Older Persons and the HIV/AIDS Epidemic in Cambodia

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INTRODUCTION

The AIDS epidemic has had a devastating toll around the world, not just on individuals, but also on families and communities (United Nations Population Division 2003). Researchers, policy makers and programmers are still working to understand the wide-ranging and long-term affects of the epidemic on survivors. The role of older persons in the AIDS epidemic however, has been largely ignored. This is most likely because infection rates in this group are relatively low. However, quantitative evidence from Cambodia and Thailand indicates that while older people may not be infected at as high rates as younger cohorts, as parents of adults with AIDS they are very much affected by the epidemic (Knodel 2006). Scattered research from other settings suggests similar situations (Knodel and VanLandingham 2002). These parents, who are typically in advanced ages, commonly provide caregiving during illness, pay financial and material support and, funeral expenses, and in many cases foster grandchildren orphaned by AIDS. In addition, older-age parents can provide moral guidance and discourage risk behavior of their adult children and grandchildren. In addition to the devastating emotional distress this experience undoubtedly causes, these older people potentially suffer economic hardships, physical distress, negative community reactions, and loss of financial and caregiving support from the deceased child. Despite the large numbers of older persons who may be indirectly, but heavily, affected by the epidemic, recognition of their contributions to caring and prevention and of the potentially serious impacts on their well-being is largely lacking in policy and programs worldwide and rarely addressed in academic research. Using Cambodia as a case study, this paper will provide an in-depth examination, based primarily on qualitative data, of the role of older persons in the HIV/AIDS epidemic and its consequences on their physical, financial, emotional, and social well-being. More specifically, we examine possible ways that parents contribute to the day to day caregiving and the consequences for them of the illness and death of their AIDS afflicted sons or daughters.

CONCEPTUAL FRAMEWORK

Older parents can potentially be involved at all different stages of the HIV/AIDS progression and impacts may reverberate for years afterwards. We consider their possible contributions during the time of relative wellness, especially in cases where a child is taking ART and opportunistic infection medications, during the terminal stages of the AIDS illness, and then following the death of the child. We also discuss the possibility of contributions to care and support to the adult child with HIV/AIDS by other caregivers, either individuals, informal and formal organizations, or the government. In this context, care and support provided by others may relieve some of the burden placed on older caregivers.

We also consider a variety of potential adverse consequences on older caregivers' own well-being, during the illness and after the death of their child. These may include grief, financial hardship or debt, loss of old age support, physical strain, social stigma, and the difficulties involved with caring for orphaned grandchildren. Finally, we recognize that even under these difficult circumstances, there may be a few positive consequences of the role older people play in their child's illness. They may experience supportive reactions from community members or emotional fulfillment from living with their grandchildren. It is also possible that grandchildren, particularly older ones, may provide support to their grandparents.

SETTING AND CONTEXT

Cambodia has experienced the worst HIV/AIDS epidemics in Asia. It is also very poor, has a weak and under-funded government health system, and was just recovering from decades of violent conflict when the HIV/AIDS epidemic hit in 1991. Despite these constraints, Cambodia is arguably a leader in HIV/AIDS response. The government has been open about the epidemic and with the international community has managed to mobilize scarce financial resources and human capital to develop strong prevention, care, and support programs. The success of these programs is clearly demonstrated by the decline in adult HIV/AIDS prevalence from 3% in the late 1990s to 1.6% in 2005, as well as the widespread and successful ART treatment program (UNAIDS 2006; Buehler et al 2006). However, Cambodia has yet to thoroughly plan and implement programs in the area of impact mitigation. Older caregivers could figure heavily in this area.

Cambodia is an interesting case study for this topic of older caregivers and HIV/AIDS. Because of the vast changes in the provision of care and support for HIV/AIDS within the past three years, we are able to reach a broad spectrum of people, from those who have received few if any services, to those who have received a full spectrum of medical care, home-based care, and other support services.

METHODS

This paper will be primarily based on the results of a series of 25 semi-structured open-ended interviews of older caregivers in Cambodia. We are currently undertaking these interviews and plan to complete them all by the end of October 2006. This series of interviews is designed to address the current situation of the rapid increase in provision of anti-retroviral therapy (ART) and home-based care around Cambodia; it includes parents of adults who have already died of AIDS and of adults living with HIV/AIDS who are currently taking ART. To capture the different experiences, opportunities, and amenities available to rural and urban residents, we are doing interviews in Phnom Penh and in rural villages in several provinces. The interview guidelines are included in Appendix 1.

We plan to conduct thematic analysis of the interview data using NVivo qualitative data analysis software. Our interpretation of the qualitative results will be aided by the extensive representative quantitative survey data collected in 2004 and 2005.

RESULTS

Based on our interview guidelines, and the interviews that have been completed thus far, we intend to present details of the following topics in our results section:

- Living arrangements of the ill child in relation to the parents
- Types of care given by older caregivers- daily living (food, cleaning), nursing care, medication (anti-retroviral therapy and for opportunistic infections) support, amount and type of financial support, emotional and spiritual support
- Length of caregiving period
- Other caregivers- treatment (medications and stays in hospitals or hospices), home-based care, PLHA support groups, emotional or spiritual support, financial and material assistance
- Knowledge of how to give care and advice or training received on caregiving
- Community reaction to the parents and infected adult child
- Impacts on older caregiver- financial, community reaction, physical health problems, emotional stresses, long-term care of grandchildren.

DISCUSSION AND CONCLUSION

We plan to discuss the significance of these results of the open-ended interviews, using representative quantitative data to provide a wider context within which to interpret the results.

We will review the situation up to the present of older persons as parents of adults who become ill and die of AIDS and interpret these results within the Cambodian context. We will also speculate the implications for the role older persons of the ongoing rapid changes in the role of Government and NGOs in treatment and care and particularly the expanding access to ART and OI treatment. Finally we will discuss the relevance of the experience in Cambodia for better understanding the role of older persons in the HIV/AIDS epidemics in other countries in the region and worldwide.

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APPENDIX A

Topics for interviews of parents with adult children who died of AIDS

1. Introduction

Background

2. Background info
    a. Respondent's background info
    b. Other people in the house
    c. Respondent's children
3. Characteristics of person who died of AIDS (PDA)-
    a. Personality, place of residence (before and during sickness), education, work, age, help to household, remittances or money to household, marital status, children

Caregiving and support for caregiving

4. Caregiving to PDA
    a. Who cared for PDA
    b. What kind of care, daily care, special care, blood and bandages
    c. Training or advice on caregiving
5. Knowledge and beliefs about HIV/AIDS and caregiving
    a. How to keep PDA healthy
    b. Concerns about caregiving to PDA
    c. Source of information (health clinic/hospital, NGO, TV, radio …)
6. ART and other modern medications
    a. Ever heard of ART
    b. PDA received ART, did you help administer it, did it help
    c. Use of other medications, did you help administer, did it help
7. Home-based care assistance- Who, what did they do, was it helpful
8. Support groups- Who went, how often, where, was it helpful
9. Treatment for PDA- Government clinic, hospital, other
    a. Why or why not used these services
    b. What kind of treatment, cost, was it helpful
10. Other assistance- NGO, wat/monks, community group, village health volunteer, other
    a. What kind of help, was it helpful, cost/payment
    b. Other assistance that was available but PDA didn't use- why not

Impacts

11. Financial impact
    a. Expenses for daily living, medications, doctor visits, funeral and ceremonies
    b. How did you get money- savings, extra work, selling assets or gold, borrow, family or community gave money
12. Community reaction
    a. Community members- positive and negative reactions
    b. Community leaders- positive and negative reactions
13. Physical health of caregiver- physical health problems related to caregiving
14. Emotional/mental health of caregiver
    a. Stress or depression symptoms
    b. Received any counseling or help from organization or individuals
15. PDA's family
    a. Spouse

b. Grandchildren- what kind of care does OP provide, who else helps provide care, community reaction to grandchildren, schooling

Interviewer observations – respondent's attitude and visible health, condition of house, household possessions, kitchen garden etc.