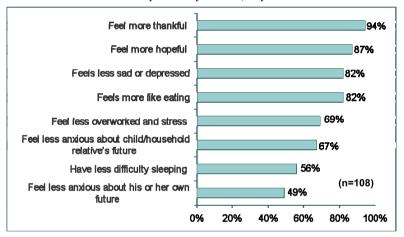
mother of daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

While only 8 of the 108 respondents suffered a physical disability, 5 of the 8 said that the physical disability affected their caring. Similarly, while only 7 of 50 respondent spouses suffered a physical disability, 3 of the 7 had a physical disability that affected their caring.

After their children and household relatives started to take ART elderly respondents generally felt better, although some still experienced difficulties and felt anxious about their own future (Figure 14).

Figure 14. Percentage of Respondents Experiencing Various Feelings after Children and Household Relatives Started to Take Antiretroviral Therapy,

Banteay Meanchey Province, May 2008



Almost two-thirds (69 or 64 percent) of the 108 respondents acknowledged that there were people with whom they could confide and talk about their situation. These people included relatives such as children, children-in-law, and spouse and non-relatives such as neighbors, friends, home based care team members, and government health care workers.

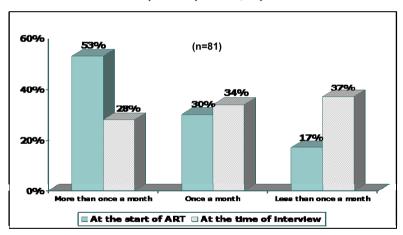
Support Services Provided to Elderly Caregivers

In the six communes studied home based care teams led by NGOs assisted respondents' children/household relatives on ART. Some NGOs pursued their work more intensely than others and the activities of these NGOs left more of an impression on the elderly respondents. While respondents may have known the names of home based care team

members they may not have been aware that these NGO workers, government health center staff, or village volunteers were part of a 'home based care program.' Often these visitors were simply referred to as *kru pet* or doctor. As a result participation in home based care programs may have been underreported even though 81 (75 percent) of the 108 households surveyed acknowledged the involvement of their ART recipient children/household relatives in such programs.

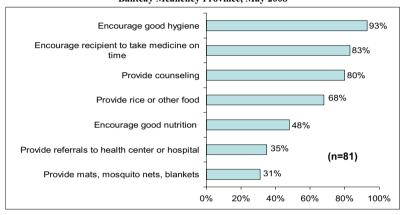
Among the 81 households cognizant of their HIV/AIDS positive children's/household relatives' involvement in the home based care team program 75 percent reported that NGO workers had made home visits, 60 percent mentioned that health volunteers had made home visits, and 33 percent indicated that government health workers had made home visits. Perhaps not surprisingly home based care team visits became less frequent from the start of ART treatment to the time of the interview as the PLHA in general experienced improved health and less difficulties (Figure 15).

Figure 15. Percent Frequency of Home Based Care Visits at the Start of Taking ART and at the Time of the Interview, Banteay Meanchey Province, May 2008



Respondents in the 81 households involved in the program reported that the home based care teams supplied goods and services to the ART recipients. The teams encouraged the ART users to take their medicine on time, to eat nutritious foods, and to practice good hygiene. The teams also provided the ART recipients with counseling and made referrals for them to health centers and hospitals. In some instances the teams provided ART beneficiaries with material goods such as sleeping mats, mosquito nets, and blankets (Figure 16). Notably, almost all (98 percent) of the 81 households involved in the program found the home based care visits helpful.

Figure 16. Percent Frequency of Goods and Services Mentioned by Respondents as Provided by the Home Based Care Teams,
Banteay Meanchey Province, May 2008



We receive support for my daughter and grandson from the NGOs in the home care program. At first the NGO gave us 30 kilograms of milled rice, cooking oil and salt every month. After one year they stopped but then another NGO started to give us five kilograms of rice each person, soy sauce, canned fish and noodles each month. This NGO also stopped but another came and gave us rice but not so much. At the beginning we received a lot of rice, more than we needed. Now we have to do more for ourselves. [57 year-old divorced mother of daughter on ART and with grandson on ART, Kompong Svay commune]

My daughter has received assistance from different people and organizations. She has received milled rice, fish sauce, noodles, and even sarong, blankets and money. She has also received clothes for her child. Sometimes she has received more than she needs. She has also received counseling from the organizations. [68 year-old widowed mother of daughter on ART, Teouk Thla commune]

The NGO provides support to me and my two grandsons. Every month they give us 30 kilograms of milled rice, canned fish, and cooking oil. The NGO also gives me 200 Thai Baht every two months to travel to Siem Reap province to get the medicines. Some people living nearby also give us money for buying food. My daughter living in Poipet commune sends money to me once a month. My elder grandson works and also earns some money. [81 year-old widowed mother of

daughter deceased with AIDS and with grandson on ART, Preah Ponlea commune]

ART recipients and respondents participated in group meetings for PLHA and this participation was highly valued. A large number (94 or 87 percent) of the 108 respondents reported that their children/household relatives on ART had attended PLHA group meetings. Of these 94 respondents, 81 percent said that their children/household relatives had gone to these meetings at least once a month, 97 percent maintained that these meetings were helpful for their children/household relatives, and 71 percent indicated that their children/household relatives shared information with them about the meetings.

By comparison, respondents and/or their spouses in about half (53 or 49 percent) of the 108 households surveyed had participated in PLHA group meetings. Within these 53 households, 60 percent of the respondents and/or their spouses had gone to these meetings at least once a month, all had found the meetings helpful for them, and 91 percent had shared information with their HIV/AIDS positive children and household relatives about the meetings.

Sometimes I go to the meetings for HIV positive persons. I don't feel ashamed now because I have seen other village families with HIV positive members. Last time I went to the meeting they gave me 70 Thai Baht and a packed lunch. [66 year-old mother of daughter deceased with AIDS and with granddaughter on ART, Teouk Thla commune]

Community Reaction

Besides the home base care team, 40 (37 percent) of the 108 respondents noted that family members outside of the household or other people in the community had given help to their children or household relatives on ART during their illnesses. The 40 respondents most frequently mentioned neighbors (35), family members outside of the household (18), and friends (14) as people who had given the assistance. Similarly the 40 respondents most frequently mentioned food (28), money (19), and material goods such as mats, mosquito nets, and blankets (6) as types of help provided by family members outside the household or other people in the community.

While some discrimination towards HIV/AIDS positive children and household relatives existed before they came to be on ART, the prejudice was not particularly severe. A high incidence of respondents reported that neighbors had visited even before the start of ART treatment. During this time some neighbors even bought food or medicine. This noted, ART use had beneficial effects on community reactions. After ART treatment began the incidence of respondents reporting visits by neighbors increased while the incidence of respondents noting avoidance and gossip by neighbors decreased (Table 6).

Table 6. Neighbors' Engagement with HIV/AIDS Positive Children and Household Relatives Before and After ART, by Respondent, Banteay Meanchey Province, May 2008

After ART Before ART Number Percent Number Percent Neighbors visited 74 69 93 86 Neighbors looked after patient 15 25 16 23 Neighbors bought food or medicine 42 43 45 46 Provided transportation or went with respondent to health center 26 24 24 22 Neighbors avoided talking 29 respondent or others in the household 31 11 10 Neighbors gossiped 41 38 9 8 N=108

These findings are consistent with a recent study conducted in Cambodia on community reaction to older age AIDS caregivers and their families. This study examines community reactions to families from the point of view of older age parents of adults who died of AIDS or currently receive ART. Based primarily on qualitative data from opened-ended interviews the research reveals a mixture of reactions with respect to social relations, interactions with local officials, gossip, business patronage, funeral participation, and grandchildren. While both positive and negative reactions were present, positive support was often dominant and reactions typically improved significantly over time. Misplaced fears of contagion through casual contact accounted for most negative reactions.

Our neighbors do not discriminate against us. They often give us food and are on good terms with us. They show compassion to our family. No one wants to have HIV/AIDS. [52 year-old widowed mother of son on ART and with grandson on ART, Preah Ponlea commune]

I am speaking honestly. I think my daughter should not be ashamed for having this disease. She is a victim. She got infected from her husband and not because she was working as a prostitute. Everyone in the village knows that and respects her. [51 year-old widowed mother of daughter on ART and with grandson on ART, Preah Ponlea commune]

Before my daughter died of AIDS some people in our village were scared to be near her. We could not afford to be scared since she was our family member. Even now some neighbors do not let their children play with my grandchildren for fear of getting infected. But most people have more awareness now. They have learned a lot from NGOs at meetings on how to behave with HIV/AIDS persons and that HIV infection is transferred through sexual intercourse. We still feel

²⁵ See Knodel, John, Nathalie Williams, Sovan Kiry Kim, Sina Puch, and Chanpen Saengtienchai, "Community Reaction to Older Age Parental AIDS Caregivers and Their Families: Evidence From Cambodia," *Research on Aging*, Volume 32, Number 1, 2010.

somewhat uneasy about eating meals together with my HIV positive son-in-law but we are all right. People in the village eat meals with him and nobody talks about getting infected from him. [51 year-old widowed mother of daughter deceased with AIDS and with son-in-law on ART, Teouk Thla commune]

My grandson told me that sometimes other children at school will not play with him because he has HIV/AIDS. He told me that he gives them cake so that they will let him play with them. Some adults also tell children not to play with my grandson for fear of getting infected. Most people now have more awareness and realize that HIV/AIDS is everywhere. They had been taught how HIV infection occurs and how to behave with people with HIV/AIDS. People are no longer scared of HIV infection and know that they should just avoid behavior that exposes them to it. [55 year-old stepmother of stepdaughter deceased with AIDS and with step grandson on ART, O'Ambel commune]

Conclusions and Policy Implications

The widespread provision of ART in Cambodia has transformed the role of older persons in HIV/AIDS care giving and treatment assistance. The number of PHLA on ART in Cambodia increased sharply from 71 in 2001 to 12,355 in 2005 to 37,315 in 2009. Notably the 2009 figure represented about 95 percent of the PLHA in need of ART. As documented in this study the consequences of ART use were truly remarkable. Many of the elder caregivers, who had endured the burden of seeing their children and household relatives wasting away and near death, now observed miraculous recoveries once the AIDS infected persons had started to take ART. Nearly all the ART recipients cared for by the elders were able to attend to their own needs and experienced improved health. High percentages were able to work again and contribute to the support of their households. The benefits which accrued to the PLHA reverberated to family members including the older-age caregivers by reducing their care giving and financial burdens.

Prior to the era of near universal access to ART, the AIDS epidemic had taken a severe toll in Cambodia. From its initial detection in 1991 adult prevalence rates of HIV/AIDS reached a peak of 3 percent in 1997 before declining to 0.9 percent in 2006. The sharp decline in adult prevalence rates attested to the effectiveness of the government's response to the epidemic which included home based care programs and outreach services implemented in partnerships with NGOs. Still by 2003 it was estimated that 94,000 people had died of AIDS related illnesses and that 123,000 people were living with HIV or AIDS. Beyond the PLHA directly affected, the toll extended to family members including elders who often sustained the emotional, economic, and social consequences of intensive care giving and the premature deaths of their relatives. This was due in part to the absence of a viable public health system in Cambodia

Major Findings

The study reveals that elderly respondents and/or their spouses in 101 (94 percent) of the 108 households surveyed provided care to HIV/AIDS positive children and household relatives. Moreover in these households elderly women comprised 82 percent of the primary care givers. The pronounced role of elderly women in care giving was striking considering their demographic and social characteristics. A majority of the 107 female respondents or spouses were separated, divorced or widowed without partners to rely on, nearly half had never attended school, two-thirds were still working to support their households, and just over half were 60 years of age or over. Despite these constraints elderly women generally assumed primary responsibility for the care of HIV/AIDS positive children and household relatives.

Talking about their care giving experiences in open-ended interviews the elderly women gave voice to the deep emotional ties which bound them to their children and household relatives reiterating their willingness to sacrifice for their sakes. One mother upset about

the seeming irresponsible behaviour of her daughter mused that, "Some children listen to their parents. Others do not. But she is my daughter. I had no choice but to take care of her." Retelling the story of her AIDS infected orphaned grandson, an elderly grandmother concluded, "I care more about his life than my own." Similarly a grandmother of an AIDS infected orphaned granddaughter explained, "Taking care of my granddaughter takes a lot of time.... Although I am hungry, I make sure she has good meals because I am afraid that she will die." Another grandmother despite the diminished vitality of her age refused to abandon her AIDS infected grandson, "In the hospital I stayed awake by his bedside to care for him, even though I am old and have no strength.... My other children told me to take the child to an orphanage but I would rather keep him and take care of him." Older persons' and especially older women's commitment to caring for their AIDS infected children and household relatives was strongly evidenced in the quantitative and qualitative data of the research.

The care giving of the elders came at a cost. Slightly more than 90 percent of the elderly respondents incurred financial expenses for the care and treatment of their HIV/AIDS positive children/household relatives apparently before receiving the ART medicines for free. Most elders making these payments had depleted their savings and/or borrowed money. Many had sold land, gold or jewellery. Elderly respondents likewise incurred financial burdens as a result of HIV/AIDS deaths in their families. In all, 28 of the 41 respondents who had experienced the death of a family member to HIV/AIDS had helped to pay some of the medical expenses; 25 of the same 41 respondents had helped to pay some of their funeral expenses. While more than 40 percent of the elderly respondents complained of poor or very poor health, the elders generally did not associate specific health complaints with the consequences of care giving.

The ART recipient survey conducted as part of this study helps to place the more comprehensive results of the older-age persons' interviews in context. Information gathered from 382 ART recipients revealed that three-fifths of the respondents had at least one living parent and that nearly three-fourths of those with a surviving parent lived in the same household or location as their parents. This placed parents in an advantageous situation to monitor and support ART use. More than two-fifths of the ART recipient parents, and almost two-thirds of the co-resident parents, often or daily reminded their children to take their ART medicines. Compared to older parents, younger parents and especially co-resident younger parents reminded their children often or daily to take ART. Moreover, among ART recipients who had a living parent, more than three-fifths had a parent who reminded them to get their medicines from the hospital or health center. Similarly almost one-third had a parent who had actually taken them to get medicines.

The older-age persons survey conducted with 108 respondents likewise underscores the active involvement of parents in assisting with ART treatment adherence and even prior to this in encouraging PHLA to get tested for HIV and to seek ART treatment. Almost three-fourths of the elderly respondents and/or their spouses encouraged children/household relatives to get tested for HIV/AIDS. Once ART medicines became available, about two-thirds of the elders encouraged them to seek ART treatment. After the PLHA started ART treatment, a large majority (88 percent) of the older people

reminded them to take the ART medicines. A minority (42 percent) of the elders normally paid the transportation costs for children/household relatives to get ART from the hospitals or health clinics.

Of note, time spent in care giving dropped sharply between the periods before and after ART use. Before ART, elders in three-fourths of the 101 care giving households spent more than half of the day in providing care. Since ART the pattern was reversed with elders in nearly three-fourths of the same 101 care giving households spending very little time during the day to provide care

To provide effective assistance with ART treatment adherence, elders must have sufficient understanding of the treatment regimen. The study examined the association of ART knowledge and the extent to which older persons received instruction from the ART treatment program. The result indicated a strong association between the extent of instruction received and ART knowledge. This suggests that receiving advice from program sources considerably improves older persons' knowledge.

In the study communes home based care teams led by NGOs assisted respondents' children/household relatives on ART. While respondents may have known the names of home based care team members not all were necessarily aware that they were part of a home based care team program. As a result participation in home based care programs may have been underreported even though three-fourths of the households' surveyed acknowledged their PLHA's involvement in such programs. According to respondents in these households, the teams encouraged the ART users to take their medicine on time, to eat nutritious foods, and to practice good hygiene. The teams also provided ART recipients with counseling and made referrals for them to health centers and hospitals. In some instances the teams provided ART beneficiaries with material goods such as sleeping mats, mosquito nets, and blankets.

Elders and their AIDS infected children/household relatives likewise participated in PLHA group meetings and this participation was highly valued. A large majority (87 percent) of the 108 respondents reported that their children/household relatives on ART had attended PLHA group meetings. By comparison, elders in about half (49 percent) of the 108 households surveyed had participated themselves in PLHA group meetings. Nearly all the respondents reporting either type of involvement acknowledged that the meetings were helpful for their PLHA children/household relatives and/or for themselves.

While some discrimination towards HIV/AIDS positive children and household relatives existed before they came to be on ART, the prejudice was not particularly severe. A high incidence of respondents reported that neighbors had visited even before the start of ART treatment. During this time some neighbors even bought food or medicine. This noted, ART use had beneficial effects on community reactions. After ART treatment began the incidence of respondents reporting visits by neighbors increased while the incidence of respondents noting avoidance and gossip by neighbors decreased.

Policy Implications²⁶

Cambodia's response to its AIDS epidemic has been remarkably effective albeit highly dependent on donor funding. Rigorous life long treatment adherence to ART regimens is crucial to sustain the health benefits achieved and lessen drug resistance associated with treatment failure. The ongoing success of Cambodia's response to the disease relies on developing culturally appropriate, pragmatic and cost effective approaches to long-term ART adherence. This entails not only continued provision of drugs and medical personnel to dispense them, it requires persons to supply social and psychological support as well. The formation of PLHA support groups and home based care teams to augment treatment adherence constitutes the prevailing strategy in Cambodia to address this challenge. The results of this study which empirically document the contributions made by elders in response to HIV/AIDS suggest opportunities for expanding this strategy to include older-age persons and other family members.

Compelling arguments emerge from the research for involving older-age persons and other family members more inclusively in ART adherence programs. Elderly persons often live with or nearby ART patients and have deep emotional reasons for wanting the patient to achieve and maintain restored health. They are highly committed to caring and are often present at the specific times that medicines need to be taken. Moreover, they neither ask nor expect to be paid for their assistance. In short, older-age persons represent a largely unrecognized resource in Cambodia's organized response to the AIDS epidemic.

The underutilization of older-age persons in Cambodia's ART adherence programs is perhaps due to health professionals' perceptions that their advanced ages and general lack of formal education render them incapable of providing useful assistance. But as evidenced in this study neither their older ages nor their low levels of education and literacy prevented the elders from understanding the basic requirements of treatment adherence. Indeed ART knowledge was strongly associated with the extent of instruction received suggesting that training from program sources substantially improved older persons' knowledge. This has implications for involving PLHA support groups more proactively in the education of older-age persons and other family members. Working in tandem PLHA support groups and older-age persons could generate greater synergy and contribute significantly to Cambodia's response to the AIDS epidemic which will likely confront the country for years to come.

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²⁶ Policy implications presented in this section benefit from, and support, those made by Knodel et al, Older-age Parents and the AIDS Epidemic in Thailand.

Appendix 1. ADI Trainees and Team Researchers

ADI Trainee Researchers

Thong Thavrin Aphivat Strey

Keo Chantha Cambodian Elder Support Organization

Moung Mearedey Cambodian Women's Crisis Centre
Sin Ly Pao Cambodian Women's Crisis Centre
Ket Noeun Cambodian Women's Crisis Centre

Meach Sothea Church World Service

Chea Samnang Enfants & Développment

Se Sorng Farmer Organic for Development Association

Kim Sotheavy Khmer Volunteer Organization

Chheak Sothea Krousar Yoeung

Chry Monyrath Khmer Women's Cooperation for Development

Oeuk Pisith Lutheran World Federation

Leurm Sreylis People Center for Development and Peace

Chhim Raymong Puthi Komar Organization
Pen Sony The New Life, Cambodia

Meas Chanthan Urban Sector Group

Mour Meng Hong Vicheasthan Bamreu Neaksamrabsamroul

Karngea Akphiwat

Lor Monirith World Vision Cambodia

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Hak Sochanny

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Kung Seakly

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Ly Sokhoing

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Cooperation Committee for Cambodia/ADI Project

List of ADI Research Studies

(www.ccc-cambodia.org)

- Chapter 4 Access to Natural Resources: Case Studies of Cambodian Hill Tribes In Land and Cultural Survival: The Communal Land Rights of Indigenous People in Asia, Asian Development Bank, 2009.
- Chapter 9 Negotiating Tenure Conflict in Indigenous Villages of Ratanakiri Province and Chapter 17 Mobilizing Villagers to Stop Illegal Fishing along the Srepok River in Ratanakiri Province In Emerging Trends, Challenges and Innovations, CBNRM Learning Institute, Volume II, 2009.
- Selling to Survive: Market Vendors in Kampong Cham Town Making their Living in the Informal Economy, November 2008.
- Land Titling and Poverty Reduction: A Study of Two Sangkat in Prey Nup District, Sihanoukville Municipality, November 2007.
- Understanding Social Capital in Response to Floods and Droughts: A Study of Five Villages in Two Ecological Zones of Kompong Thom Province, August 2007
- Growing Old in the Former Khmer Rouge Stronghold of Pailin, November 2006
- The Challenge of Living with Disability in Rural Cambodia: A Study of Mobility Impaired People in the Social Setting of Prey Veng District, Prey Veng Province, March 2006
- Impact of the Garment Industry on Rural Livelihoods: Lessons from Prey Veng Garment Workers and Rural Households, October 2005
- Domestic Violence in a Rapidly Growing Border Settlement: A Study of Two Villages in Poipet Commune, Banteay Meanchey Province, May 2005
- Indigenous Response to Depletion in Natural Resources: A Study of Two Stieng Villages in Snoul District Kratie Province, September 2004
- Understanding Drug Use as a Social Issue: A View from Three Villages on the Outskirts of Battambang Town, April 2004
- Experiences of Commune Councils in Promoting Participatory Local Governance: Case Studies from Five Communes, March 2004

- Labour Migration to Thailand and the Thai-Cambodian Border: Recent Trends in Four Villages of Battambang Province, December 2003
- The Impact of the Tourism Industry in Siem Reap on the People Who live in Angkor Park, December 2002
- Small-Scale Land Distribution in Cambodia: Lessons from Three Case Studies, November 2001

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