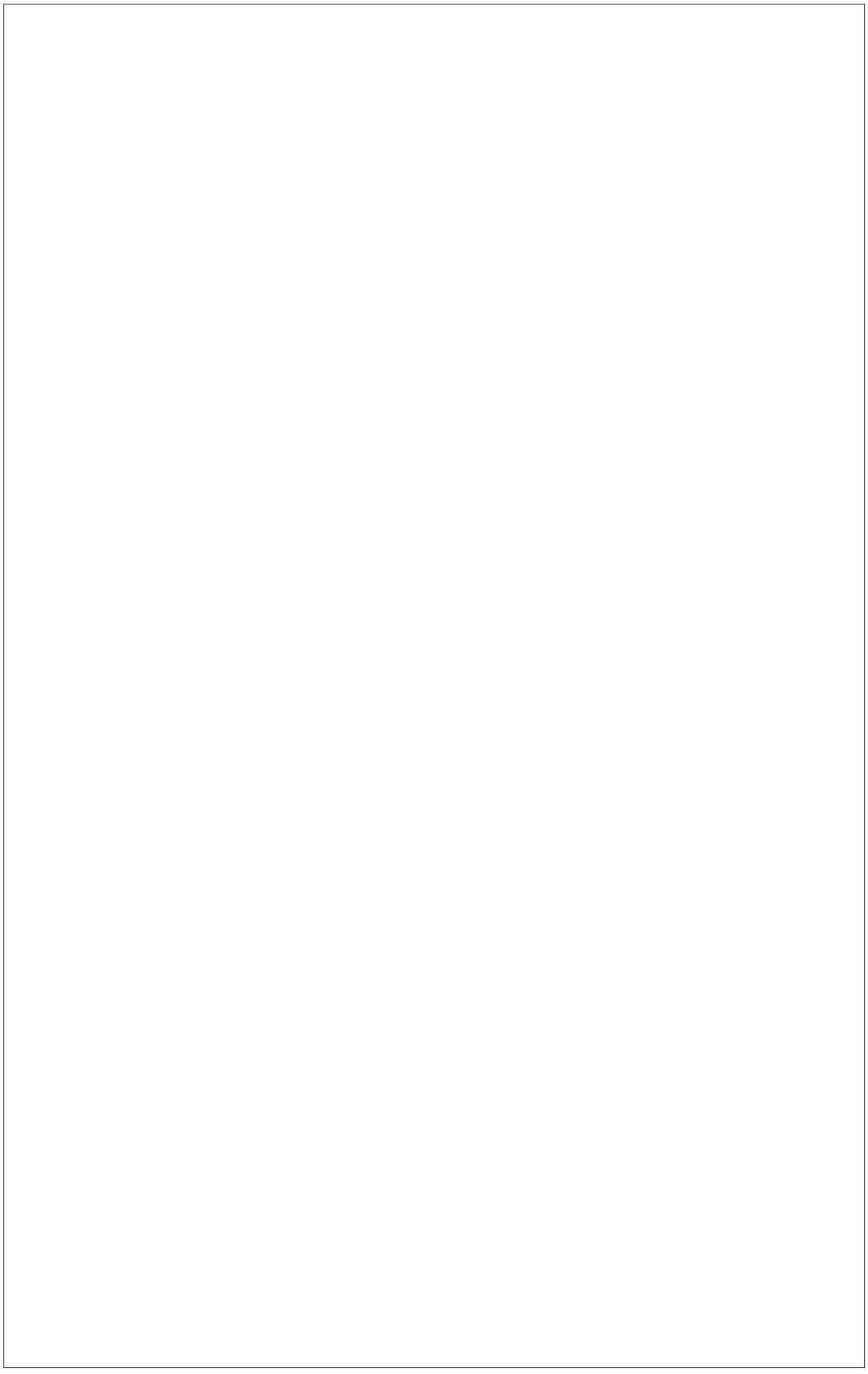
Older-age parents and the AIDS epidemic in Thailand

Changing impacts in the era of antiretroviral therapy



Older-age parents and the AIDS epidemic in Thailand

Changing impacts in the era of antiretroviral therapy

UNITED NATIONS
ESCAP
Economic and Social Commission for Asia and the Pacific

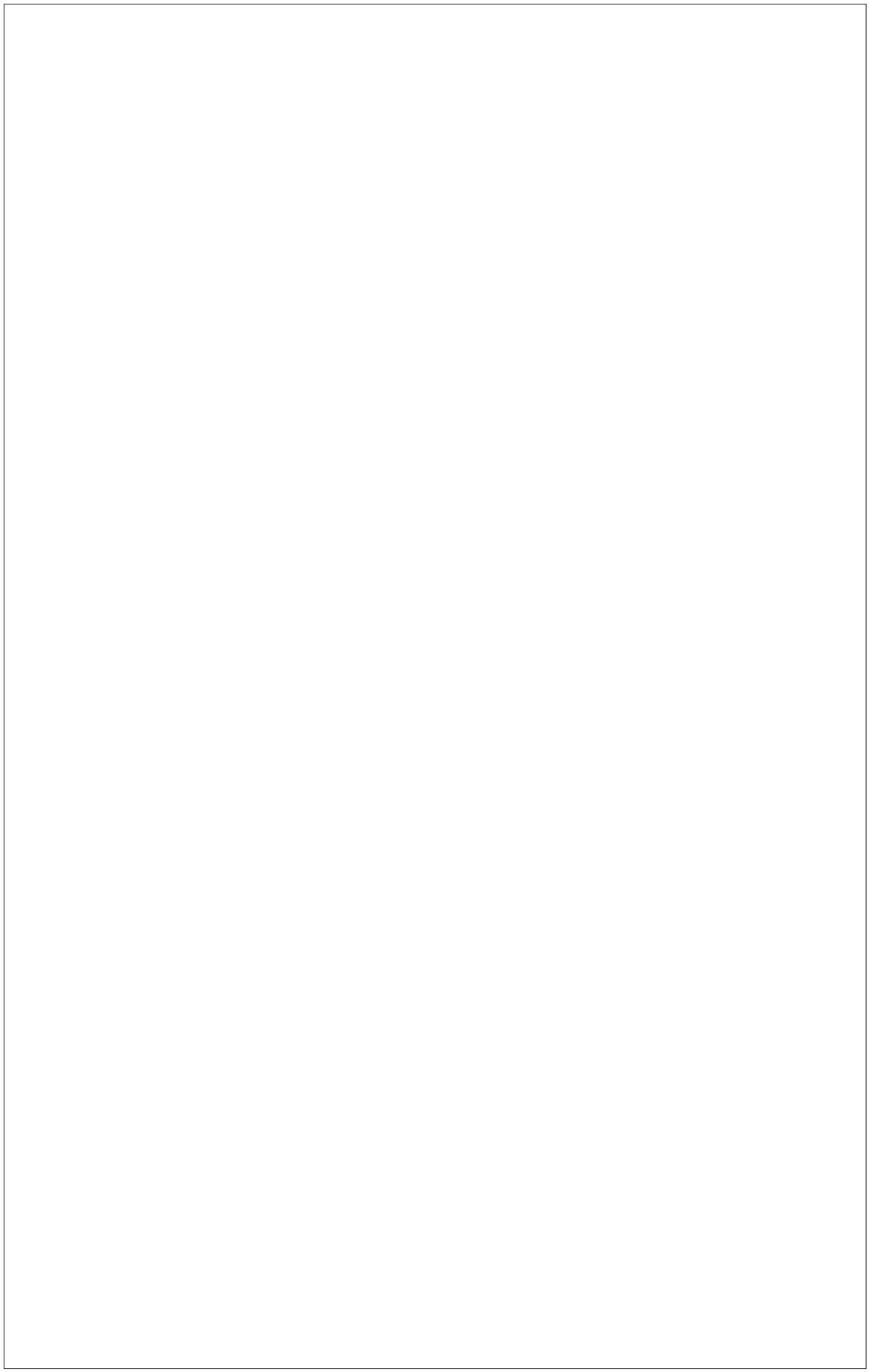
This report was prepared by John Knodel, Jiraporn Kespichayawattana, Chanpen Saengtienchai and Suvinee Wiwatwanich. The opinions, figures and estimates set forth in this publication are the responsibility of the authors, and should not necessarily be considered as reflecting the views or carrying the endorsement of the United Nations. This research was supported by a pilot subgrant from the National Institute on Aging (US) Grant P30 AG012846. The research was approved by the Institutional Review Boards at Chulalongkorn University and the University of Michigan. The authors would like to express their appreciation to Pornthip Khemngern for information on the Thai ART programme; Srachon Wungthan for information on PLHA groups in Thailand; Wiwat Peerapatanapokin for information relevant to the projections of the AIDS epidemic in Thailand; and Jerrold Huguet, Sayuri Cocco Okada and Marco Roncarati for their review of and comments on the draft publication.

PREFACE

As the number of older persons is set to double at an unprecedented rate in the ESCAP region over the next few decades, it is becoming increasingly important to engage and address the issue of older persons in development. In view of the impact of ageing in Asia and the Pacific, ESCAP has been working actively to build the capacity of its member States in their ageing readiness. At the 2002 Second World Assembly on Ageing, Governments came together to adopt the Madrid International Plan of Action on Ageing, 2002, which for the first time recognized the contribution and role of older persons in international development. ESCAP provided the forum to scale this framework down to the regional level through the Shanghai Implementation Strategy for the Madrid International Plan of Action on Ageing and Macao Plan of Action for Asia and the Pacific, which was adopted in 2003. One area that these international and regional frameworks of action on ageing have highlighted is the specific need for action to promote support systems for elderly caregivers of persons living with HIV/AIDS.

The purpose of this publication is to disseminate the findings of the report on "Older-age parents and the AIDS epidemic in Thailand: Changing impacts in the era of Antiretroviral Therapy" to assist policymakers addressing similar contextual environments to further understand the epidemic and its impact on elderly caregivers. The report represents one of the few research works on the impact of HIV and AIDS on the lives of persons living with HIV/AIDS and their families in the region. It serves to fill the gap in the dearth of research on the implications of the AIDS epidemic on older aged parents, in particular in the context of the increasing availability of antiretroviral therapy.

The Social Development Division of ESCAP has produced other publications to assist policymakers and further knowledge in the area of HIV/AIDS, ageing and related issues (for further information, please visit the ESCAP website http://www.unescap.org). This report helps to shed further understanding of the epidemic, the role of older parents in providing support for persons living with HIV/AIDS and intervening factors of this support. The findings will thus be of interest to policymakers, gerontologists and researchers working on issues of elderly caregivers and of HIV/AIDS in the region and beyond.



EXECUTIVE SUMMARY

Background and report objectives

Almost three decades into the worldwide HIV/AIDS epidemic, older persons remain marginal in the discourse of the international and national agencies charged with dealing with AIDS. Persons age 50 and older constitute a modest but growing share of the HIV worldwide caseload. Since most adults living with HIV/AIDS have one or both parents surviving, far greater numbers of older persons are affected through the illness and death of their adult sons and daughters.

Previous research on the impact of the AIDS epidemic on older persons has been quite limited. Nevertheless, the results that have emerged, including from Thailand, make clear that many experienced a range of adverse emotional, economic, and social consequences. Yet their needs have been largely ignored by programmes intended to mitigate the epidemic's impact. At the same time, older persons have contributed substantially to how societies cope with the epidemic, especially by providing personal care, emotional support and material assistance to their infected adult sons and daughters and foster care to their orphaned grandchildren. In recent years, access to antiretroviral therapy (ART) has been increasing rapidly in many low- and middle-income countries. As a result, HIV/AIDS is becoming a chronic but manageable condition rather than one leading to debilitating illness and certain near-term death. This has important implications for parents and other family members of persons living with HIV/AIDS (PLHA) and the contributions they make.

This report examines the situation in Thailand and focuses primarily on parents of adults on ART but also includes some comparisons with other family members. Thailand provides a particularly appropriate setting given the extensive progress made in the country towards universal access to ART and the large number of older persons involved. Estimates suggest that by 2010 about 150,000 Thai parents will have a surviving HIV infected adult child on ART. In addition, most older age Thais continue to co-reside with an adult child and at more advanced ages depend on adult children for their material support and personal care. Many other developing countries, including in Asia, share these features of familial support for older-age parents with Thailand. Thus the results and the recommendations stemming from the present study are likely to be relevant for many other settings where ART is now becoming widely accessible to PLHA.

Methods

The results presented are drawn primarily from two sources: an ART Recipient Survey in which 912 adults on ART completed a short self-administered questionnaire at 18 distribution sites in five provinces and Bangkok and 108 extensive face-to-face interviews with parents of adult children on ART from all four regions of the country (Parent Interviews). Although the ART Recipient Survey is not based on a probability sample, it covered a wide range of settings with respondents recruited both from provincial and community hospitals in each sample province and two large hospitals in Bangkok. Comparisons with the national caseload of adult ART patients indicate that the sample is similar in terms of its gender distribution and the sources of government insurance used. Although the Parents Interviews were largely limited to cases where parents lived in the same locality as their adult child on ART, and thus to those who are particularly likely to be involved, the results are at least relevant for this substantial subset of parents. Also, since core members of PLHA support groups assisted in the recruitment of cases, most interviewed parents lived in localities where such groups were active. Thus the reported role of PLHA support groups as reflected in the Parent Interviews may be more extensive than it would otherwise be if recruited respondents had also included parents in localities not covered by PLHA groups.

Improved health and its consequences for parents

In the Parent Interviews, respondents reported major improvement in overall health of their HIV infected sons and daughters and large declines in a whole range of symptoms following ART initiation. The average number of 21 potential symptoms commonly associated with HIV/AIDS that were experienced declined from 7.2 just prior to ART initiation to only 1.5 by the time of interview. This in turn was associated with major reductions in parental caregiving and assistance. For example, of 16 potential caregiving tasks, the average number of parents that reported doing so declined from 4.2 prior to