

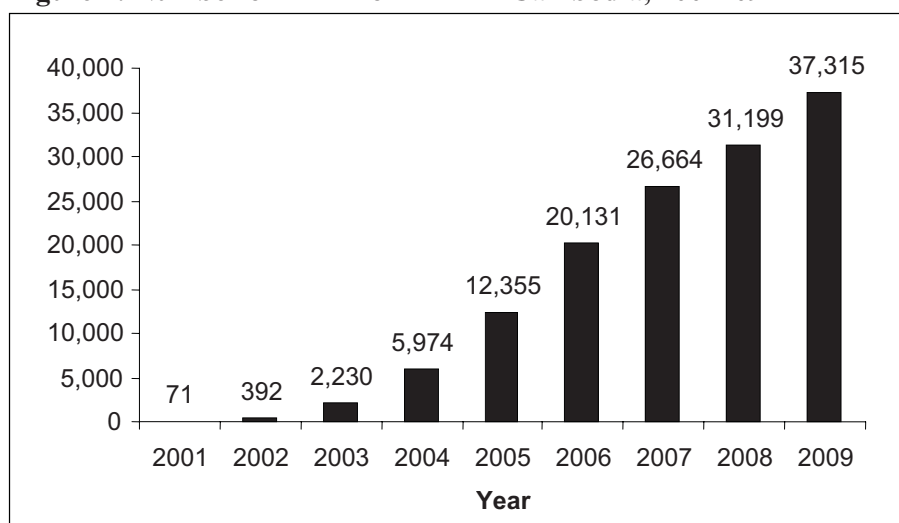
# Older People Support Anti-Retroviral Treatment Adherence Programmes in Banteay Meanchey Province<sup>1</sup>

## Introduction

In Cambodia, access to anti-retroviral therapy (ART) accelerated rapidly in the past decade, altering the circumstances and experiences of those dealing closely with the AIDS epidemic. Until very recently, HIV-infected persons in Cambodia who had contracted opportunistic infections associated with AIDS were destined to endure debilitating illnesses leading inexorably to death. Beyond those infected, the epidemic affected family members, including parents, who often bore the emotional, economic and social consequences of intensive care giving and the premature deaths of their children. Expanded availability of ART drastically reconfigured the situations of those affected by the disease. With ART, AIDS-related infections could now be treated effectively and the health of the patient restored. Meanwhile, increased testing for HIV enabled ART treatment to begin before opportunistic infections like tuberculosis became symptomatic and started to take their toll. As persons living with HIV/AIDS (PLHA) experienced improved health on ART, family members similarly benefited as the adverse effects of the disease were mitigated or at least substantially delayed (see ADI 2010).

ART was piloted in Cambodia in 2001 by the NGOs Medecins Sans Frontieres, Medecins du Monde and Centre for Hope. Although the government and donors were initially reluctant

**Figure 1: Number of PLHA on ART in Cambodia, 2001–09**



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

to support ART provision, the early outcomes convinced the Ministry of Health that the ART programme could be viable. The National Centre for HIV, AIDS, Dermatology and STI (NCHADS) assumed management of the programme which expanded rapidly with generous donor support. The number of PLHA on ART increased from 71 in 2001 to 12,355 in 2005 to 37,315 in 2009 (Figure 1). According to the NCHADS director, the 2009 figure represented about 95 percent of the PLHA in need of ART (Mean Chhi Vun 2009). With Cambodia still in the process of developing a viable public health system, this was truly a remarkable accomplishment.

## Research Objectives

Older persons are largely ignored in the discourse concerning the AIDS epidemic despite the fact that they are intimately involved. This article focuses on older persons' support to HIV-positive children and household relatives on ART in Banteay Meanchey province. More specifically, the study seeks to examine the role and involvement of elders in care giving and assistance with treatment adherence, to assess the financial and health impacts of care giving

<sup>1</sup> This article was prepared by Hak Sochanny, Khuon Candore, Dane So and John McAndrew of the Analysing Development Issues (ADI) Project of the Cooperation Committee for Cambodia. The researchers acknowledge the advice and support of Professor John Knodel, Population Studies Center, University of Michigan.

on the older people, to identify the consequences of ART use for the elders and their children/household relatives and to explore the incidence and importance of training provided to the elderly care givers.

### Research Methods

The research 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. This ART recipient survey helps to place the more comprehensive results of the older persons' survey in context.

In May 2008 in the same communes, a total 108 respondents 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 surveyed about their care-giving experiences. In July 2008, 10 of the 108 survey respondents were approached again for qualitative in-depth interviews. In Phnom Penh and Banteay Meanchey, the study also interviewed government officials involved in the provision of ART and NGOs involved in home-based care support.

### ART Recipients Report Assistance from Parents

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

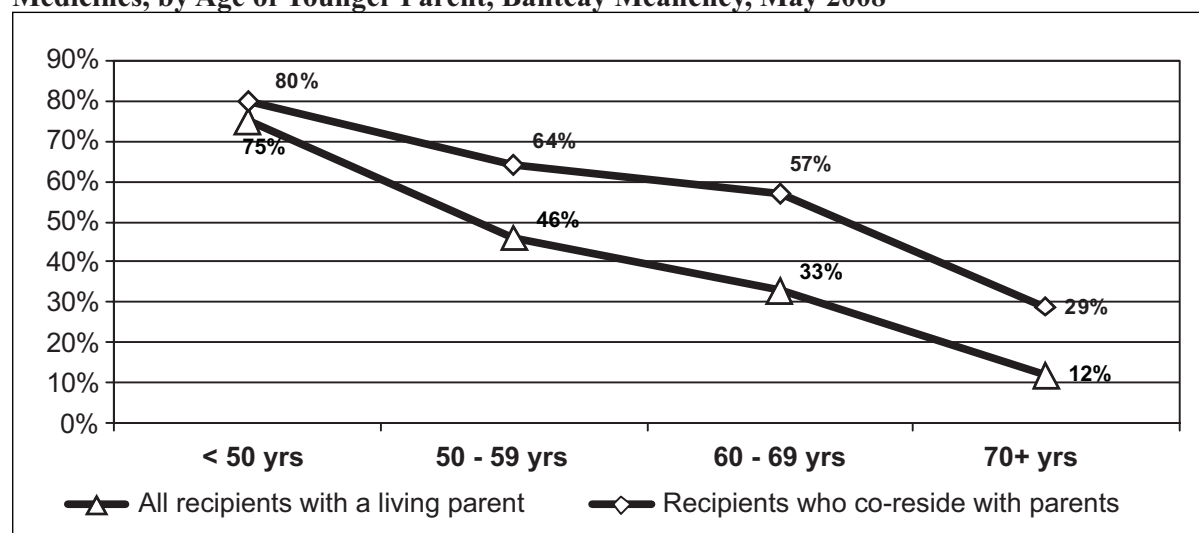
their parents. This placed parents in an advantageous situation to monitor and support ART use. More than two-fifths of the ART recipient parents, and almost two-thirds of the ART co-resident parents, often or daily reminded their children to take their ART medicines. Younger parents and especially co-resident younger parents more than older parents reminded their children often or daily to take ART (Figure 2). 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 centre. Similarly, almost one-third had a parent who had actually taken or accompanied them to get medicines.

### Older People's Commitment to Care Giving

The older people's survey reveals that elderly respondents and/or their spouses in 101 (94 percent) of the 108 households interviewed provided care to HIV-positive children and household relatives. Moreover, in these households elderly women were 82 percent of the primary care givers. The involvement of women as care givers was greater than that of men. In total 97 (91 percent) of the 107 women and 35 (67 percent) of the 52 men provided some care to their HIV-positive children or household relatives (Figure 3). Reasons given by elders surveyed for not providing care were commonly that their spouse did so or that the ART recipient's spouse or children did so.

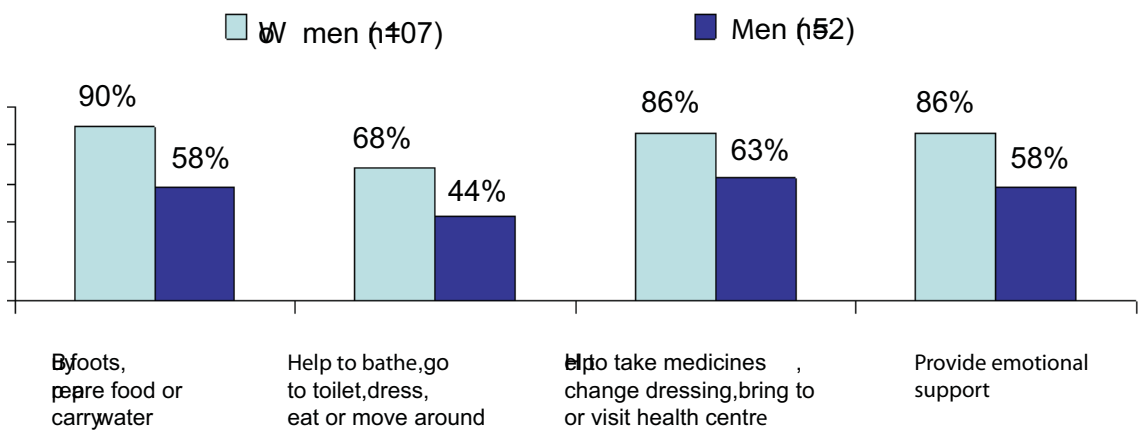
The pronounced role of elderly women in care

**Figure 2: Percent of ART Recipients Whose Parents Remind Them Often or Daily to Take Their Medicines, by Age of Younger Parent, Banteay Meanchey, May 2008**



Source: Survey of 382 ART recipients

**Figure 3: Elderly Respondents and their Spouses Engaged in Four Areas of Care Giving, Banteay Meanchey, May 2008**



Source: Survey of older persons

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-positive children and household relatives.

While older persons' and especially older women's commitment to caring for HIV-positive children and household relatives was strongly evidenced in the research, their care giving came at a cost. Slightly more than 90 percent of the elderly respondents incurred expenses for the care and treatment of their HIV-positive children and household relatives, apparently before receiving the ART medicines for free. Of those elders with expenses, 71 percent had depleted their savings and 62 percent had borrowed money; 32 percent had sold land and 43 percent had sold gold or jewellery. Of the 41 respondents who had experienced the death of a family member to HIV/AIDS, 28 had paid some of their medical expenses, while 25 had paid 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.

#### Consequences of ART Use

"ART is a sacred medicine provided by God." These words spoken by an 81-year-old grandmother who was among the 108 respondents surveyed

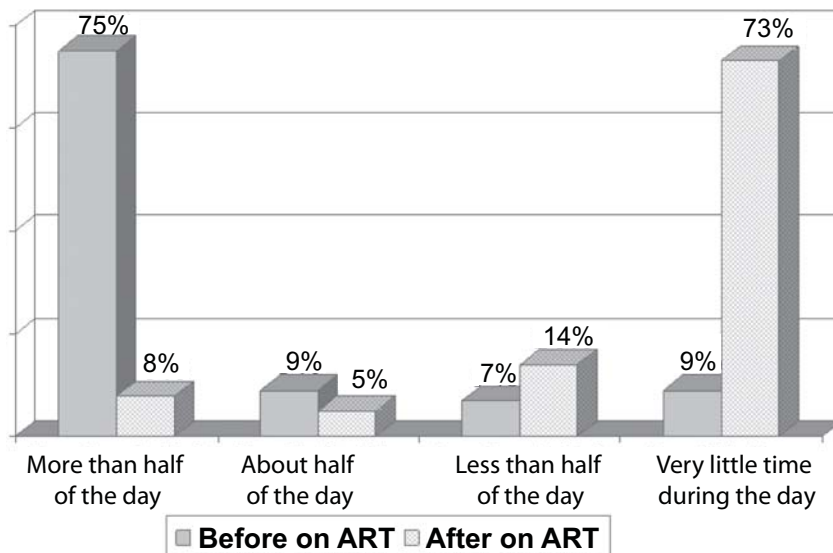
captured the sentiments of many of the older persons interviewed. Many who had experienced their children and household relatives literally dying before their eyes now witnessed miraculous recoveries once the patients started to take ART.

*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, Kompong Svay commune, Banteay Meanchey)*

*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 jewellery 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, Tuek Thla commune, Banteay Meanchey)*

**Figure 4: Percentage of Time Spent in Care Giving before and after Antiretroviral Therapy, 101 Households, Banteay Meanchey, May 2008**

*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. 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, Banteay Meanchey)*



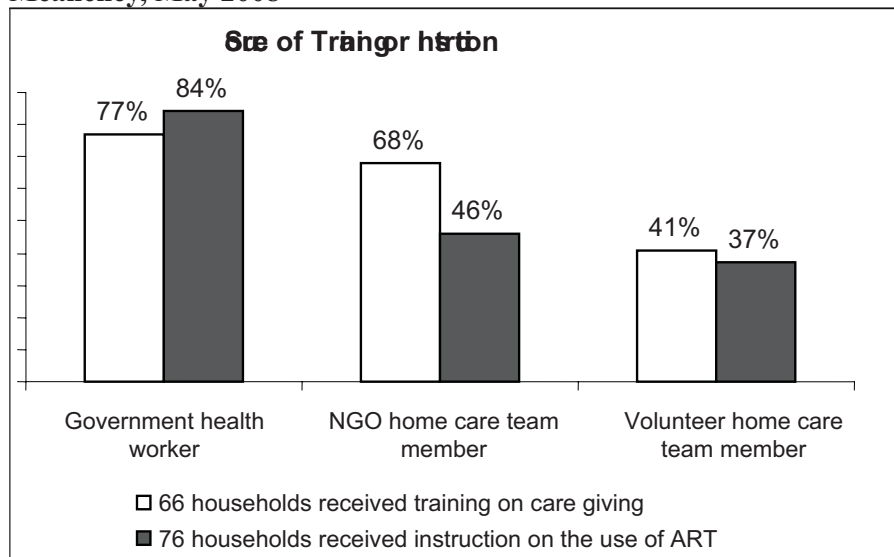
Source: Survey of older persons

ART use 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 recipients were able to return to work and more than half had ART recipient children/household relatives who were able to contribute to the household income. While the time spent by the elders in care giving dropped sharply after ART use (Figure 4), the elderly respondents remained actively involved in reminding the ART recipients to take their medicines.

**Older Care Givers and Training**

While elders were actively engaged in care giving, they 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 highly relevant matter. Care givers in these 66 households received training mostly from government health workers and NGO home-based care teams and less so from volunteer home-based care teams. By contrast, slightly more elders received training on how to care for ART recipients. Respondents

**Figure 5: Percentages of Households Reporting Source of Instruction on HIV/AIDS Care Giving and Use of Antiretroviral Therapy, Banteay Meanchey, May 2008**



Source: Survey of older persons

and/or their spouses in 76 (70 percent) of the 108 households received instruction on the use of ART. Care givers in these 76 households received instruction predominantly from government health workers and less so from NGO and volunteer home-based care teams (Figure 5).

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 programme. The result indicated a strong association between instruction received and ART knowledge. This suggests that receiving advice from programme sources considerably improves older persons' knowledge and, by implication, the quality and effectiveness of their support (see Knodel *et al.* 2010).

### Policy Implications

Cambodia's response to its AIDS epidemic has been remarkably effective albeit highly dependent on donor funding. Rigorous lifelong 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 but also persons to supply social and psychological support. The formation of PLHA support groups and home-based care teams to augment treatment adherence constitutes the prevailing strategy to address this challenge. The results of this study, which empirically document the contributions by elders in response to HIV/AIDS, suggest opportunities for expanding this strategy to include older persons and other family members.

Compelling arguments emerge from the research for involving older persons and other family members more inclusively in ART adherence programmes. Elderly persons often live with or near ART patients and have deep emotional reasons for wanting the patient to restore and maintain 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 persons represent

a largely unrecognised resource in Cambodia's organised response to the AIDS epidemic.

The underutilisation of older persons in Cambodia's ART adherence programmes is perhaps due to health professionals' perception 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 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 programme sources substantially improved older persons' knowledge. This has implications for involving PLHA support groups more proactively in the education of older persons and other family members. Working in tandem, PLHA support groups and older 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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