

Information, Education, and Communication Materials and Caring for People Living with HIV/AIDS

A partnership between PATH and FHI

July 2004

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The Final Narrative Report on Information, Education, and Communication Materials and Caring for People Living with HIV/AIDS is the result of a partnership between PATH and Family Health International (FHI) to bring attention to the lack of appropriate information, education and communication materials for people living with HIV/AIDS and their care providers. Funding for the project was provided by FHI, while PATH, in close collaboration with FHI, led the process of information gathering and report preparation.

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List of abbreviations

BCC	Behavior change communication
FHI	Family Health International
GTZ	Gesellschaft für Technische Zusammenarbeit
IEC	Information, education, and communication
IDU	Injection drug user
MDM	Medecins du Monde
NASB	National AIDS Standing Bureau
NGO	Nongovernmental organization
PLWHA	Person/people living with HIV/AIDS
SCF UK	Save the Children United Kingdom
SHAPC	STDs/HIV/AIDS Prevention Centre
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDCP	United Nations Drug Control Program
VICOMC Control	Vietnamese Community Mobilization Centre for HIV/AIDS
WHO	World Health Organization
UNICEF	United Nations Children Fund
VND	Vietnam Dong

Executive summary

Approximately 135,000 individuals in Vietnam are infected with HIV, and the number grows by roughly 10,000 each year. The needs of this country's burgeoning population of people living with HIV/AIDS (PLWHA) are rapidly increasing. To date, however, the vast majority of resources and projects sponsored by government, international, and multilateral agencies in Vietnam have focused almost exclusively on prevention and epidemiological studies. High-quality care is rarely available to PLWHA, because most services are provided by people with limited knowledge of HIV infection and AIDS and of the physical and psychological needs of PLWHA.

As a step toward redressing this problem, PATH, through a contract from Family Health International (FHI) and the IMPACT Project, carried out a qualitative assessment of the information, education, and communication (IEC) materials that are available on the subject of care and support of PLWHA. The assessment included a review of existing home-based care-giving activities and the roles that professional and nonprofessional caregivers (e.g., family members) play in addressing the day-to-day needs of PLWHA.

PATH staff and consultants interviewed more than 70 PLWHA from both rural and urban settings (Ha Noi, Hai Phong, and Quang Ninh) and consulted 11 international and local nongovernmental organizations (NGOs) about their experiences with such programs. In addition, 12 of the most commonly used IEC materials aimed at care and support of PLWHA were analyzed in depth. Separate open-ended qualitative research instruments were developed for use with the PLWHA and organizations consulted so that we could gauge the knowledge, attitudes, and practices of PLWHA with regard to HIV infection and AIDS while identifying the common health problems and health-seeking behaviors of this population. We also wanted to uncover the information gaps and risk behaviors that affect the well-being of PLWHA, to identify the services and IEC materials available to and used by PLWHA, and to determine what IEC resources were lacking.

The assessment process went according to plan, and field activities were completed without major problems in the data-gathering process. An initial summary of the information was produced in July 2002, and on 26 to 27 August 2002, a consultation workshop was held so that representatives from government organizations and NGOs could react to the results of the assessment.

The assessment uncovered a number of problems in the existing public services provided to PLWHA and significant weaknesses in self-care, as well as in the home care provided by families of PLWHA. This situation could be alleviated by improvements in the content and dissemination of the information supplied to PLWHA. To achieve this, given that the need is great today and will continue to grow in the coming years, a significant increase in resources for care and treatment programs may be required. But mobilizing more resources should not be the only focus. Linking IEC materials and outreach activities so that a more effective strategy for disseminating information is created, one in which ideas can be shared more successfully with caregivers, is a must.

The assessment also uncovered the extent to which national and international agencies must focus on reducing the social stigma associated with HIV infection and AIDS. The stress felt by PLWHA who become social outcasts after their HIV-positive status is known has clear and tangible effects on the health of these individuals. Such stigmatization is a burden for families, fractures communities, and generally impedes positive responses to the epidemic. Therefore, before significant changes can be made in Vietnam, the behaviors of policymakers, government leaders, and health officials—as well as PLWHA and caregivers—must be targeted, so that these groups will take a stand and provide the care that PLWHA need and deserve.

This report provides more detailed information about existing government and international responses to this problem, shares the responses of PLWHA to questions about a range of related issues, and comments in detail on the IEC resources that exist to support care for PLWHA.

I. Background

As of September 2002, 53,349 HIV people were reported to be positive, with 7,586 AIDS cases of whom 4,121 had died of AIDS in Vietnam. Almost 60% of HIV positive individuals were between 20 and 29 years of age, 21% were between 30 and 39 years of age, and the majority were men. The National AIDS Standing Bureau (NASB) predicted that there would be approximately 11,500 new AIDS cases and 11,000 deaths due to AIDS by the year 2005.

Large urban areas and select border provinces have seen dramatic increases in the number of HIV positive individuals and are now looking at the need to treat and care for people living with HIV. “Social evils” campaigns against drug users and sex workers have made it harder for PLWHA to get access to care, and community and family stigmatization of individuals with HIV often prevents them from receiving high-quality care at home or in health care facilities. Treatment with antiretroviral medications is virtually nonexistent, which heightens the need for improved home- and community-based care and treatment.

Government HIV interventions, such as mass media campaigns and epidemiological studies, have been implemented on a national scale. Few organizations, however, have focused on the care and treatment of PLWHA. Although there have been several efforts to develop IEC materials for people who provide care to PLWHA, there has been little coordination between organizations or involvement of PLWHA. Few materials are available that support care and treatment activities.

The purpose of this project was for FHI and PATH to initiate a process that would improve the types and delivery of IEC materials available for care and treatment of PLWHA. The project focused on identifying the needs of PLWHA as a step toward informing future materials development and activity implementation. The major activities carried out as part of this work were as follows:

1. To define the needs of PLWHA and their families, as well as of caregivers, in urban and rural areas affected by HIV (Ha Noi, Hai Phong, and Quang Ninh).
2. To identify existing home and community care activities in Vietnam and to determine what materials were available that had been developed for home care.
3. To conduct a community-based consultation with international NGOs, international organizations, PLWHA, community-based caretakers, peers, and informal groups involved in home care for PLWHA.
4. To summarize the results of the consultation in the context of strategy and program development.

Field assessment methodology

PATH assessed self-care, home care, and IEC materials for PLWHA and their caregivers in the cities of Ha Noi and Hai Phong, as well as in more rural areas in Quang Ninh province, in August 2002. (See appendices for a list of the organizations and groups that were visited) In preparation for this assessment, and as part of our follow up, PATH interviewed a number of international and local organizations. PATH also met with 20 PLWHA—5 from Quang Ninh, 5 from Hai Phong, and 10

from Ha Noi. Fifteen caregivers, including health staff, were interviewed, 4 of whom lived in Quang Ninh, 6 of whom lived in Hai Phong, and 5 of whom lived in Ha Noi. Two open-ended questionnaires were developed, one for use with organizations and groups working with PLWHA and one for use with PLWHA. The results of that review follow.

II. Review of care and support for PLWHA and their caregivers

A. Government responses

Historically, the Vietnamese government has had very little investment in care, support, and treatment of PLWHA. Virtually no resources were available during the early stages of the country's HIV/AIDS epidemic (1990 to 1995). In the period from 1995 to 1999, awareness of the needs of PLWHA gradually increased, and programs for counseling and care for PLWHA and some administration of antiretroviral drugs were started. In national terms, however, the response was hardly noticeable. It was not until the year 2000—after the Ministry of Health of Vietnam issued Decision No. 1451/2000/QĐ-BYT (8 May 2000)—that a clear set of policies was put in place to direct and guide public-sector HIV infection and AIDS diagnosis and treatment. This directive provided some hope that new initiatives might be developed for care, support, and treatment of PLWHA.

The story of Vietnam's HIV/AIDS programs is representative of trends in the region. There was a certain degree of denial in the early stages of the epidemic, followed by a nationwide mobilization of government agencies and related agencies, which were brought into something called the National AIDS Committee. Through the efforts of the Ministry of Health; the Ministry of Planning and Investment; the Ministry of Labor, Invalids, and Social Affairs; the Ministry of Education and Training; the Fatherland Front; the Vietnam Youth Union; the Vietnam Women's Union; the Vietnam Red Cross; and mass media outlets, there has been a huge jump in the proportion of people who have improved knowledge about HIV infection and AIDS. HIV/AIDS interventions, however, have been less successful in effecting behavioral change among high-risk groups and in improving the response to individuals who are already infected by the disease. National budget allocations for treatment of HIV infection and AIDS, for instance, represent only a small fraction of the National AIDS Program funding.

There are many other types of care and support institutions and centers in Vietnam that help link PLWHA, high-risk groups, the general population, and marginalized people to government programs and health care services. These include counseling café, voluntary HIV counseling and testing sites managed by NGOs, and condom and IEC café.

1. QCT (management, care, and counseling) model

In 1996, the AIDS division of the Ministry of Health launched a pilot model of community-based HIV/AIDS care and support in two provinces (An Giang and Thanh Hoa) and one city (Ho Chi Minh City). This model was called "QCT," which stands for management, care, and counseling in Vietnamese. The QCT model consists of four components: clinical management, nursing care, counseling, and social supports. The purpose of the model was to create a network of HIV/AIDS care and counseling

systems in areas where HIV infection and AIDS were endemic, as well as to increase the capacities and competencies of provincial personnel to cope with the HIV/AIDS endemic. This model worked with local organizations at the community level, such as the Women's Union, the Youth Union, and the Vietnam Red Cross. Since then, the model has been expanded to include 17 new provinces. The results of a cross-sectional survey showed that QCT had significant positive effects, particularly on behavior change, through activities directed at high-risk groups and through mobilization of families to provide support for PLWHA. However, there were some weaknesses, including limited use of QCT resources by PLWHA and lack of coordination, capacity to respond to diverse situations, care and support provision, peer support and network, and involvement of NGOs.

2. Friend-Help-Friend Club model

The first Friend-Help-Friend Club model was established in 1995 by the Ho Chi Minh City AIDS Committee; since then, the model has been expanded to other provinces. This model was developed to provide a peer network for PLWHA and opportunities for involvement in prevention and care activities. Activities at these clubs consist of monthly meetings among PLWHA and families, counseling, spiritual support, and nursing care, with mobilization of families, volunteers, and health personnel and mass organizations such as the Vietnam Women Union, and the Vietnam Youth Union. According to the Ministry of Health, the Friend-to-Friend Club model demonstrates the importance of involving PLWHA and its effectiveness to accelerate access to the care delivery points.

3. Training manuals

The NASB, with funding from Gesellschaft für Technische Zusammenarbeit (GTZ), has prepared a training manual, *Home Care for People Living with HIV/AIDS*, and a booklet on care and support for educators and injection drug user (IDU) peer counselors. The manual was developed for a three-day training event for the Friend-Help-Friend Club program and was based on a World Health Organization (WHO) home-care book that was edited by the NASB for use in Quang Ninh and Ha Noi. PLWHA were not involved in the editing or development of the manual. Two training events have been conducted in Quang Ninh using the manual, but no feedback is available.

The NASB, with funding from the United Nations Drug Control Programme (UNDCP), has developed the *AIDS Prevention and Control Manual* for peer educators, and the Ho Chi Minh City AIDS Committee has developed books, the *Taking Care of HIV/AIDS Infected People at Home*, *Taking Care of Your Loved Ones at Home*, and *Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care*.

B. International initiatives

The leading players in the international community have been World Vision International, Medecins du Monde (MDM)/United Nations Children Funds (UNICEF), and NASB/GTZ, which have made notable efforts in developing programs and materials specific to the care and support of PLWHA. Family Health International, UNICEF, and the Vietnam Red Cross are also playing a role in care and

support activities. CARE International mentions care and support for PLWHA as part of a project for confronting AIDS in the workplace. Other organizations, such as Save the Children United Kingdom (SCF UK), WHO, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) are interested in developing programs and IEC materials in care and support but have not been as active as others. The following provides some description of the activities of these organizations.

1. World Vision International

World Vision International worked with the Le Chan district AIDS Committee (in Hai Phong City) from June 2000 to August 2002 to implement a project entitled “Capacity Building for HIV/AIDS Care and Support in Mekong Region.” The project expanded from Vietnam and Myanmar to China and Laos in 2003. The project includes three main components: care and support, capacity building, and a toolkit for home-based care.

The care and support program includes health status checks, a home medicine box with necessary supplies, training health care staff to treat opportunistic infections, and providing a quick test for HIV, medical supplies, and medicine to health care facilities. The program improves emotional support resources for PLWHA by offering training courses for social workers; developing morning exercise programs, sporting competitions and support groups (with monthly meetings); improving communications within communities; and providing home visits and loans for PLWHA.

To build new capacities for care and support of PLWHA, a working group of health staff, social workers, community members, PLWHA, and family members was assembled. This group provides training and works with the community to plan care and support efforts.

The toolkit, which was introduced in August 2002, is entitled *Home-Based Care and Support for People Living with HIV/AIDS*. It is in two volumes. The first volume is used by PLWHA, relatives of PLWHA, and other caregivers. The second volume is aimed at health workers, social workers, and caregivers and at community workers who manage care and support systems. The toolkit is designed to be disseminated to community centers for reading at the centers, rather than to individual PLWHA. In addition to the toolkit, World Vision International developed two small booklets for dissemination to PLWHA. *When We Are Together* includes information about daily care and treatment of opportunistic infections; practical information about making sterilizing solutions, oral rehydration salts, etc.; use of traditional herbal medicines; and methods for reducing discrimination. *A Green Candle* is an original work based on the life of an HIV-positive young man in Hai Phong. It is designed for general dissemination and is intended to show how PLWHA can improve their quality of life and reduce discrimination they encounter.

2. MDM

MDM developed a training manual entitled *Taking Care of Your Loved Ones at Home: A Manual for AIDS Home Care* and a corresponding training curriculum for health workers (*Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care*) in 1999. The Ho Chi Minh City AIDS

Committee approved the 1999 version of this manual and printed 1,000 copies. MDM planned to support the Friend-Help-Friend Club network by making training available and providing honoraria for members of this network in district number 6 in Ho Chi Minh City. The organization also planned to provide home-care intervention after October 2002.

3. UNICEF

UNICEF has adapted a manual to accompany their video *With Hope and Help* as part of a regional initiative in care and support for PLWHA. The video was filmed in early 2002. UNICEF conducted a three-day training event in Ha Noi to test two translated manuals entitled *With Hope and Help*, one for communities, the other for PLWHA. Australian Red Cross, SCF UK, FHI, Vietnam Red Cross, Vietnam Women's Union, and Vietnam Youth Union staff attended. UNICEF worked with the Ministry of Health Center for Health Education to adapt the manual to the Vietnamese context. Although UNICEF plans several national programs, it intends to focus its HIV/AIDS activities, particularly those involving mother-to-child transmission prevention, on five high-prevalence provinces namely Ho Chi Minh City, Quang Ninh, Hai Phong, An Giang, and Lang Son.

4. Vietnam Red Cross

With support from the Australian Red Cross, the Vietnam Red Cross was involved in developing a manual on care and support for Vietnam Red Cross volunteers and staff who work with PLWHA.

5. CARE

CARE has focused mainly on preventing the spread of HIV. However, their project for confronting AIDS in the workplace touches on care and support issues. They have developed a number of booklets, but none that are specific to care and support. "Confronting AIDS in the Workplace", a three-year project that began in November 2000, includes an orientation workshop, a policy-development workshop, and an annual operational plan workshop for company managers and middle managers. The project goal is to reduce the spread of HIV in Quang Ninh. Twenty coal companies have participated. The project trains company-employee IEC officers at a rate of 1 IEC officer for every 100 employees and has trained 600 officers to benefit 60,000 employees. Coal company employees have been targeted because many work away from home and are separated from their families for long periods, making them vulnerable to high-risk behaviors such as using injection drugs and frequenting female sex workers.

A smaller part of the project included the establishment of eight support clubs organized through the Vietnam Women's Union in Ha Long and Cam Pha districts, with the objective of providing psychological, social, and physical support to PLWHA. Anyone concerned about HIV infection can join the clubs, including PLWHA, IDUs, female sex workers, and women whose husbands or children are HIV positive or involved in risky behavior. The support clubs were in the beginning stages in late 2002, and staff had not yet focused on producing IEC materials that describe the clubs or have information about caring for PLWHA. IEC materials, particularly

those including information about how HIV is transmitted and methods of avoiding transmission, likely will be solicited from the Ministry of Health.

6. WHO

WHO is interested in care and support issues and will be developing IEC materials, with a focus on reducing the stigma attached to HIV infection and discrimination against PLWHA, for World AIDS Day. They are working with DKT on prevention of infection and social marketing of condoms, particularly among high-risk groups, such as IDUs and female sex workers.

7. SCF UK

SCF UK is doing work on prevention of infection and youth education. As part of these programs, the organization encourages PLWHA to speak out to help eliminate discrimination, but SCF UK has not developed any IEC materials related to care and support. The need for resource materials that address care and support is recognized.

8. PATH

PATH is currently involved in prevention, advocacy, and stigma-related HIV work and is in the process of developing an HIV/AIDS counseling, care, and treatment strategy. Lessons learned by PATH in other countries are being included in PATH's Vietnam work. The *Stay Fit—Feel Good* manual was developed by PATH on the basis of findings from a project entitled "Community-Level Case Management of Infection in Settings with a High Prevalence of HIV/AIDS," which was carried out in 2001 in Thailand. The manual was edited and tested in Vietnamese settings. The project's objectives were:

- To develop practical care guidelines for community caregivers.
- To build the capacities of community caregivers for care and support of PLWHA.
- To determine whether and how much care practices had improved among community caregivers.
- To strengthen community care networks.
- To link home care with health facilities and social support centers.
- To assess the impact of community care for PLWHA.

The project evaluation demonstrated that *Stay Fit—Feel Good*, in combination with associated interventions, significantly improved community care capacities.

9. FHI

The collaborative consultation on the materials needs of PLWHA and caretakers described here was initiated by FHI out of concern over the uncoordinated and often duplicative development of materials to support home-care needs in Vietnam. FHI is working with a number of populations at high risk of HIV infection, including male and female IDUs. This activity was prompted by the desire of FHI to identify perceived needs of user audiences and to evaluate the effectiveness of existing materials, so that appropriate materials could be adapted or adopted for use in FHI projects.

FHI has developed a number of audience-specific materials that do not already exist in Vietnam. These include a pictorial/text booklet adapted from an earlier WHO Global Programme on AIDS revision of *Living with AIDS in the Community*, which was originally developed by the AIDS Support Organization of Uganda. In collaboration with GTZ, FHI has developed materials for IDUs that specifically address concerns about prevention of infection (*IDU and HIV*) and about living with HIV infection and AIDS (*IDU and AIDS*) and that provide information that will help families and communities understand addiction, detoxification, and the requirements of rehabilitation. Both materials have undergone intensive pretesting and are being developed in consultation with the users. These materials may be reproduced by anyone who wishes to use them.

C. Local initiatives

1. Vietnamese Community Mobilization Center for HIV/AIDS Control (VICOMC)

VICOMC works with the NASB to develop manuals that address HIV infection and AIDS issues and advises World Vision International in the development of their toolkit. VICOMC has also worked on a manual for counselors (*Improving the Capacity of AIDS Counseling*) and a prevention manual for social workers at city and district level centers for drug treatment.

2. STDs/HIV/AIDS Prevention Center (SHAPC)

The SHAPC distributes the NASB document *With Hope and Support* during training courses at various project sites.

D. Care and support needs expressed by PLWHA and their caregivers

1. Self-care

PLWHA, particularly those who have not developed opportunistic infections or chronic illnesses, desire to be independent. They can and want to take care of themselves. They wish to live normal lives; they are able to perform daily activities independently and make their own decisions based on their interests and capacities. They are capable of taking care of their own health and attending to personal hygiene.

"Presently I care for myself. Self-care is better than depending on others."
—PLWHA, during consultative meeting

"Generally speaking, I am still concerned about my health. I must drink and eat balanced meals. I must eat good, clean food and exercise as others."
—Young man living with HIV in Ha Noi

"The doctor did not inform me about my health situation, but told my relatives. I personally have the right to make a decision on my own, particularly about my health, not my wife or elder brother and sister."
—Young man living with AIDS in Hai Phong

Injury prevention is seriously considered both in the home and work setting. At home, PLWHA take careful precautions not to infect others, such as keeping their personal

items (blades and toothbrushes) separate and not coming into contact with others when they are scratched or have open wounds and sores. PLWHA who work in jobs that put them at higher risk for injuries, such as construction workers, cooks, and security guards, are very aware of injury prevention methods.

"When I am scratched, I avoid washing vegetables, bowls, or anything related to food."

—*Young man living with HIV in Ha Noi*

PLWHA are continually concerned about the uncertainty of their health. They are always worried about getting sick or acquiring opportunistic infections. PLWHA want more information about the progression and different stages of HIV infection, AIDS, and opportunistic infections. Limited knowledge about the different stages of HIV infection and AIDS contributes to confusion, anxiousness, and constant concern about the future. PLWHA become very sensitive to any signs of sickness, such as chills, fatigue, and runny nose, and are worried that they will die soon.

"Today, I got a little headache and fever. So I think that my disease will develop into AIDS, and I will die tomorrow."

—*Woman with HIV in Hai Phong*

"I always live in fear and concern. Every time there are symptoms of an illness, then I am worried because I don't know if it is due to the disease."

—*PLWHA, during consultative meeting*

In-depth interviews also show that PLWHA resume productive and social lives. A young man living with HIV continues to focus on his study at university; another young PLWHA cares for himself by washing his own clothes and cooking for his family. Socializing and entertaining continue to be important aspects of the lives of PLWHA. They still go frequently to cafes and nightclubs with close friends. Many spend their free time reading newspapers or magazines or watching TV. The media, which are easily accessible and enjoyable, are the most common forms of entertainment for PLWHA.

Many individuals who are HIV positive express the desire to be economically self-sufficient through working. Most are eager to find jobs that contribute to their own and their family's economic stability. PLWHA want others to know that they are helpful to their families and are still needed within their families.

"My family raises chickens and I take care of them. I will also work if there is a job. I am a builder. I am now staying at home because my mother is currently busy."

—*Young man living with HIV in Ha Noi*

"He a young man living with HIV] earned 500,000 VND and he gave us 500,000 VND. I received his money and gave him 50,000 VND back for alcohol."

—*Father of young man living with HIV in Ha Noi*

2. Home care

The majority of caregivers interviewed in this study were middle age or older. Most retired parents who are caregivers of PLWHA do not have enough money to take care of their children. Therefore, they depend on financial support from other siblings and relatives. Despite this, some parents are reluctant or do not want to ask for support from those who are not immediate family members because of concern about neighbors or other people becoming aware of their situation.

"Regarding our budget, we do not have enough money. We need help from his uncles. I don't have my pension now because I was retired a long time ago. If anything happens, his aunts and uncles will solve the problem."

—*Father of a young man living with AIDS in Ha Noi*

Family members who care for PLWHA infecting drug find it hard to continue giving care. Many such families have lost considerable amounts of money to injection drug use and have faced the additional economic losses associated with costs such as the cost of placing an IDU family member in a rehabilitation center. When former IDUs develop AIDS, their families often lack the financial resources, knowledge, skills, and energy to help them.

"Due to the pressures of caring for a close relative who was a former injection drug user, my family is very tired. When this person developed an AIDS-related illness, my family did not have the energy and mental drive to provide care anymore."

—*Caregiver, during consultative meeting*

3. Nutrition

The family's economic situation, knowledge, and practices affect the nutritional status of the PLWHA. Lack of knowledge about appropriate amounts and types of nutrients required for PLWHA, specifically for those who have opportunistic infections, prevents many PLWHA from receiving adequate nutrition. In addition, many families do not have enough time to prepare meals according to recommended procedures or regimens suggested in IEC materials.

"We try to provide him with good meals and enough fruit, that's all. We cannot do more because it depends on our budget."

—*Father of a PLWHA in Quang Ninh*

"We do not want to know how many calories are in each type of food. We are concerned only about the simple cooking processes in order to have enough food and drink. Let's think about how many hours each day we have to earn money or do other daily work."

—*Parents of a PLWHA*

4. Avoiding stigmatization and discrimination and their effects on mental health

PLWHA and their caregivers experience shame, embarrassment, alienation, and isolation as a result of stigmatization and discrimination. Lack of community education about HIV infection and AIDS and of information about the rights of PLWHA is a primary contributing factor. Many PLWHA perceive that they will be discriminated against if others know that they are infected with HIV. This is

especially evident in health care settings where many PLWHA and caregivers have been refused treatment or have been stigmatized. PLWHA worry that others will not interact with them or will treat them differently. Consequently, some self-isolate or distance themselves from family, friends, and community members. During the consultative group meeting, PLWHA reiterated this sentiment.

"I wish people would not treat me differently. Right now I distance myself from others, whereas before I was not like this. This is because if people know about my condition, they will look at me differently and they will not want to be close to me or interact with me."

—PLWHA, during consultative meeting

"I have knowledge about HIV/AIDS. Although I know that HIV cannot be transmitted through hugging, I still cannot be close to my children."

—PLWHA, during consultative meeting

"Even a small action such as refusing to share a cigarette makes me feel I am treated differently."

—PLWHA, during consultative meeting

According to PLWHA and caregivers, the use of the term "PLWHA" and the medical classification "HIV/AIDS" reinforce negative stereotypes of PLWHA. Feedback from the consultative group indicated that a distinction should be made between people who are infected with HIV and those who care for and share living space with HIV-infected people, two groups that are sometimes both described by "PLWHA." The participants concluded that a more humane term and definition need to be used—one said, for example, "PLWHA are people who are normal. They are only different because they have HIV, therefore, they should not be distinguished." In addition, the father of a young man living with HIV stated that HIV/AIDS should be categorized as a chronic, terminal illness, similar to cancer or hepatitis.

Stigmatization also increases vulnerability and the risk of HIV transmission, because the social stigma attached to HIV infection makes it more difficult to inform sex partners about HIV positivity. Although some people inform their partners about their HIV-positive status, others do not. Because of the rejection, discrimination, and differentiation of treatment that are experienced by HIV-positive individuals, many people hesitate to reveal that they are infected with HIV. One family allowed their son to marry but did not inform their new daughter-in-law of the son's status. The daughter-in-law acquired HIV from her husband and became a widow.

PLWHA who were interviewed in this study reported that they felt despondent, lonely, abandoned, and alienated. Many of these feelings are due to stigmatization and discrimination. Acceptance and emotional support, particularly from family members, friends, and relatives, are important. Some PLWHA are abandoned by their families and as a result lose a primary source of care and social support. Many people express a need for love, closeness, attention, and most importantly, to be treated in the same way as those who are not infected with HIV. PLWHA often do not receive comforting words or actions during care. They would like to hear words of encouragement and to be hugged, stroked, and have their hands held.

"I wish to hear comforting words from the doctor and people close to me, especially when they pay a bit more attention to me."

—*PLWHA, during consultative meeting*

"In a number of families, there is already a distinction such as not sharing face towels. Therefore, love and closeness, as well as not treating infected people differently, are what they want."

—*PLWHA, during consultative meeting*

"If I have support from others, I can make the effort. I often feel self-pity. If others pay attention to me, I am glad."

—*Young man living with HIV in Ha Noi*

PLWHA wish to communicate with others who understand and sympathize with them about their thoughts, feelings, and experiences. In Hai Phong, respondents stated that they did not have a youth center where they could get more information about HIV infection and AIDS or interact with other peers. One PLWHA said that there was nobody in whom she could confide or to whom she could talk, because she felt her experiences and feelings were different from those of her friends. Some PLWHA don't make an effort to communicate and interact, because they feel unable to talk about their situation with others. One recommendation from PLWHA who attended the consultative meeting was to provide HIV/AIDS information to community members, to help more people understand not only the virus but also the needs and experiences of PLWHA. This will help to increase awareness and change perceptions; currently, there is limited interest in knowing more about the disease.

People who give care to PLWHA react and cope differently with the situation. In some families, a sense of fatalism contributes to the acceptance of the disease, and family members all contribute to the care and support of PLWHA. In others, family members experience anger, shame, embarrassment, alienation, and isolation. Like PLWHA, many caregivers do not want to let others know that a family member is infected with HIV. They know others do not fully understand the virus or the situation and, therefore, cannot empathize with the family. Caregivers also fear that they will be perceived or treated differently if others become aware that they live with or care for a PLWHA. In some cases, even family members who live in the same house are not informed. Many caregivers feel a great deal of stress, because they are unable to communicate their difficulties to others.

"When I found out my son was HIV positive, I wished he would die of a drug overdose, not because of HIV/AIDS. [The son was an IDU and was infected through sharing of needles]. Living with a person with HIV/AIDS makes other people look at me strangely. Many times I want to talk to my close friends to help me reduce my burden, but I cannot. It makes me more worried."

—*Mother of a PLWHA*

"If the others do not have knowledge about HIV/AIDS, they cannot help us. They may make it more difficult for my son to cope."

—*Father of young a man living with AIDS in Ha Noi*

All of the caregivers who were interviewed wanted to be able to discuss their situation in a supportive environment. Many female participants in the consultation were grateful for the chance to communicate. It provided them with an outlet for talking about their experiences, feelings, and concerns, which made their situation easier to cope with.

5. Treatment of opportunistic infections

Common opportunistic infections among the PLWHA who were interviewed are tuberculosis, pneumonia, fungal diseases, and skin diseases. Several care interventions have been effective in decreasing the spread of infectious diseases that are common among PLWHA. These include drug treatments, such as cotrimoxazole prophylaxis for specific bacterial infections (e.g., bacterial pneumonia and diarrhea) and preventive therapy with isoniazid for tuberculosis. Most opportunistic infections require treatment and follow-up in a health care setting.

PLWHA and their caregivers often lack awareness of appropriate skills and knowledge with regard to drug therapy. People who are HIV positive receive a variety of drugs for treatment of HIV infection and prevention of opportunistic infections. However, education, communication, and counseling through which patients become better informed about their options are needed in addition to appropriate medical treatment. Patients are particularly interested in information about different kinds of interventions for treatment and care that will improve the body's capacity to fight opportunistic infections. Information comes from mass media, health care staff, pharmacists, training for giving care to PLWHA, and older or more experienced PLWHA. A young man living with HIV in Ha Noi said, "I saw instructions on using oral rehydration salts to treat diarrhea from television, I tried to use it and it helped me to overcome the diarrhea."

Information about and access to effective drug treatments are limited. Most of the information about drug treatments for HIV infection and AIDS in Vietnam that is found in magazines and newspapers is scattered and not comprehensive. Moreover, there is a plethora of newspaper stories and advertisements claiming that certain medications and treatments can cure HIV infection and AIDS or describing substitute drugs that are cheaper than those produced overseas.

Generally, medication that is prescribed or recommended by doctors is meant to increase the energy levels of PLWHA and to treat opportunistic infections. Respondents stated that health care providers would prescribe or recommend a medication but did not provide further explanations or information. Many PLWHA and their families spent a large proportion of the family income on recommended or prescribed drugs, only to find that the medications are ineffective and expensive. For example, a bottle of Vilec costs approximately 850,000 VND, and multivitamins cost 35,000 VND for 10 tablets. Moreover, many people do not complete prescribed regimens, because they experience side effects that make them feel worse or result in a loss of appetite, fatigue, and nausea.

Herbal medicine is also often used to strengthen the energy levels of PLWHA and to increase their capacity to fight infections and stay healthy. Herbal medicines such as Chinese mushrooms and bile taken from a bear's gallbladder are commonly taken but are often abandoned because of their ineffectiveness and cost.

6. Treatment with antiretroviral drugs

Effective antiretroviral drugs for treatment of HIV infection and the required management services remain expensive and inaccessible to most families in Vietnam. Access to appropriate treatment depends on the family's economic situation and on service availability. Effective drugs are imported and extremely costly—out of range for a typical Vietnamese family. Although antiretroviral drugs are provided through government programs, none of the interviewees included in this study had been able to get access to such treatment.

"Whenever I hear about medicines, I try to borrow money to buy them."
—*Woman living with AIDS in Hai Phong*

"I know he is infected, so what makes us worried most is to have enough money to buy drugs [for treatment] for him. I don't worry about anything else."
—*Father of a PLWHA*

Caregivers of PLWHA normally contact health providers for information about free medication for treatment of HIV infection and AIDS, and where and how to access drugs. Most families express a need for strong support from government, access to subsidized or low-cost treatment, and quality comprehensive care.

"I think the government should support HIV-positive people by giving them a sum of money every month. We hope that the government pays attention not only to detoxification of drug users, but also provides money and medicine whenever we have difficulty in buying medicine. The government should share this cost with us."
—*Parent of a man living with HIV who is a former drug user*

"I think the government should have drugs to help him maintain his current status."
—*Parent of a PLWHA*

7. Detoxification and rehabilitation of IDUs

The families of PLWHA who are or have been IDUs stress the importance of finding ways to prevent relapses into drug use. The families know that continued recreational drug use further weakens the compromised immune systems of PLWHA. More importantly, recurrent injection drug use and needle sharing often result in chronic infection with other pathogens, such as hepatitis B and C virus or other strains of HIV. As a result, effective community-based rehabilitation programs need to be developed to keep PLWHA who were former IDUs from relapsing into drug use and to help those who continue using drugs to overcome addiction. Currently, community-based rehabilitation programs, including drug-substitution programs, are not available in Vietnam.

8. Reproductive and sexual health

PLWHA have reproductive health and sexual needs. Some express a desire to have children and want more information about preventing the transmission of HIV to their

partners and to newborns. PLWHA also have sexual desires. One young man living with HIV still engages in sexual relationships with multiple partners. This study found that some PLWHA used condoms to protect their partners, but others did not. A district health staff reported that 35 percent of PLWHA who were identified in her district used condoms properly. Some abstain from sexual activity after discovering that they are infected with HIV, either because they are afraid of transmitting the disease to others or because they don't have the energy to engage in sexual intercourse.

9. Women's needs

Women assume a heavier workload in their families. They have responsibilities as mothers spouses, and/or workers, and in some cases, they are also living with HIV or AIDS. Women generally put their families' well-being before their own and neglect to take care of themselves. They are usually the last to receive care, and, as a result, their health suffers. The needs of this group should be explored further. The following quote illustrates:

"My husband has full-blown AIDS. I have recently found out that my three-year-old son and I are both HIV positive. I have to take care of them and myself. My husband continues to use heroin twice a day and he still looks excited after using drugs. But I am always tired. I do not know if I have any chance to enjoy life like him."

—30-year-old woman living with HIV in Hai Phong

Information about how to manage the symptoms of AIDS-related problems that are common among women is needed. This is particularly important because currently, as a result of the high percentage of IDUs among men needing care, there is a tendency to overlook the specific health care needs of women.

10. Health care services

Government health care services and government-supported programs are underused by PLWHA and their caregivers. Unfamiliarity with government health care services, discrimination, unfriendly health care workers, inadequate health care services, and lack of money deter PLWHA and caregivers from using the health care services available to them. Moreover, some government care and support programs are inaccessible (depending on the location), and many people are not aware of those programs.

Failure to have used health care services before diagnosis of HIV infection or AIDS often is associated with delay in seeking health care services after diagnosis. In general, PLWHA are unlikely to have used health care services before they were diagnosed with HIV infection. One PLWHA stated that he had not been to a hospital in 20 years and that he still has not been to the hospital since becoming aware that he is infected with HIV. He prefers to stay at home for self-care, rather than receiving care from health providers or volunteers from the Vietnam Women's Union or Vietnam Red Cross. He also voiced a need to assert his independence by caring for himself: "I am young. I should take care of myself. Support from others is unnecessary to me. I will suffer the illness on my own." Others only seek health care when they cannot stay at home to get treatment or when severe symptoms arise, as in

the case of a young man who drank too much and developed a fever, body pains, and burning. He decided to go to the hospital for the first time since he had been diagnosed with HIV.

PLWHA and their caregivers experience many barriers when they seek health care services. Discrimination is often cited; some health care providers refuse to provide care for patients with HIV infection or AIDS. Some patients are turned away. Others have to wait for a long time before they receive care. Some caregivers do not inform health care staff of their child's HIV status, because they fear the patient will be refused or will be treated poorly. PLWHA are uncomfortable about their situation and prefer to receive care in a group setting in which they are among peers and can receive support and enjoy solidarity.

"I don't dare to ask too much. The difficulty is when I seek treatment at hospitals, as doctors will refuse to treat me if they know I am HIV positive. All the doctors will shake their heads, they do not want to treat me although they are common illnesses such as a headache or runny nose."

—*PLWHA, during consultative meeting*

"I think they will treat me differently. I know from a newspaper report that once doctors know you are a PLWHA, they will keep away from you. I really think they will treat me differently, not like non-HIV patients."

—*Young man living with HIV in Ha Noi*

"I brought him to the hospital when he had pneumonia. There, they didn't know that he is HIV positive, so there was no distinction."

—*Parents of young man living with HIV in Ha Noi*

Health care providers' limited knowledge and skills with regard to appropriate care and support of PLWHA also deter many families from seeking health care services. The families know the health care providers do not have in-depth knowledge that would enable them to provide adequate care and support for PLWHA, as well as to treat patients with respect and dignity. In addition, some families do not welcome home visits and counseling from volunteers who belong to local organizations such as the Vietnam Red Cross, the Vietnam Women's Union, or the Vietnam Youth Union. Caregivers are aware that these volunteers do not have sufficient knowledge and skills to provide care. Some caregivers acknowledge that health care providers and volunteers are not interested in or motivated to learn information that would help improve care and support of PLWHA.

"We would not worry if their knowledge about the disease was good, but most people do not sympathize with him once they know that he is HIV infected. They will keep away from him . . . We can support him to have better treatment. We can do this by ourselves. They do nothing for him . . ."

—*Father of a young man living with HIV*

". . . I asked about treatment, and they introduced me to a military doctor who then taught me very briefly how to take care of my son. But I saw that the doctor's knowledge about this disease was limited."

—*Father of a PLWHA*

During the consultative group meeting, one health care provider emphasized the need to increase use of health services among PLWHA and their caregivers. Building more skills and capacity for project officers, health staff, and local leaders is very important. It will increase understanding among people who work with PLWHA and caregivers of PLWHA and provide them with a system of improved care and support.

11. Capacity to provide care and support

Family caregivers of PLWHA have a basic knowledge of HIV infection and AIDS and continually seek more information so that they can provide better care and support. They help PLWHA take precautions against injuries and opportunistic infections. Many encourage PLWHA to resume daily activities, such as working, exercising, socializing with others, and attending family events and provide supportive environments by not excluding or separating PLWHA from family activities such as eating and going out. One family even developed ground rules at home that included not using taboo words or insults.

Many PLWHA and caregivers who were interviewed said that they know how to clean contaminated clothes and dispose of bandages and gauze pads that contain mucus and blood. However, observations showed that they do not properly wash contaminated clothes in chlorine and dispose of soiled bandages and gauze pads by burning or disinfecting them. Some caregivers mentioned pouring boiled water on clothes to disinfect them. Caregivers may also separate personal household utensils and items belonging to PLWHA from those of other family members. Caregivers are very concerned about the process of cleaning wounds. One father said that specific types of skills and knowledge, such as knowing to clean a wound from the outside first, proceeding inward, need to be demonstrated and practiced and cannot be learned solely through reading IEC materials.

Caregivers, however, continue to experience many difficulties, and some feel unable to help PLWHA. Health care providers and volunteers from organizations such as the Vietnam Women's Union and the Vietnam Red Cross described various challenges they face in providing care and support for both PLWHA and caregivers, such as a limited capacity for providing in-depth counseling and a lack of family cooperation and support. Family members who provide care feel they lack appropriate strategies, skills, and finances to offer adequate care and support. In general, caregivers said they need to be trained in how to provide psychosocial support and health care for PLWHA. The caregivers interviewed in this study expressed interest in learning how to properly care and clean wounds and open sores; prevent opportunistic infections and illnesses and care for PLWHA who have them; provide care during the various stages of HIV infection and AIDS; identify HIV infection and AIDS and prevent transmission of the infection; gain knowledge of different types of medication and use of such medications at home; provide adequate nutrition and exercise for PLWHA; and enshroud an individual with AIDS after his or her death.

"I usually go to a health group. They guided us to treat an open sore. For example, in applying medicine, we normally apply medicine from the inner to outer side. It will spread. They taught us that we should limit the application to one area. Application of medicine is allowed in one area at a time. We

attended some training or workshops in order to know how to deal with small things like this."

—*Father of a young man living with HIV in Ha Noi*

Many who assume a caregiver role are concerned about the risk to them and their families of HIV infection, because they are in close contact with PLWHA. Caregivers take precautions to prevent transmission, such as washing clothes separately; using antiseptic solutions, including chlorine; wearing gloves when cleaning wounds; and making sure that PLWHA do not scratch themselves.

"I told him that he should be careful while playing with children. He shouldn't let children touch him if he is scratched."

—*Father of a PLWHA*

"In general, it is fine not to wear gloves. But in the case that he is wounded, scratched, or when there is pus from the wound, especially when he has ulcers, then you should use gloves because you never know if you have scratches in your hands."

—*Father of a young man living with HIV in Ha Noi*

Caregivers are also concerned about transmission of common infections and diseases, because they are most likely to transmit infection to PLWHA and most vulnerable to transmission of infection from PLWHA. This is a particular problem at homes where space and air circulation are inadequate. Many households that were visited in this study experienced similar problems. Inadequate air circulation facilitates the transmission of common illnesses such as tuberculosis, acute respiratory infections, colds, influenza, and conjunctivitis.

12. Health care planning

Most families interviewed had not developed their own health care plans. Health care planning is important; it helps families prepare for and cope with their situation, particularly as new issues or emergencies arise. It also helps families prepare for the final stages of AIDS and for the death of the patient. Health care planning can provide useful strategies for saving money for health services, deciding when to seek health care services, and preventing injuries and infections.

When PLWHA and their caregivers initially become aware that the PLWHA is infected with HIV, neither the PLWHA nor the caregivers are prepared to cope with the situation. They normally delay seeking health services until the PLWHA develops severe symptoms. Some PLWHA only ask their families to take them to the hospital if the family cannot provide care at home. Financial planning does not occur until health services are sought and families realize the importance of allocating money to pay for such services, especially for medical emergencies. One family reported that they had set aside a reserve fund of 500,000 to 1 million VND for health care. For more expensive health services, most families borrow money from their relatives. In addition, many families are interested in knowing how to prepare for the death of the PLWHA and what to do after death occurs.

13. IEC materials

The need for IEC materials is reflected throughout the preceding discussion. More specifically, PLWHA and their caregivers expressed a need for more information about self-care. The currently available IEC materials, such as brochures, leaflets, posters, and television programs, still lack details and information about effective and practical strategies for self-care. The contents of and illustrations in such materials are unclear and confusing. Many people already have a basic knowledge of the disease and don't want to read the same information about the virus or transmission modes again. They want to receive updated information in the form of a resource package or book that addresses their needs. The format of the materials and guidelines for how to use them are very important; PLWHA and caregivers need to be able to quickly find the information they want. Related topics should be divided into chapters that make it easy to find information quickly. Books should be medium sized, have medium-to-large letters and greater durability, and be easier to use and read.

"There are many kinds of books/manuals about HIV/AIDS. Each material describes HIV/AIDS differently. Each book mentions the disease and opportunistic infections with different names. I get confused and do not know which book is right and what information I should follow. I wish these materials could have similar designs and disease names."

—*PLWHA, during consultative meeting*

"I got more information and knowledge from books my brother brought home. Leaflets and brochures don't work. There is not enough information or illustrations. Many people don't understand and the contents aren't clear."

—*Father of a young man living with HIV*

"We have three televisions at home . . . Information on the television, leaflets, banners, posters usually are too general. We need the detailed, accurate information in terms of important subjects like care and support to HIV-infected and -affected people. A qualified book can help me."

—*Father of a young man living with HIV in Ha Noi*

PLWHA and caregivers also express a need to educate community members about HIV infection and AIDS and to disseminate information and make it available to the public. They consider this to be important in raising awareness and reducing stigmatization and discrimination.

"We should distribute/launch the IEC materials. People will read and understand. Nowadays, not only my son is PLWHA, but many others are . . ."

—*Father of a young man living with HIV*

"There is a need to change the community's knowledge and attitudes to PLWHA, so they can live the normal lives. There are urgent needs to develop information for the community in general."

—*PLWHA from Hai Phong, during consultative meeting*

III. Review of IEC materials for PLWHA and their caregivers

Printed IEC materials have many functions, including educating patients about behavioral change, anxiety reduction, distress amelioration, and pain relief; increasing patient satisfaction; allowing patients to actively participate in their care; and enhancing informed choice. Because current treatment options for HIV infection and AIDS are limited in Vietnam, the functions of print IEC materials are particularly important. Comprehensive care for PLWHA must include medical, psychological, and social support to help people cope with the implications of having a life-threatening disease and the economic and social consequences of the disease. IEC materials can be an important aid to coping with the stress, change, crisis, disability, and uncertainty that are associated with HIV positivity. By providing access to information, we can help individuals to gain a semblance of control over their health and to actively participate in their own care.

To assess IEC materials that exist for PLWHA and their caregivers in Vietnam, PATH used two complementary methods of IEC review. First, through in-depth interviews with representatives of multilateral, nongovernmental, and other types of international organizations, PATH completed a general survey of existing materials. Second, PATH carried out a comprehensive assessment, including consultations with PLWHA and caregivers, of 12 representative documents that are commonly used in programs for PLWHA (table 1).

Table 1. Information, education, and communication materials available to people living with HIV/AIDS and their caregivers

Title	Organization	Year
<i>Home-Based Care and Support for People Living with HIV/AIDS, Vol. I</i>	Le Chan AIDS Committee, World Vision International, AusAID	2002
<i>Home-Based Care and Support for People Living with HIV/AIDS, Vol. II</i>	Le Chan AIDS Committee, World Vision International, AusAID	2002
<i>Care for People Living With HIV/AIDS</i>	Vietnam Ministry of Health, AIDS Division	1998/2001
<i>With Hope and Support</i>	National AIDS Standing Bureau	2001
<i>HIV/AIDS Prevention in the Community</i>	National AIDS Standing Bureau, Ha Noi School of Medicine	2001
<i>Stay Fit—Feel Good</i>	PATH	2001
<i>Family and People Living with AIDS</i>	Ho Chi Minh City AIDS Prevention Committee	1995
<i>A Green Candle</i>	Le Chan AIDS Bureau, World Vision International	2002
<i>When We Are Together</i>	Le Chan AIDS Bureau, World Vision International	2002
<i>Handbook: Taking Care of HIV/AIDS Infected People at Home</i>	Ho Chi Minh AIDS Committee	2000
<i>Taking Care of Your Loved Ones at Home</i>	Ho Chi Minh City AIDS Committee, Medecins du Monde/UNICEF	1999
<i>Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care</i>	Ho Chi Minh City AIDS Committee, Medecins du Monde/UNICEF	1999

PATH’s consultants facilitated a process in which an established standard was used to assess five different aspects of the documents: (1) involvement of PLWHA in the development of the material, (2) layout and design, (3) message components, (4) approach, and (5) text and illustrations.

A. Perspectives of PLWHA and caregivers

During in-depth interviews conducted in July and August 2002 and through the group discussions conducted as part of this consultation, a number of informational needs and gaps were identified by PLWHA and caregivers. Participants expressed confusion about the difference in the names and terms used in different materials and voiced a need for simplification and standardization. They also expressed a preference for a medium-sized, durable book that is easy to carry, clearly written, printed in large type, and divided into chapters that are indexed to make it easier to find information.

In terms of content, a recurring theme in the discussions highlighted the financial needs of PLWHA. PLWHA want to take care of themselves and be economically self-sufficient. Information about finding jobs is desired, so that PLWHA can contribute to

the economic stability of their families. Both PLWHA and caregivers were concerned about the high cost of medications and hospitalization. Many caregivers are parents who are retired, have limited financial means, and often become dependent on other family members for financial assistance with caring for PLWHA. Caregivers need assistance with financial planning for long-term medical costs when associated with AIDS-related illnesses.

Participants in the review consistently expressed a need for clearer information about HIV infection, progression to AIDS, and opportunistic infections. They need basic information about the skills needed to manage illness (e.g., preparing oral rehydration salts and taking a temperature), and they want to know the risks of further transmission of HIV and opportunistic infections such as tuberculosis, influenza, conjunctivitis, and diarrhea.

Participants want to know what opportunities they have for staying healthy for as long as possible. They want detailed, non-technical information about nutrition, including recommendations about what foods to eat and tips on saving time and money in preparation. They are less concerned about calories than about how to eat well with limited time for cooking and limited financial resources. They want recommendations about exercise. They want information about hygiene, so that they can limit their exposure to pathogens. They also want information about rehabilitation services for IDUs.

Participants revealed a significant gap in knowledge about medications and were specifically interested in updated, scientific information about antiretroviral treatments. All of the participants mentioned hearing from various sources about medications that can cure HIV infection, and they easily fall prey to scams, wasting money and energy on useless treatments. PLWHA and caregivers had received medication recommendations from health care workers without adequate clarification of the purpose of the medication. Participants also asked for clear information about vitamins, preventive medications, treatment of opportunistic infections, traditional remedies, and the cost of drug treatments.

Participants also expressed a need for emotional support for both PLWHA and caregivers. PLWHA need emotional support to cope with the fear, worry, anger, and other emotions they experience. They want specific suggestions for avoiding isolation and abandonment. Caregivers also need support networks to share information and relieve stress. Specific suggestions about where PLWHA and caregivers can find counseling services and support groups is desired. Caregivers expressed a need for information about planning for and gaining the skills necessary to care for PLWHA when they become severely ill and preparing for the death of their family member.

In summary, PLWHA and their caregivers requested that IEC materials be assembled in a medium-sized, durable book in which topics are easy to identify and find, including information about the following:

- Stages and development of HIV infection and AIDS.
- HIV transmission and prevention.
- Practical alternatives and supplementation to therapy for staying healthy, including nutrition and exercise.
- Prevention of opportunistic infections.

- Prevention of transmission of contagious opportunistic infections to family and caregivers.
- Skills needed for PLWHA and caregivers, including safe use of medications.
- Currently available and new antiretroviral therapies.
- How to maintain mental health (for both PLWHA and caregivers).
- Overcoming drug addiction.
- Financial planning and assistance.
- Care of dying and palliative care; planning for death.
- Pregnancy and HIV; care of HIV-positive children.

B. Expert analysis and discussion

None of the publications reviewed met all of the needs identified through the FHI/PATH consultation process. Each has different strengths and weaknesses.

1. General assessment

Of the 12 publications, *Home-Based Care and Support for People Living with HIV/AIDS, Volume I*; *Taking Care of Your Loved Ones at Home*, and *Stay Fit—Feel Good* provide the clearest information and meet the greatest number of the needs described by PLWHA and caregivers. The first volume of *Home-Based Care and Support for People Living with HIV/AIDS* and *Taking Care of Your Loved Ones at Home* also contain sections on sexually transmitted infections and the relationship of such infections with HIV. These publications, in combination with a few others (such as *Care for People Living with HIV/AIDS*, *HIV/AIDS Prevention in the Community*, and *When We Are Together*, which supply information about medications) can meet a majority of the information needs of PLWHA and their caregivers.

The two volumes of *Home-Based Care and Support for People Living with HIV/AIDS* and *With Hope and Support* most closely meet the size and durability needs of PLWHA and caregivers. These books are 15 by 21 cm and are bound between card-stock covers. *Stay Fit—Feel Good* has the best presentation; the use of color is good, and tabbing is included for ease in identifying specific topics. However, illustrations are overused and tend to clutter the pages. *Taking Care of Your Loved Ones at Home* has a comprehensive table of contents, which is useful for locating specific items.

Home-Based Care and Support for People Living with HIV/AIDS, Volume I provides comprehensive information about the HIV virus, the stages of development of HIV infection and AIDS, and the signs that clinical AIDS has developed. A few of the terms should be simplified, such as “congenital syndrome” and “masses of nervous tissue, called ganglions,” but overall it provides good, detailed information about HIV infection and AIDS. *HIV/AIDS Prevention in the Community* also provides comprehensive information about the HIV virus, the stages of development of HIV infection and AIDS, and the signs that clinical AIDS has developed. However, a reader needs medical training or a background in biology to fully understand the text in this publication.

Many of the publications (*Home-Based Care and Support for People Living with HIV/AIDS, Volume I*; *Care for People Living with HIV/AIDS*, *With Hope and Support*, *Family and People Living with AIDS*, *Taking Care of HIV/AIDS Infected People at Home*, and *Taking Care of Your Loved Ones at Home*) provide clear and

accurate information about HIV transmission, including how the infection is transmitted and how it is not transmitted. The first volume of *Home-Based Care and Support for People Living with HIV/AIDS*, *Care for People Living with HIV/AIDS*, and *With Hope and Support* offer the most options for preventing transmission of HIV. *With Hope and Support* has the best layout, with clear headings identifying the elements of HIV prevention.

The publications that provide the most practical information about illness and the basic skills required for caring for ill people are *Stay Fit—Feel Good* and *Taking Care of Your Loved Ones at Home*. Both offer comprehensive information about common illnesses and symptoms and are clearly written. All medical terms have been simplified or explained. The subjects discussed include fever, diarrhea, dehydration, skin problems, wound treatment, scabies, shingles, allergic reactions, bed sores, mouth and throat problems, thrush, herpes, tooth and gum care, tuberculosis, coughing and difficulty breathing, genital problems, nutrition problems, nausea and vomiting, pain management, fatigue and weakness, and dementia and confusion. Other publications cover all or most of these topics but use more clinical terminology, which makes them less user-friendly.

When We Are Together provides a good list of practical skills under a single heading, including how to use oral rehydration salts, salt-rice soup, chlorine solution, alcohol solution, potassium permanganate, gentian violet, salt water for washing wounds, and salt water for rinsing mouths; how to take a temperature; how to sterilize syringes/needles; and how to make gloves. This approach, in which practical skills are gathered in one place, rather than scattered among other topics, makes the information easier to find and use. However, the list is incomplete. The first volume of *Home-Based Care and Support for People Living with HIV/AIDS* also has a separate section on practical skills, which includes instructions on how to take a pulse and measure breathing rates. *Taking Care of Your Loved Ones at Home* describes how to move bedridden patients and change bedding. *Stay Fit—Feel Good* has practical information about nutrition and medicinal plants. That publication provides a list of daily foods that are available to low-income people and that will increase physical energy.

HIV/AIDS Prevention in the Community is the only publication with detailed information about antiretroviral therapy; however, the presentation of the information would need to be simplified or clarified for it to be useful to PLWHA and caregivers who do not have medical training or a background in biology. *Stay Fit—Feel Good* offers simple and practical information about use of medications for treatment of opportunistic infections. This publication has an excellent section on medicinal plants, although this would need to be revised for Vietnam. *Care for People Living with HIV/AIDS* provides detailed information about the use of azidothymidine to prevent mother-to-child transmission during pregnancy. *When We Are Together* provides the only detailed information about traditional remedies, and it also includes a section on the use of Western medicines for treatment of common symptoms and illnesses.

The publications that best address the issue of maintaining mental health, including the mental health of PLWHA and caregivers, are *Stay Fit—Feel Good*, *Home-Based Care and Support for People Living with HIV/AIDS, Volume I*; and *Taking Care of Your Loved Ones at Home*. These contain the most detailed information about

providing emotional care and support for both groups but do not include information about where to find additional support, counseling, or support groups. None of the publications offer practical information about overcoming drug addiction. *Taking Care of Your Loved Ones at Home* has a section on drug addiction, but it does not include practical or specific information about how to overcome a drug addiction—it is focused on helping caregivers to cope with the drug addiction of family members. *Stay Fit—Feel Good* and *Taking Care of Your Loved Ones at Home* include information about caring for dying PLWHA.

2. Gaps in information

There are five significant gaps in the information provided by these IEC materials. PLWHA and caregivers expressed needs for information about the following topics, none of which are adequately addressed by the available publications:

- Maintaining good health to prevent opportunistic infections: *Home-Based Care and Support for People Living with HIV/AIDS, Volume I; Family and People Living with AIDS,* " *When We Are Together,* and *Taking Care of HIV/AIDS Infected People at Home* cover issues of sanitation, and *Care for People Living with HIV/AIDS, With Hope and Support, When We Are Together,* and *Taking Care of Your Loved Ones at Home* review hygiene. However, comprehensive information about nutrition and exercise is lacking in these publications.
- Income generation and financial assistance: None of the publications address financial issues.
- Support services: None of the publications pay enough attention to identifying social services; medical clinics or hospitals that specialize in treatment of HIV infection and AIDS; support groups; services that provide financial assistance or emotional support and counseling; or funeral services, and none provide good information about long-term planning for medical care, wills, and care for surviving children of PLWHA. A number of publications mention support groups, such as Friend-Help-Friend groups, but none provide information about what services are available at what agency or organization with an accompanying list of addresses and telephone numbers. *Family and People Living with HIV/AIDS* includes a list of addresses and telephone numbers but does not include information about what services are available at these locations.
- Mother-to-child transmission: Although *Care for People Living with HIV/AIDS* supplies information about the use of azidothymidine to prevent mother-to-child transmission during pregnancy, other methods of avoiding mother-to-child transmission are omitted. Information about delivery procedures that reduce the risk of infection and breastfeeding guidelines would be beneficial to PLWHA.
- Antiretroviral therapies: None of the publications help to build understanding of the management of antiretroviral therapies. Many PLWHA and caregivers have unrealistic expectations about obtaining and using antiretroviral

therapies. A discussion of antiretroviral therapies should include a description of the availability (or lack of availability) in Vietnam, cost, time schedules, side effects, limitations, and what is needed for someone to really benefit from use of antiretroviral drugs.

C. Additional information from the assessment

The attached appendices provide extensive details on the criteria for assessing the 12 publications (Appendix A) that were assessed, the numerical scores resulting from the assessment (Appendix B), a detailed narrative review for each of the 12 publications (Appendix C), and a table summarizing the entire review (Appendix D).

IV. Recommendations

The organizations mentioned in this report that have invested time and energy in the development of IEC materials and programs for PLWHA should be applauded for their pioneering work. Where there was nothing just a few years ago, there are now a number of publications available to PLWHA and their primary caregivers that address a variety of subjects significant to the lives of these people. Nevertheless, the existing materials are not yet sufficient in terms of content, format, or availability. We make the following recommendations to interested agencies.

Devote more resources to communication programs for PLWHA. The most straightforward and obvious recommendation coming out of this assessment is that local governments, international NGOs, government agencies, multilateral agencies, and other funders need to dramatically increase the level of resources devoted to the communication needs of PLWHA and their caregivers. In considering these needs, program plans must recognize that the number of PLWHA will swell over the coming years. Keeping pace with this rapidly growing number of PLWHA and caregivers is a tremendous challenge that will require significant commitments of human and financial resources.

Support positive behaviors among PLWHA. Obviously, one of the more important concerns expressed by people is that PLWHA represent a risk that HIV infection will spread. Successful BCC strategies would uncover positive thoughts and messages that would lead PLWHA to adopt safer sex practices and to use clean needles if they use injection drugs. However, the difficulty of modifying behaviors in this regard should not be underestimated.

Find the proper balance between self-care and clinic-based care. The assessment indicated that PLWHA have a negative attitude toward the clinic-based care offered by the public sector. The assessment also indicated that PLWHA want to take care of themselves. We know, however, that certain ailments that PLWHA develop as a result of HIV require clinical treatment. A well-designed BCC initiative would work to uncover the difficulties clinical staff encounter in treating PLWHA, as well as the fears that PLWHA have about going to clinics. PLWHA and their caregivers need to differentiate between situations in which self-treatment is appropriate and situations in which clinic-based care is required. Decisions about this differentiation should be made in a joint discussion between PLWHA and caregivers and should be informed by up-to-date knowledge about HIV infection and AIDS.

Strengthen interactions between public services and PLWHA. PLWHA use of health services is low. Services that PLWHA do seek out are often inadequate, and staff are often ill-informed or unwilling to provide treatment to people who are infected with HIV. This is discouraging, because for the vast majority of PLWHA and their caregivers, only government-run public services and government-provided information are available. In the short run, at least, there is little chance that international or local NGOs will fill the direct service needs of PLWHA living across the country. Thus, the focus of work aimed at supporting PLWHA over the next three to five years must look to strengthen services at the

local levels of the public health system—to integrate services for PLWHA and to provide support and training for their caregivers.

Give information and choices regarding prospects for living. Most people in Vietnam who are infected with HIV live with the assumption that they are likely to die in the not-so-distant future. Of course, this is not completely accurate; some people who are HIV positive live without developing AIDS for many years. Lifestyle and behavior changes can dramatically increase lifespan, and as new medical treatments become available, the prospects for living near-normal lifespan have increased dramatically.

Support the needs of caregivers. In resource-poor settings such as Vietnam, and among families already impoverished by the drug addiction of a family member, the added burden of caring for an HIV-positive family member can be overwhelmingly stressful. Because of the stigma associated with HIV infection and AIDS, many families try to cope with this situation in silence. Successful BCC strategies would analyze the opinions of such caregivers and identify messages that would produce an environment in which the community would support the needs of PLWHA and caregivers and would clearly answer questions about the best way to maintain a loved one's health, with or without antiretroviral drugs.

Focus on reducing social stigma. The social stigma associated with HIV infection and AIDS is great, particularly in Vietnam where the principal modes of HIV transmission are through injection drug use and commercial sex. Strategies designed to overcome such stigmatization are as important as overall prevention interventions.

Link IEC materials to program outreach. This assessment also suggests that the links between materials developed for PLWHA and the implementation strategies created to get information to target groups in an effective manner are weak. IEC materials that never reach PLWHA do PLWHA no good. Nor is it useful for IEC materials to reach PLWHA without the necessary support from outreach staff who can facilitate the transfer of information.

Dialogue with public officials and community leaders. Many prevention programs make the mistake of trying to scare the public about the risk of HIV infection. Although this may increase awareness of the disease, such a tactic is ultimately counterproductive, because it stigmatizes PLWHA and discourages them from disclosing their HIV status and from seeking out medical and social support. Effective BCC strategies would open dialogues with public officials and community leaders to analyze their interest in issues associated with HIV infection and AIDS to work on developing messages for dissemination within the community that would both support PLWHA and enhance prevention efforts.

Get support from policymakers for scale up. Although pilot projects implemented by international agencies are important because of the materials they produce and the models they develop, success indicators should focus on the government sector's ability to adapt and scale-up models that rapidly expand service coverage for PLWHA. Programs for PLWHA must be coupled with communication

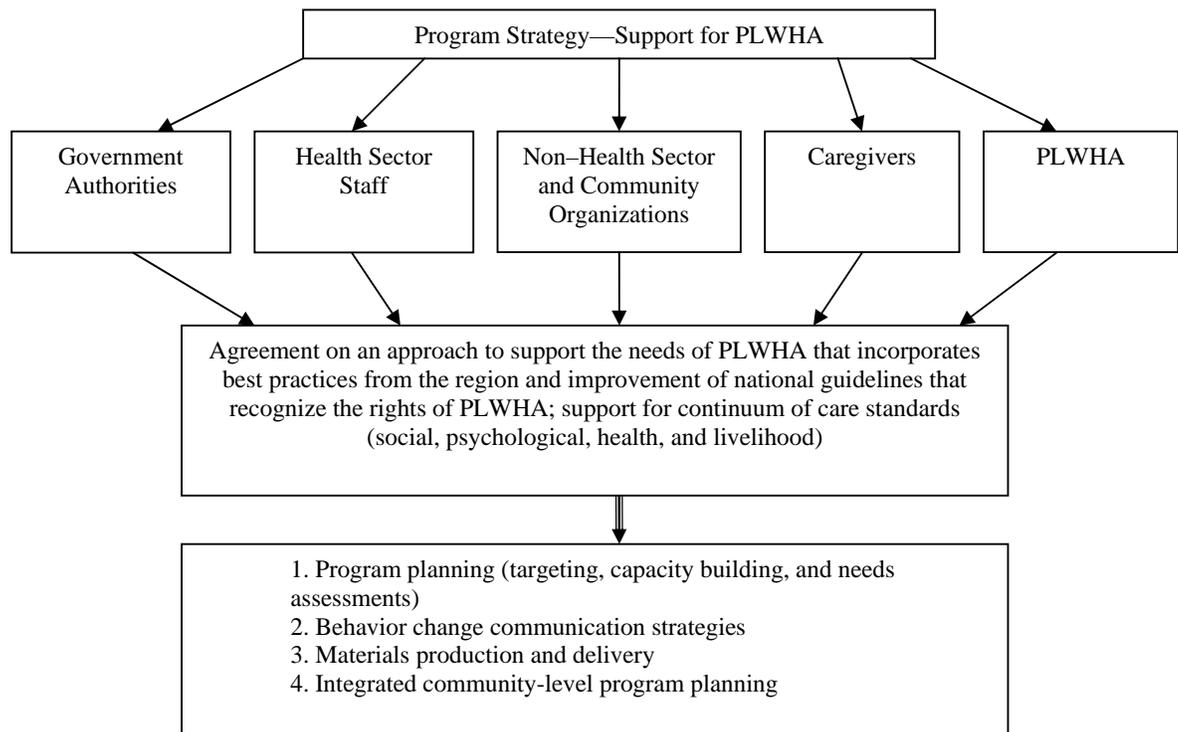
strategies that will engage all levels of the government, encourage sharing of information, and spread best practices. The focus of work for PLWHA cannot be limited to PLWHA and their caregivers. Behavior change communication (BCC) activities must also aim to influence a host of players, including government officials and health care staff, that can support a positive environment for interacting with PLWHA, regardless—for example—of whether a PLWHA happens to be an IDU. In this sense, strategies for improving advocacy programs at national and provincial levels may be as important as programs meant to design and develop IEC materials and behavior change communication programs at the local level.

V. Implementation strategy

Perhaps the most daunting aspect of developing programs for PLWHA is the high volume of information that PLWHA request and the broad range of subjects in which they are interested. This reflects the needs of individuals who, after becoming HIV positive, face a series of life-altering changes in their physical condition and social status. That HIV infection and AIDS have an impact that reaches beyond health issues is a truism. How dramatic this social and emotional impact of HIV infection and AIDS on the lives of PLWHA is was certainly reinforced by the responses collected in this assessment.

There are a number of ways to approach the task of developing communications capacity and transferring information to PLWHA in ways that will influence their behavior. One approach would be to focus on the creation and distribution through various channels of materials on the basis of expert analysis and use of vertical structures within the health system and/or mass organizations such as the Vietnam Women's Union and Vietnam Youth Union. The obvious advantage of this approach is that it might provide an efficient way of distributing information nationwide as quickly as possible. Another approach would be to develop the capacity of teams at appropriate levels (health, social, mass organization, NGO, religious) to strengthen their understanding of the challenges that PLWHA face and the information and services that they require. Out of such capacity-building processes, teams could be developed that can facilitate the transfer of knowledge from expert sources to the community on demand. We support the latter approach (figure1).

Figure 1. Program strategy for support of people living with HIV/AIDS (PLWHA)

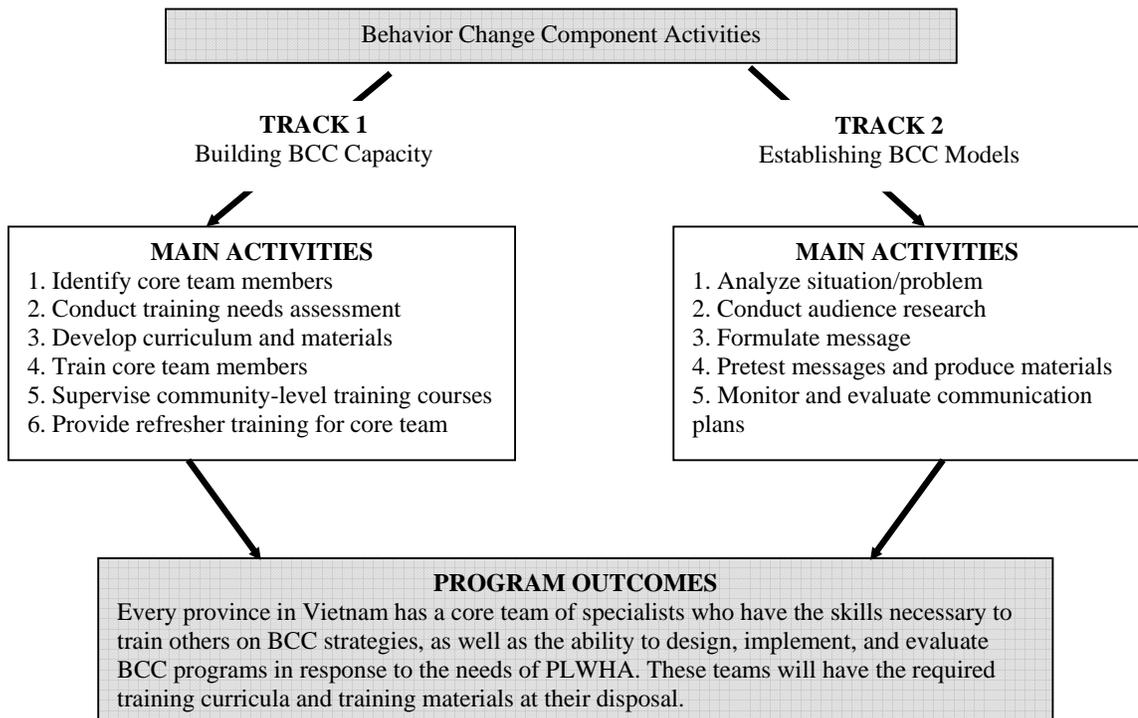


The social issues associated with HIV infection and AIDS are rapidly evolving and require a constantly changing response. If interested agencies can build a knowledge base of teams, as appropriate, at provincial, district, commune, and village levels, such teams will have an opportunity to adapt their responses to the disease as the physical and social characteristics of the epidemic evolve. A concrete example of something that will certainly evolve over the next three to five years is the prospect of long-term survival among Vietnamese PLWHA. PLWHA will look to caregivers and public institutions for support and guidance as scientific advances are made and antiretroviral drugs become available even to poorer households.

There is another reason to support an approach in which the local health sector develops a skill base that allows adaptation of services as needs evolve: it is impossible, in the immediate term, to create IEC materials that adequately address the range of subjects that PLWHA feel are important. An obvious example is the expressed desire of PLWHA for information about how to earn a living after infection with HIV. A national-level, top-down program will not provide the necessary information; specific knowledge about the opportunities that are present locally, in the areas where PLWHA reside, is the practical response required.

We suggest that the best way to facilitate transfer of knowledge to communities and PLWHA is through BCC strategies. By “BCC strategies,” we mean a process wherein agencies interested in support of PLWHA train a core group to become BCC specialists. Once BCC skills have been developed, these specialists would be able to use situation analysis and audience research to identify problems and produce communication messages. With BCC capacity in place, such teams will also have the ability to pretest and produce quality materials and to evaluate communication materials and strategies that the team implements (figure 2).

Figure 2. Simplified steps in behavior change communication (BCC) strategies for people living with HIV/AIDS (PLWHA)



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Appendix A. Description of criteria for assessing selected information, education, and communication materials for people living with HIV/AIDS and their caregivers

1. Involvement of PLWHA and caregivers

Item 1.1. Has the information, education, and communication (IEC) material been tested to determine usefulness to PLWHA or caregivers? The fundamental question to be answered in reviewing the print materials is their usefulness to PLWHA and caregivers and their effectiveness in educating, promoting behavior change, alleviating anxiety, enhancing informed choice, and allowing people to be active participants in their care. These questions are best answered by the end user—in this case PLWHA and caregivers. PLWHA provide a unique perspective, and their involvement not only strengthens the IEC material, but also reduces stigma and discrimination and empowers PLWHA¹. Thus, a key question in the checklist is whether the document has been tested with PLWHA and caregivers and adapted accordingly. A rating of poor was given to documents that were not tested prior to publishing, a rating of fair was given to documents that were tested without involving PLWHA, a rating of good was given to documents that were tested with PLWHA, and a rating of excellent was given to documents that were developed with the assistance of PLWHA and tested with PLWHA.

2. Layout/design

Item 2.1. Is the material medium-sized and durable, which is defined as (1) dimensions of 18 to 22 cm by 14 to 16 cm, (2) bound, and (3) covered with card stock or heavier material? Documents that included none of the three components were rated poor, documents that included one of the three components were rated fair, documents that included two of the three components were rated good, and documents that included all three components were rated excellent.

Item 2.2. Are the messages arranged in a sequential, logical manner? Documents with no clear order were rated poor, documents that identified key topics (e.g., medical, psychosocial, transmission, and aspects of daily care) but interchanged these topics more than once were rated fair, documents that identified key topics and addressed each separately were rated good, and documents that identified key topics and addressed each topic separately and in a logical sequence were rated excellent.

Item 2.3. Are specific messages/topics easy to locate? Inclusion of subject headings, a table of contents, an index, and tabs facilitates location of specific pieces of information. Documents that did not provide a table of contents, index, tabs, or subject headings were rated poor; documents that included subject headings were rated fair; documents that included subject headings and a table of contents were rated good; and documents that included subject headings, a table of contents, an index, and tabs were rated excellent.

3. Message components

¹ Joint United Nations Programme on HIV/AIDS. *From principle to practice: greater involvement of people living with or affected by HIV/AIDS*. September 1999. Available at: <http://www.unaids.org/publications/documents/persons/una9943e.pdf>. Accessed September 15, 2002.

Item 3.1. Explanation of HIV/AIDS. Discussion of HIV/AIDS should include a simplified, scientific description of HIV and its effect on the body. Discussion of HIV/AIDS should include discussion of disease progression, including the window period (the early stage of HIV infection before antibodies will show up on a test), the incubation period (the stage when HIV is present, but the person shows no symptoms), and AIDS (including the role of opportunistic infections and common signs of the onset of AIDS). Documents that included information about one of the above items (description of HIV, window period, incubation period, signs of AIDS onset, and role of opportunistic infections) were rated poor, documents that included two to three of the above items were rated fair, documents that included four of the above items were rated good, and documents that included information about all five items were rated excellent.

Item 3.2. Clear, accurate information about HIV transmission and prevention

Item 3.2.1. One measure of the tone or overall approach of the material is how it presents the risk of HIV infection and whether the material exaggerates the risk of infection through relatively low-risk activities (barbers, injections at hospitals). Documents that identified modes of transmission other than high-risk activities (unprotected sexual intercourse with an infected person or a person whose HIV status is unknown, direct contact with infected blood, and mother-to-child transmission) and that fail to clarify how it is not transmitted were rated poor; documents that identified unprotected sexual intercourse with an infected or potentially infected person, direct contact with infected blood, and mother-to-child transmission as the main modes of transmission but also warned about ordinary social contact with an infected person were rated fair; documents that only identified unprotected sexual intercourse with an infected or potentially infected person, direct contact with infected blood, and mother-to-child transmission as modes of transmission were rated good; and documents that clearly identified unprotected sexual intercourse with an infected or potentially infected person, direct contact with infected blood (through a shared injection needle, an unscreened blood transfusion, or an open wound), and mother-to-child transmission as the mechanisms for spreading HIV and that identified how it is not spread were rated excellent.

Item 3.2.2. Another mark of quality in a document is the recognition that PLWHA and caregivers have different needs and living conditions that require a range of options for care and support². One alternative for prevention of HIV will not meet the needs of all PLWHA and caregivers, and, short of tailoring the document to each individual, a range of options should be provided³. Thus, the documents were assessed on the basis of the number of alternatives for avoiding transmission provided for each mode of transmission (sexual transmission, transmission through blood, and mother-to-child transmission). Documents that did not cover all three modes of transmission or provided only one prevention option for each mode of transmission were rated poor, documents that covered all three modes of transmission and provided more than one prevention option for at least one mode of transmission were rated fair, documents that covered all three modes of transmission and provided at least two prevention options for each mode of transmission were rated good, and documents

² Dixon-Woods, 2001

³ Kreuter et al., 1999

that covered all three modes of transmission and provided at least three prevention options for each mode of transmission were rated excellent.

Item 3.3. Clear, simple information about prevention of opportunistic infections with practical alternatives for staying healthy.

Item 3.3.1. Sanitation information should include (1) which household items should be kept separate, (2) which household items are safe to share, (3) how to clean items contaminated with blood, feces, or other bodily fluids, (4) how to prepare disinfecting solutions, and (5) where to purchase disinfecting supplies. Documents that addressed one to two of these topics were rated poor, documents that addressed three of these topics were rated fair, documents that addressed four of these topics were rated good, and documents that addressed all five were rated excellent.

Item 3.3.2. Hygiene information should include (1) hand washing, (2) bathing, (3) washing clothes and bedding, and (4) food hygiene—washing fruits and vegetables and thoroughly cooking food. Documents that addressed one of these topics were rated poor, documents that addressed two of these topics were rated fair, documents that addressed three of these topics were rated good, and documents that addressed all four were rated excellent.

Item 3.3.3. Diet and nutrition information should include (1) daily food (not calorie) requirements (e.g., 5 servings of fruits or vegetables), (2) specific food suggestions, (3) tips for people who are having difficulty eating, and (4) ideas for getting adequate nutrition on a limited budget or with limited time for cooking and preparation. Documents that addressed one of these topics were rated poor, documents that addressed two of these topics were rated fair, documents that addressed three of these topics were rated good, and documents that addressed all four were rated excellent.

Item 3.3.4. Exercise information should include (1) frequency of physical activity, (2) duration of physical activity, and (3) suggested activities. Documents that did not address physical activity/exercise were rated poor, documents that addressed one aspect of physical activity were rated fair, documents that addressed two of these topics were rated good, and documents that addressed all three were rated excellent.

Item 3.4. Practical information about illness and basic skills for caring for ill people.

Item 3.4.1. Information about illness should include (1) a description of each of the common symptoms (fever, diarrhea, skin problems, mouth and throat problems, coughing and difficulty breathing, nausea and vomiting, and pain), (2) an explanation of treatment for each symptom, (3) when to seek medical assistance, and (4) where to go for medical assistance. Documents that did not address common symptoms/illnesses were rated poor; documents that described each of the seven symptoms/illnesses were rated fair; documents that described each symptom, treatment information, and when to seek medical assistance were rated good; and documents that described all of the above and included information about where to go for medical assistance were rated excellent.

Item 3.4.2. Basic skills for caring for ill people should include (1) preparation of oral rehydration solution, (2) how to take a temperature, (3) cleaning wounds, (4) taking a

pulse, (5) using drugs with a prescription and following-up, and (6) moving someone who is bedridden (to prevent of bedsores). Documents that addressed one of these topics were rated poor, documents that addressed two of these topics were rated fair, documents that addressed three to four of these topics were rated good, and documents that addressed five to six of these topics were rated excellent.

Item 3.5. Updated, clear information about antiretroviral treatment and medications for treatment of opportunistic infections. PLWHA and caregivers who participated in the PATH/FHI consultation and in-depth interviews were very interested in accurate information about antiretroviral therapy and other medications. Documents should include information about (1) antiretroviral drugs (how they work; who can/can't benefit; what is required to manage treatment; what is the course of treatment, including laboratory monitoring; availability in Vietnam; cost; and side effects), (2) other medications commonly prescribed by doctors for boosting energy, (3) management of simple symptoms/using drugs safely, (4) traditional medicine that can be helpful, (5) Western medications that can be harmful, and (6) warnings about unsubstantiated cures. Documents that addressed one of these topics were rated poor, documents that addressed two of these topics were rated fair, documents that addressed three to four of these topics were rated good, and documents that addressed five or all six were rated excellent.

Item 3.6. Help in maintaining mental health should include (1) the range of emotional responses to an HIV diagnosis for PLWHA, (2) the emotional needs of caregivers, (3) at least three activities that PLWHA can do to maintain mental health (e.g., meditate, exercise, maintain friendships and family ties, and join support groups), (4) emotional assistance that caregivers can provide, (5) specific information (name, address, and/or phone number) of resources for psychosocial support for PLWHA, and (6) specific information about resources for caregivers. Documents that addressed one of these topics were rated poor, documents that addressed two to three of these topics were rated fair, documents that addressed four to five of these topics were rated good, and documents that addressed all six were rated excellent.

Item 3.7. Financial planning/assistance information should include (1) information about assistance in finding employment, (2) realistic information about the long-term costs of medications and hospitalization, (3) financial planning for long-term care and continued financial stability of the family, and (4) resources for financial assistance (names, addresses, and/or phone numbers). Documents that addressed one of these topics were rated poor, documents that addressed two of these topics were rated fair, documents that addressed three of these topics were rated good, and documents that addressed all four were rated excellent.

Item 3.8. Explanation of HIV testing should include (1) the benefits, (2) what voluntary counseling and testing is and why counseling is an important part of the test, (3) how HIV tests work, and (4) where to get a confidential HIV test. Documents that did not cover HIV testing were rated poor, documents that addressed one aspect of HIV testing were rated fair, documents that addressed two of these topics were rated good, and documents that addressed three to four topics were rated excellent.

Item 3.9. Explanation of home care should (1) define the term, (2) explain why it is advantageous, (3) explain why it is safe, and (4) discuss preparing for death, planning,

and emotional and palliative care. Documents that did not cover home care were rated poor, documents that addressed one aspect of home care were rated fair, documents that addressed two of these topics were rated good, and documents that addressed three to four topics were rated excellent.

Item 3.10. Is the information about HIV transmission and nontransmission, prevention, care, and support accurate? The 1993 *World Health Organization Handbook on AIDS Home Care*⁴ was used as the reference standard for accuracy. Documents that contained five or more factual inaccuracies were rated poor, documents that contained three to four factual inaccuracies were rated fair, documents that contained one to two factual inaccuracies were rated good, and documents that contained no factual inaccuracies were rated excellent.

Item 3.11. Are there factual discrepancies/omissions in statements or visuals that can lead to misinterpretation? Discrepancies or omissions in a message can produce a misinterpretation of information. Documents that contained five or more factual discrepancies or omissions were rated poor, documents that contained three to four factual discrepancies or omissions were rated fair, documents that contained one to two factual discrepancies or omissions were rated good, and documents that contained no factual discrepancies or omissions were rated excellent.

4. Approach

The following items were used to measure the broad approach of the document: whether it uses fear, moralizing, encouragement, or another approach to convey its message.

Item 4.1. Do the visuals convey fear or anxiety? Visuals in an IEC document can help clarify or emphasize points of information, break-up text to make the information appear less dense, and make unpleasant information more palatable by injecting humor or images of smiling, upbeat people. Negative images of sad and dejected people or fear-inducing portrayals of HIV infection or other conditions can have the opposite effect and increase the anxiety and fear of PLWHA. Documents that contained three or more negative visuals were rated poor, documents that contained one to two negative visuals were rated fair, documents that contained no negative images and one to two positive or neutral images were rated good, and documents that contained three or more positive visuals that supported the text were rated excellent.

Item 4.2. Is the message targeted to a particular group/individual? Targeting of print IEC materials allows inclusion of more detailed information that is most relevant to the target group; such materials can contribute to greater behavior change than can generic materials.⁵ Documents that were directed at the general population were rated fair, documents that targeted PLWHA and caregivers were rated good, and documents that targeted a subpopulation of PLWHA (e.g., women, injection drug users [IDUs], or female sex workers) were rated excellent.

⁴ World Health Organization, Global Program on AIDS. *AIDS Home Care Handbook*. Geneva. 1993

⁵ Kreuter et al., 1999

Item 4.3. Are HIV infection and AIDS portrayed as the problem of a particular group or type of individual (e.g., men who have sex with men, IDUs, or female sex workers)? The approach can be assessed by the degree to which the document suggests that HIV infection and AIDS are the problem of a particular group or type of individual. Documents that claimed a particular group or type of individual causes HIV infection and AIDS or perpetuates the HIV/AIDS pandemic were rated poor, documents that stated that risky activities, not a particular group, cause or perpetuate HIV infection and AIDS were rated good, and documents that identified risky activities as the source of HIV infection and that included information about reducing stigmatization of and discrimination against PLWHA, men who have sex with men, IDUs, and female sex workers were rated excellent.

Item 4.4. Does the document cast aspersions on certain sexual orientations? Documents that made negative comments about men who have sex with men (using such terms as “social evil,” “evil,” “bad,” “immoral,” and “irresponsible”) or claimed that being homosexual is a risk factor for HIV infection were rated poor, documents that identified unprotected sexual intercourse (both vaginal and anal) as a risk factor and made no mention of homosexuals were rated good, and documents that identified unprotected sexual intercourse (both vaginal and anal) as a risk factor and stated that homosexuality and normal social contact with homosexuals is not a risk factor were rated excellent.

Item 4.5. Is the tone harsh or condemning? Documents that referred to PLWHA and/or their activities using condemning or harsh words (such as “evil,” “bad,” “immoral,” and “irresponsible”) were rated poor, documents that referred to PLWHA and their activities using neutral language were rated good, and documents referred to PLWHA using encouraging language (such as “value,” “dignity,” “good,” “admirable,” and “worthy”) were rated excellent.

5. Text

The readability of the text influences the quality of the document. Simplification of medical terms and use of colloquial expressions can make a document more interesting and understandable. Illustrations can add clarity, help to emphasize a particular point, and add visual appeal to the document.

Item 5.1. What is the reading level of the material? Reading grade level is commonly used to determine the readability of documents⁶. For these documents, Microsoft Word was used to establish the reading grade level, and all documents were reviewed by a group of Vietnamese individuals to confirm that the reading level of the Vietnamese versions conformed with the reading level of the English version. For the majority of the documents, the entire document was scanned for reading grade level. For both volumes of *Home-Based Care and Support for People Living with HIV/AIDS* and for *Taking Care of Your Loved Ones at Home*, 20 randomly selected pages (using a random-numbers table) were scanned for reading grade level. The ideal reading grade level selected was 6th grade. Higher grade levels can be too difficult for most readers, and lower grade levels can be over simplified to the point of providing insufficient information. Documents written at a 1st-grade level or at an 11th-grade level or higher were rated poor; documents written at a 2nd-, 3rd-, 9th-, or 10th-grade

⁶ Chen and Schroeder, 1987

level were rated fair; documents written at a 4th-, 5th-, 7th-, or 8th-grade level were rated good; and documents written at a 6th-grade level were rated excellent.

Item 5.2. Is the text easily understandable—are local language or dialect and colloquial expressions used? Documents written for a different culture (in which colloquial expressions from other cultures, such as “evil eye” and “witchcraft” were used) were rated poor, documents in which technical medical terminology was used were rated fair, documents written in Vietnamese and in which simplified medical explanations were used were rated good, and documents written in a local dialect or in which local colloquial expressions were used were rated excellent.

Item 5.3. Are the visuals culturally appropriate (familiar)? Documents in which technical diagrams, symbols, and photographs were used were rated poor, documents in which non-Asian-looking people were shown were rated fair, documents in which Asian-looking people were shown were rated good, and documents in which Asian-looking people and locally familiar household objects were shown were rated excellent.

Item 5.4. Do visuals clarify, enhance or emphasize important points in the text or are they irrelevant to the text? Documents with more than one visual per page that was irrelevant to the text were rated poor, documents with one or fewer visuals per page that were irrelevant to the text were rated fair, documents with one or fewer visuals per page that clarified, enhanced, or emphasized portions of text were rated good, and documents using more than one visual per page that clarified, enhanced, or emphasized portions of text were rated excellent.

Item 5.5. Are visuals easy to understand or do they rely heavily on the text to convey meaning? Documents with three or more visuals that depended on the text to convey their meaning were rated poor, documents with one to two visuals that depended on the text to convey their meaning were rated fair, documents with visuals that were clear but were used for visual appeal rather than to expand on the text were rated good, and documents with clear visuals that expanded on the text were rated excellent.

Appendix B. Results of assessment of selected information, education, and communication materials

Category	Score for indicated publication ^a											
	1	2	3	4	5	6	7	8	9	10	11	12
1. Involvement of PLWHA and caregivers												
1.1. Has the IEC material been tested to determine usefulness to PLWHA/caregivers?	4	4	—	—	—	—	—	—	—	—	3	—
2. Layout/design												
2.1. Is the publication medium-sized and durable?	4	4	4	4	3	3	2	2	2	2	3	3
2.2. Are the messages arranged in a sequential, logical manner?	3	3	4	4	4	4	3	4	4	3	4	4
2.3. Are specific messages/topics easy to locate?	3	3	3	2	3	4	2	3	2	2	3	2
3. Message components												
3.1. Explanation of HIV/AIDS	4	—	2	3	4	2	1	—	1	1	3	—
3.2. Clear, accurate information about HIV transmission and prevention												
3.2.1. Transmission	4	—	4	4	1	1	4	—	1	4	4	—
3.2.3. Prevention	4	—	4	4	—	1	1	—	1	1	1	—
3.3. Clear, simple information about prevention of opportunistic infections, with practical alternatives for staying healthy												
3.3.1. Sanitation	3	—	2	1	1	4	4	—	3	4	1	—
3.3.2. Hygiene	1	—	3	3	2	4	1	—	3	1	4	—
3.3.3. Diet and Nutrition	2	—	1	2	1	3	1	—	1	1	2	—
3.3.4. Exercise	2	—	1	2	1	2	1	—	1	1	2	—
3.4. Practical information about illness and basic skills for caring for ill people												
3.4.1. Illness	3	—	3	3	3	4	4	—	3	4	4	—
3.4.2. Basic skills for caring for ill people	3	—	1	3	1	4	1	—	4	1	3	—
3.5. Updated clear information about anti-retroviral treatment and medications for treatment of opportunistic infections	2	—	3	1	3	3	2	—	3	2	2	—
3.6. Mental health	3	3	1	2	1	4	1	—	1	1	3	—
3.7. Financial planning & assistance	1	—	1	1	1	—	1	2	1	1	1	—
3.8. HIV testing	2	—	2	1	3	—	1	—	1	1	1	—
3.9. Home care	4	—	1	4	2	4	1	—	3	1	4	—
3.10. Accuracy	2	—	4	4	4	4	3	—	4	3	4	—
3.11. Omissions/discrepancies	3	—	4	4	4	—	3	—	3	3	3	—

Category	Score for indicated publication ^a											
	1	2	3	4	5	6	7	8	9	10	11	12
4. Approach												
4.1. Do the visuals convey fear?	4	4	—	4	3	4	3	4	4	3	1	—
4.2. Does the publication target a particular group?	3	4	3	3	4	4	3	3	—	3	3	4
4.3. Is HIV/AIDS portrayed as the problem of a particular group?	3	—	3	3	3	—	3	4	3	3	3	3
4.4. Does the publication cast aspersions on certain sexual orientations?	3	—	3	3	3	—	3	3	3	3	3	3
4.5. Is the language harsh or condemning?	4	4	3	4	3	—	3	4	3	3	4	4
5. Text and illustrations												
5.1. Reading level	1	1	2	2	1	4	2	4	3	2	2	2
5.2. Is the text easy to understand?	2	3	2	3	2	4	2	3	3	2	3	3
5.3. Are the visuals culturally appropriate (familiar)?	4	4	—	4	1	4	3	4	4	3	3	—
5.4. Do the visuals clarify, enhance or emphasize important points?	4	1	—	4	2	3	3	4	3	4	2	—
5.5. Are the visuals easy to understand or do they rely heavily on the text to convey meaning?	4	4	—	4	1	4	4	4	4	4	3	—

NOTE. Items rated poor received a score of 1; items rated fair received a score of 2; items rated good received a score of 3; and items rated excellent received a score of 4. Dashes indicate that the item was not applicable to that publication or that the information was not available.

^a Publications were numbered as follows: 1, *Home-Based Care and Support for People Living with HIV/AIDS, Volume 1*; 2, *Home-Based Care and Support for People Living with HIV/AIDS, Volume 2*; 3, *Care for People Living with HIV/AIDS*; 4, *With Hope and Support*; 5, *HIV/AIDS Prevention in the Community*; 6, *Stay Fit—Feel Good*; 7, *Family and People Living with AIDS*; publication 8, *A Green Candle*; 9, *When We Are Together*; 10, *Taking Care of HIV/AIDS Infected People at Home*; 11, *Taking Care of Your Loved Ones at Home*; and 12, *Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care*

Appendix C. Narrative reviews of selected information, education, and communication materials

Home-Based Care and Support for People Living with HIV/AIDS, Volume I was developed by the Le Chan AIDS Committee and World Vision International, with funding from AusAID, in 2002. It is a medium-sized (15 by 21 cm) booklet with a spiral binding and a pastel-colored card-stock cover that shows clasping hands inside a heart. The publication's target audience is people living with HIV/AIDS (PLWHA) and caregivers. Chapter 1 discusses the reasons for and advantages of home care for PLWHA, including physical and mental care. Chapter 2 includes information about basic health care skills, common symptoms and illnesses, sanitation, and care during the last stage of AIDS. Chapter 3 has essential information about HIV infection and AIDS, including a description of the virus, the progression of the disease, transmission and prevention of HIV, and sexually transmitted infections (STIs). Chapter 4 addresses behavior change, participatory learning and action methods, and leading a positive life.

The booklet is presented in the format most desirable to PLWHA and caregivers. It is easy to carry, durable, and medium-sized. The table of contents is fairly detailed, but an index or tabs would make it easier to find specific subjects.

The information in this publication about the stages and development of HIV and AIDS is well developed and includes a description of the signs that AIDS has developed, and clear, non-technical language is used. Information about transmission and prevention is detailed, but injection drug use is not mentioned. Multiple alternatives for prevention of transmission through sexual intercourse, transmission through blood, and mother-to-child transmission are presented, including detailed instruction for condom use and needle sterilization (for prescription medications). However, the information on prevention of sexual transmission of HIV is not included with the sections on prevention of transmission through blood and mother-to-child transmission. Instead, this information follows a section on STIs. The inclusion of STI information is important; however, placing sexual transmission of HIV at the end of the discussion of STIs has the effect of de-emphasizing sexual transmission of HIV.

Basic information about the prevention of opportunistic infections and staying healthy is covered, although pieces of information are scattered in various sections (e.g., sanitation is covered at the end of the illness section, nutrition and food hygiene are covered in the section on home care, and exercise is covered in the positive living section). The publication lacks detailed information about nutrition (daily food suggestions and preparation tips), exercise (frequency and duration and type), and hygiene (hand washing and bathing). Some of this information is inaccurate and could lead the reader to believe that HIV can be spread through casual contact—for example, the publication recommends that PLWHA wash their own underwear and that towels used by PLWHA should not be shared by others. In addition, inconsistent information is given about pregnancy in HIV-positive women. One section states that HIV-positive women should not get pregnant, and another section confirms the right of an HIV-positive woman to have children.

Practical information about illness is covered in detail, with helpful information about treatment and when to seek medical help. All of the main symptoms and illnesses are

covered, including fever, mouth sores, nausea, diarrhea, cough and dyspnea, skin problems, pressure sores, pain, weight loss, and tuberculosis. Some clinical terms could be better explained or presented in lay terms (e.g., “dyspnea,” “jaundiced,” “candidiasis,” “methylene blue,” and “sacrum”). Some descriptions are ambiguous, such as seek medical assistance for “prolonged fever” (no definition of prolonged) and for “bad smelling” vomit.

The section on practical care-giving skills includes instructions on taking a temperature, assessing breathing rate, taking a pulse, and observing changes in complexion and color. The section on diarrhea describes preparation of oral rehydration salts and salt-rice soup.

Inclusion of a more in-depth explanation in one place of antiretroviral drugs and other medications would more fully meet the needs of PLWHA and caregivers. Antiretrovirals are mentioned in the section on illnesses. Three medicines (zidovudine, didanosine, and dideoxycytidine) are mentioned, with the caution that these medicines are “prohibitively expensive.” Azidothymidine is mentioned in the section on mother-to-child transmission and prevention. Some Western medications are recommended for treatment of illnesses without any instruction with regard to which medicines to use and when and how to use them. Use of traditional medicines and herbs is sometimes recommended, but no specific information about which traditional medicines are good and where they can be found is provided.

Mental health, including emotional support for caregivers, is covered in the description of home care and again in the section that addresses positive living. Additional information about where to find additional support, including specific details about the locations of support groups, social services, and clinics, would more fully meet the needs of PLWHA and caregivers.

Financial planning and assistance are not covered by this booklet. Long-term planning for the health care of PLWHA, medical costs, lost wages, and financial burden on family members, especially retired parents, are significant concerns to PLWHA and caregivers that should be addressed.

The tone of the publication is compassionate and supportive of PLWHA.

Overall strengths: This publication provides detailed information about HIV infection and AIDS, transmission, and prevention; however, it contains a number of inaccuracies and conflicting statements. It includes comprehensive coverage of common illnesses and symptoms. It is presented in a conveniently sized and durable booklet. The tone is reassuring and compassionate. It makes good use of illustrations to emphasize and clarify the text.

Overall weaknesses: Information about mental health, staying healthy, and medications is not easy to find—these discussions are located in different sections and are not always well marked. An index and headings with more comprehensive coverage would clarify these issues. Specific information about where to find additional help, both medical and emotional, is lacking. Financial planning and assistance information is lacking.

Home-Based Care and Support for People Living with HIV/AIDS, Volume II was developed by the Le Chan AIDS Committee and World Vision International, with funding from AusAID, in 2002. It is a medium-sized (15 by 21 cm) booklet with a spiral binding and a pastel-colored card-stock cover that shows clasping hands inside a heart. This volume, a continuation of volume I, targets health care and social workers. Chapters cover counseling issues for PLWHA and counseling skills; gender equity, increased risk of infection for women, and stigmatization of women; policy and advocacy issues; and community mobilizing and organizing. In combination with the first volume, this publication provides more complete information about mental health and support systems. It provides general information about women and HIV, but it does not address the specific health care needs of women. As described earlier, information that is targeted to a specific subgroup will be more useful to individuals in that group. Even when these two volumes are read in combination, significant message components are missing (e.g., financial planning and assistance, medications, and where to find additional help).

Overall strengths: This publication includes detailed information about HIV transmission and some information specific to women with HIV infection.

Overall weaknesses: See the review of the first volume.

Care for People Living with HIV/AIDS was produced by the AIDS Division of the Vietnam Ministry of Health in 2001. Its objective is to strengthen care and counseling for PLWHA. The target group is not stated; however, health care workers are the implied audience. The book is divided into two parts. Part 1 covers essential information about HIV infection and AIDS, including a description of the virus, how the virus is and is not transmitted, prevention, testing, and counseling. Part 2 includes descriptions of common symptoms and information about treatment of such symptoms and when to seek medical help, as well as a section on pregnancy in HIV-positive women and guidelines for medications used to treat common symptoms and illnesses.

The book is convenient to carry and is durable and medium-sized, as preferred by participants in the PATH/FHI consultation.

The stages and development of HIV and AIDS are covered, but with technical language that may be difficult for lay readers to understand. Multiple prevention methods are mentioned. However, details about how to use condoms and how to sterilize injection needles are omitted. Methods of prevention that can be used in a medical setting are interspersed with prevention methods that can be used by individuals. This information may be moderately useful to PLWHA and caregivers.

The second part of the booklet includes comprehensive information about common symptoms and illnesses, with treatment information and guidelines about when to seek medical assistance. However, liberal use of medical terminology makes this information more useful to a health care worker than to PLWHA and family caregivers. The basic skills needed in caring for sick people are not covered.

The booklet discusses the use of azidothymidine to prevent mother-to-child transmission, but the use of combination antiretroviral treatment is not covered. The

booklet includes a detailed section on medications that are prescribed for common symptoms and illnesses, including dosage. Traditional treatments and herbs are not covered.

Common emotional responses to HIV are mentioned, but no details about how to care for emotional and mental health or about where to find additional support services are included. Financial planning and assistance and planning for long-term care are not covered.

The tone of the booklet is neutral—neither negative nor supportive. Illustrations are not used.

Overall strengths: The booklet provides detailed general information about HIV infection and AIDS and common symptoms and illnesses that could be helpful to health care workers. The section on medications is helpful to health care workers and could be adapted for use by PLWHA and caregivers.

Overall weaknesses: Liberal use of technical/clinical terminology will make this publication difficult for PLWHA and caregivers to read. Information about home care, staying healthy, skills for caregivers, and mental health is sketchy. No information about financial planning and assistance and long-term health planning is included. The booklet is not tailored to PLWHA and lay caregivers.

With Hope and Support was developed by the National AIDS Standing Bureau in 2001. Its objective is to provide basic information about caring for PLWHA. The target group is PLWHA and their families and caregivers. It is a medium-sized (15.5 by 20.5 cm) bound booklet with a card-stock cover. The booklet is divided into 4 main topics: home care for PLWHA, avoiding transmission of HIV, leading a positive life, and common diseases.

The book is a convenient size for carrying and is durable. However, the table of contents does not adequately identify all of the subjects discussed. A more detailed table of contents or an index would make identification of subjects easier.

The book provides a cursory description of HIV and AIDS. More detail about the progression of the disease, signs of the onset of AIDS, and examples of specific opportunistic infections and their role in the development of AIDS would be more helpful to PLWHA and caregivers.

The essentials of HIV transmission and prevention are covered, with descriptions of multiple options for preventing transmission. Illustrations accompanying detailed text help to emphasize and clarify appropriate methods of condom use and disposal.

The section on positive living provides some suggestions for staying healthy. Hygiene is most fully covered, including hand washing, food hygiene, house cleaning, and washing clothes and bedding. How to clean and sanitize items contaminated with blood and bodily fluids is covered in detail, including instruction for sanitizing gloves. However, nutrition and exercise are given only passing mention. Other suggestions, such as not drinking alcohol and avoiding injection drug use, are offered without any information about how to stop these activities.

The section on illness uses lay terms (with the exception of “dyspnea”) and is clearly written and detailed. For each illness, with the exception of skin problems and mouth problems, there is a description of the condition, home treatments, and when to get medical attention. The discussion of skin problems only states when to get medical attention, and that of mouth problems only lists home treatments. The practical skills needed in caring for ill people that are described include taking a temperature, preparing oral rehydration salts (this description is accompanied by an illustration), and moving a bedridden person. Discussions of these skills are scattered among the descriptions of various illnesses. A separate section for these discussions or an index would make it easier to locate this information in the booklet.

A few medications are described when treatment for some of the illnesses is discussed, but this information is very limited. Use of antiretroviral drugs and use of traditional medications to treat symptoms are not covered.

Mental health is given limited coverage in the section on positive living. Common emotional responses are listed, and families are encouraged to provide unconditional love to PLWHA. Specific suggestions for relieving stress or obtaining support are omitted. There is no coverage of care information that targets caregivers. Financial planning and assistance and long-term planning for medical care are not covered.

The tone of the publication is supportive, and no group is singled out for blame or disdain. The text is clearly written, with very limited use of technical terms; however, colloquial expressions are not used. The majority of illustrations are positive.

Overall strengths: The size of the booklet is convenient. Simple language is used well in the section describing illnesses.

Overall weaknesses: Because the table of contents is limited and no index is included, finding information can be difficult. The booklet’s coverage of nutrition, exercise, medications, and mental health is insufficient. No information about available services or about financial planning and assistance is included.

HIV/AIDS Prevention in the Community was produced by the National AIDS Standing Bureau and the Ha Noi School of Medicine in 2001. The objective of this publication is to help health care staff implement AIDS prevention activities. Its target group is health care staff at the grassroots level. The book is a medium-sized (16 by 24 cm), bound textbook, with a card-stock cover. A table of contents and subject headings are provided. This publication is written for an advanced health care worker audience. The technical terminology used would be difficult for a person without medical training to understand.

The publication contains detailed information about HIV, progression of infection and AIDS, and guidelines for clinical diagnosis of AIDS. This information could be very helpful to health workers but may be too difficult for PLWHA and caregivers without medical training to understand.

The transmission section in the original document is missing pages.

The prevention of HIV transmission section focuses on prevention in the medical setting rather than the home setting. Again this information could be useful to health workers, but it is not helpful for PLWHA and caregivers.

Information about staying healthy and preventing opportunistic infections is of limited usefulness to PLWHA and caregivers. Home care information is limited, and medical setting information is not relevant to PLWHA and family caregivers.

Essential information about symptoms and illnesses is present, including descriptions of various conditions, possible treatments, and when to seek medical assistance. Some clinical terminology is used in this section.

This publication provides detailed information about antiretroviral therapy, azidothymidine, and Western medications that can be used to treat symptoms and illnesses. An annex describes different drug combinations and dosages and the recommended medications and dosages for specific conditions. Traditional medications are not covered.

Limited information about mental health is offered. There is some discussion of emotional responses to an HIV diagnosis. The publication includes a section on counseling skills for health care workers. Emotional support and care for caregivers is not covered.

Financial planning and assistance are not covered. However, there is a discussion of how to prepare for the future, how to make funeral arrangements, and how to care for surviving children.

The tone of the publication is professional and supportive. It does not cast blame on any particular group or groups.

This booklet includes a detailed section on HIV in pregnancy, obstetric advice, and information about caring for newborns of HIV-positive mothers. Another section explores the relationship between HIV and STIs.

Overall strengths: Some of the detailed information that PLWHA desire is provided, but the language would have to be adapted to make it more accessible to PLWHA. The section on HIV in pregnancy is useful. This publication could be very useful to health professionals who have a background in biology and are familiar with medical terminology.

Overall weaknesses: This publication is too technical to be useful to PLWHA and caregivers without medical training. The information for PLWHA on practical tips for prevention and staying healthy is incomplete.

Stay Fit—Feel Good was developed by PATH in 2001, on the basis of findings of the project "Community-Level Case Management of Infection in Settings with a High Prevalence of HIV/AIDS." This project was implemented by Lampang Provincial Health Office, Thailand, in cooperation with PATH and the Ratananurak Center, with financial support from Horizons/US Agency for International Development. The needs of PLWHA were identified to be (1) understanding of common symptoms of

opportunistic infection and training in treating symptoms at home with common medicines and herbs, (2) psychological support, (3) assistance with financial problems and community discrimination, and (4) correction of improper use of drugs to treat opportunistic infections at home.

The document is bound with a durable cover. The document is a bit larger than specified by consultation participants. The page layout/design is complex, with use of different fonts, no obvious sequencing of information, and many pictures filling what could have been “white space”. A table of contents and tabs make it easier to find specific information.

It is divided into two sections. “Stay Fit” addresses opportunistic infections, symptom-based care, medicinal plants, drug use, and recommendations for PLWHA and caregivers. This section has 14 topics, each discussed in a simple format that includes three sections: (1) care at home, (2) when to visit a doctor, and (3) reminders. “Feel Good” covers six topics and addresses the psychological aspects of living with HIV/AIDS, including how to deal with psychological problems and how to assist PLWHA. This section provides practical information about how to decide, on the basis of symptoms, when to visit a doctor.

Two topics, physical care at home and medicinal plants to relieve symptoms, were developed to support self-care. The book was designed for family caregivers as a tool for the treatment of common symptoms, such as fever and skin irritation. It does not aim to enable family caregivers to diagnose and treat diseases.

The section on medicinal plants is a special part of this manual. It recommends 42 kinds of herbal medicine that are available in Thailand. A traditional medicine counseling service has been linked to this part of the book. Most of these herbal medicines are available in Vietnam.

Overall strengths: The format of this publication is excellent. A reader can easily find a desired section. The text is well written, and the language is easy to understand. The manual addresses how to respond to symptoms and signs. It assumes that its target audience will have little background in health care.

Overall weakness: This manual, which was developed to be used as a communication tool and meant to be distributed during a training program, may seem to heavy for easy carrying. The publication does not link available social services for care and support with PLWHA and caregiver. The page layout/design is complex

Family and People Living with HIV/AIDS was developed by the Ho Chi Minh City AIDS Prevention Committee in 1995. The objective and target group are not identified. The pamphlet is medium-sized (14 by 19.5 cm). The copy examined in this assessment was a photocopy, so information about binding and type of cover cannot be provided.

No description of HIV/AIDS is included in the pamphlet meets. Transmission information is accurately covered, including how HIV is not transmitted, but the only prevention method mentioned is condom use. Sanitation in the home is fully covered, including information about which household utensils can be shared, which should be

kept separate, how to clean items contaminated with blood or bodily fluids, how to prepare chlorine and alcohol solutions, and where to purchase chlorine.

Information about staying healthy identifies a number of activities and conditions to avoid, but no practical guidance about how to achieve these recommendations is given. The publication recommends avoiding malnutrition but offers no nutrition guidelines. It recommends avoiding use of recreational drugs and smoking but offers no guidance on how to break an addiction. It recommends avoiding sexually transmitted infections and tuberculosis but offers no advice on how to avoid these diseases. It recommends avoiding anxiety but offers no information about how to relieve anxiety. No hygiene or exercise guidelines are included.

The publication provides detailed descriptions of common illnesses and symptoms, including information about home treatment and when to seek medical assistance. However, the text would be easier to understand if clinical terms, such as “dermatic” and “dyspnoea,” were simplified (e.g., “skin problems” and “difficulty breathing” could be used). Practical skills for caring for ill people are not covered, with the exception of oral rehydration salts preparation.

Antiretroviral therapy is not discussed in this publication. The sections on treatment of common illnesses and symptoms list some recommended medications but do not include dosage information. A section on dangerous medications warns against the use of steroids but does not explain why or when PLWHA might come into contact with these medications. Traditional medications and herbs are not discussed.

Mental health and emotional care and support are not covered. Financial planning and assistance are not covered. The tone of the document is neutral.

Overall strengths: The publication provides detailed information about illnesses and symptoms, treatment, and when to seek medical assistance. Accurate information about how HIV is and is not transmitted is included.

Overall weaknesses: Many of the topics of significant interest to PLWHA and caregivers are omitted. The document does not include information about HIV prevention (other than sanitation in the home), how to stay healthy and avoid opportunistic infections, antiretroviral therapy, emotional care and support, or financial planning and assistance.

Green Candle was developed by the Le Chan AIDS Bureau and World Vision International in 2002. It is a small (15 by 10.5 cm) pamphlet about leading a positive life and is based on the life of a Hai Phong man. This pamphlet is more of a photo novella about how a good person can fall into drug addiction. It helps to destigmatize injection drug use by explaining that the people who are addicted to intravenous drugs are ordinary people. It also demonstrates that people who use injection drugs can turn their lives around and can lead positive and productive lives, even after being infected with HIV. This pamphlet cannot be evaluated on the basis of the criteria established for the other documents, because it is not aimed at providing education about home care.

When We Are Together was developed by the Le Chan AIDS Bureau and World Vision International in 2002. It is a small (15 by 10.5 cm) pamphlet with a card-stock cover. The pamphlet is smaller than necessary, and the small size limits its content. Its content and format are similar to those of *Family and People Living with HIV/AIDS* and *Taking Care of HIV/AIDS Infected People at Home*. *When We Are Together* does not have a table of contents or an index. Subjects covered include the advantages of home care, sanitation and preventing transmission in the home, common illnesses (including information about treatment and when to seek medical assistance), guidelines for practical skills in caring for ill people, and medications (both traditional and Western).

This publication does not cover the stages and development of HIV infection and AIDS, HIV transmission and prevention (except for sanitation in the home), staying healthy/prevention of opportunistic infections, mental health, or financial planning and assistance. It does cover essential information about common illnesses and symptoms and makes some use of local colloquial terms.

The publication includes an extensive section on practical skills for caring for ill people, including using oral rehydration salts, salt-rice soup, chlorine solution, alcohol solution, potassium permanganate, gentian violet, salt water for washing wounds, and salt water for rinsing mouths; taking a temperature; sterilizing syringes/needles; and making gloves. It has the most complete section on traditional remedies, including a list of recommended herbs and eight recipes for relief of fever, diarrhea, itching skin, and cough. A table on the back cover of the pamphlet lists nine commonly used medicines by name and gives information on price, indications, dosage, and instructions.

The tone is supportive, and the style of the illustrations is culturally appropriate. The illustrations clarify and emphasize the text.

Overall strengths: This pamphlet provides the most complete information about traditional remedies of all the publications assessed. The table of common Western medicines for treatment of illness and symptoms is the most complete and user-friendly found in any of these publications. Information on practical skills needed in caring for ill people is in a separate section, which makes it easy to locate.

Overall weaknesses: Many of the topics of significant interest to PLWHA and caregivers are omitted from this publication. The pamphlet does not include information about the stages and development of HIV infection and AIDS or HIV transmission and prevention (other than sanitation in the home), practical suggestions for how to stay healthy and avoid opportunistic infections, or information about antiretroviral therapy, emotional care and support, and financial planning and assistance.

Taking Care of HIV/AIDS Infected People at Home was developed by the Ho Chi Minh City AIDS Committee. The text of this publication is identical to that of *Family and People Living with HIV/AIDS*. Improvements in *Taking Care of HIV/AIDS Infected People at Home* include a larger font size and replacement of the dated/inaccurate photograph on the cover from a picture of two hands covering an injection needle to the single-hand method for covering needles.

Taking Care of Your Loved Ones at Home was produced by the Ho Chi Minh City AIDS Committee and Medecins du Monde, with funding from UNICEF, in 1999. The objective of this publication is to give people information about taking care of people with AIDS in the home; the target group is primarily family caregivers and secondarily PLWHA. It is a large (8.5 by 11 inch) booklet with a tape binding and plastic cover that shows an illustration of a family eating together. This booklet is divided into two parts and nine chapters and includes a detailed table of contents but no index. Part 1 covers the basics of home care and includes chapters one through seven. Chapter 1 describes home care and its advantages. Chapter 2 has detailed information about HIV, progression from HIV infection to AIDS, signs that AIDS has developed, the role of opportunistic infections, how HIV is and is not transmitted, and prevention of sexual transmission. It uses simplified terminology, yet fully describes HIV infection and AIDS. Chapter 3 covers staying healthy, including hygiene, nutrition, food hygiene, safe water, and avoidance of malaria. Chapter 4 covers emotional care for PLWHA. Chapter 5 covers emotional support and care for caregivers, including stigmatization and discrimination. Chapter 6 covers general guidelines for physical care, including practical information about care for bedridden individuals. Chapter 7 covers physical and emotional care for a dying family member.

Part 2 focuses on resources for care and includes chapters 8 and 9. Chapter 8 describes symptoms and illnesses, including fever, diarrhea, skin problems, mouth problems, tuberculosis, coughing and difficulty breathing, genital problems, nutrition, nausea, pain management, tiredness, and dementia; their treatment; and when to seek medical help. Chapter 9 covers pregnancy and birth, care for children with HIV infection or AIDS, drug addiction, and depression.

The terminology is simple enough to be easily understood by a lay reader. The essentials of transmission and how HIV is not spread are covered. Prevention of sexual transmission is carefully described, and a full-page illustration of the proper use and disposal of condoms is included. However, prevention of transmission via blood and mother-to-child transmission are omitted. Particularly relevant is the omission of information about prevention of infection for IDUs and about needle sterilization. The transmission section makes one confusing statement: It specifies that kissing on the cheeks, hands, and forehead is safe but later (on the same page) states that oral sex and kissing are not safe practices.

This publication's discussion of staying healthy and preventing opportunistic infections includes information about personal hygiene, food hygiene, nutrition (specific food suggestions are given, but not daily recommendations), and exercise. Sanitation information is limited to a small section on laundering clothing and bedding soiled with body fluids. Use of a bleach solution is recommended, but directions for preparing such a solution and a recommended concentration are not provided.

Clear and comprehensive information about common illnesses and symptoms is included, but the information about medications is limited. Some medicines and traditional treatments for specific conditions are described (e.g., gentian violet, mashed papaya, and unsweetened yogurt for cleaning wounds and gentian violet, garlic, and unsweetened yogurt for thrush). Antiretroviral medications are not

covered. The section on tuberculosis warns about the need to take the full course of prescribed medications. One confusing statement about traditional remedies advises that traditional remedies are useful as long as they are not dangerous, without elaborating on what potential dangers may be.

The two chapters on mental health and emotional support cover the range of possible emotional responses to an HIV diagnosis, multiple practical suggestions for maintaining and improving mental health, suggestions for emotional support that caregivers can provide, and information about emotional support and care for caregivers. Support groups are mentioned, but specific information about where to find support groups, counselors, and mental health care is omitted.

Financial planning and assistance information is omitted. However, the booklet does include information about long-term planning for health care needs, preparing for dying, and planning for care and support for children after the death of a parent.

The tone of the booklet is compassionate and supportive. The text is easy to understand, and the information flows logically. The few illustrations that are included serve chiefly to break up the text; many of them portray suffering.

Overall strengths: The text is well written, with easy-to-understand language, clearly labeled topics and a logical flow of information. The book provides comprehensive information about HIV and progression from HIV infection to AIDS. The language in the chapter on common illnesses and symptoms is less technical than that in any other of the publications discussed here. The chapters on mental health are comprehensive.

Overall weaknesses: Information about prevention of HIV transmission through blood, transmission through needle sharing, and mother-to-child transmission is omitted. The booklet lacks detailed information about medications and financial planning. Negative, anxiety-producing illustrations contradict the supportive text. A smaller size and the inclusion of an index or tabs would improve the presentation, although the detailed table of contents is helpful.

Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care was developed by the Ho Chi Minh City AIDS Committee and Medecins du Monde, with funding from UNICEF. This book is a companion to *Taking Care of Your Loved Ones at Home*. The objective is to help medical workers, counselors, community workers, volunteers, and families to provide good, safe, compassionate care in the home for PLWHA. The target group is health care workers; family caregivers are a secondary target. It is a large (8.5 by 11 inch) book, with a tape binding and a plastic cover that shows an illustration of a family eating together. The curriculum includes an explanation of home care, discussions of positive living and teaching skills, basic information about HIV and HIV transmission, advice on staying healthy and preventing illness, and assistance in providing physical care, emotional care, planning for the future, providing care for the caregiver, and care for the dying.

This publication must be assessed in conjunction with *Taking Care of Your Loved Ones at Home*. Specific information is included in the latter volume, and the training curriculum provides information about training health care workers to teach the

information in *Taking Care of Your Loved Ones at Home* to families and PLWHA. The strengths and weaknesses of the training curriculum parallel the information provided in the other publication. As a training tool, the curriculum could be very helpful to health care workers. On its own, it would be of limited value to PLWHA and caregivers.

Appendix D. Comments based on reviews of selected information, education, and communication materials for people living with HIV/AIDS (PLWHA) and caregivers

Characteristic	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume I</i>	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume II</i>	<i>Care for People Living with HIV/AIDS</i>
Organization or agency	Le Chan AIDS Committee, World Vision International, AusAID	Le Chan AIDS Committee, World Vision International, AusAID	Vietnam Ministry of Health, AIDS Division
Year	2002	2002	1998 and 2001
Objective	Separate objectives for each chapter.	Separate objectives for each chapter.	Strengthen care and counseling for PLWHA.
Target group	PLWHA, caregivers, and family members.	Health care and social workers.	Not stated; health care workers implied.
Information supplied			
General			
Explanation of HIV/AIDS	Detailed description of HIV and AIDS in chapter 3, including how it affects the body, progression of disease, signs that AIDS has developed.	Covered in volume I.	Clinical description of HIV and progression of disease, technical language (e.g., "CD4 reception," "lymphocytes," "epicellium").
Modes of transmission and nontransmission	Clear information about non-transmission. Transmission sections discuss mother-to-child and blood transmission, followed by detailed section on STIs and then discussion of sexual transmission.	Covered in volume I.	Covers the essentials of how HIV is and is not transmitted; uses technical terms (e.g., "encephalopinal," "peritoneum," "pleural fluid").
Methods of prevention	Prevention addressed in conjunction with transmission; includes multiple alternatives for prevention of various modes of transmission.	Covered in volume I.	Lists multiple alternatives for preventing sexual and blood transmission. Recommends that "female youth" with HIV not get married, not get pregnant, and not have abortions. Prevention of mother-to-child transmission covered in section on illnesses.
Financial planning and assistance	Not covered.	Mentions the right on PLWHA to work.	Not covered.
HIV testing	Mentioned as part of HIV/AIDS description.	Mentions that HIV testing should be encouraged, not forced.	Lists different tests, most common in Vietnam, how to interpret test results.
Definition of home care	Defines home care and its advantages.	Covered in volume I.	Not covered.
Care for PLWHA			
Staying healthy	Addresses behavior change, maintaining optimism, nutrition, hygiene, exercise, support groups,	Covered in volume I.	Lists suggestions for positive living, but not detailed (e.g., regular nutrition, do

Characteristic	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume I</i>	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume II</i>	<i>Care for People Living with HIV/AIDS</i>
	maintaining contact with friends and family		exercise, do not share needles).
Sanitation	Describes cleaning and disposal of blood and body fluid stained items.	Covered in volume I.	Mentions washing hands, using chlorine solution to clean blood and body fluid stains.
Preparation of sanitation solutions	Recommends 0.5-percent chlorine solution with mixing instructions	Covered in volume I.	Not covered.
Hygiene	Not covered.	Not covered.	Hand washing, food hygiene, toilet location, safe water covered in section on diarrhea.
Diet and nutrition	Suggests specific foods, but not daily recommendations.	Covered in volume I.	Short list of foods provided in section on diarrhea.
Exercise	Mentioned in section on leading a positive life.	Covered in volume I.	Exercise mentioned in section on positive living; little detail.
Information about common symptoms: treatment, prevention, when to seek help	Common symptoms/illnesses described, including treatment and when to seek medical help.	Covered in volume I.	Common symptoms/illnesses described, including treatment and when to seek medical help. Liberal use of clinical terms.
Medicines: Western and traditional	Mentions that antiretroviral drugs are prohibitively expensive. Recommends traditional herbal remedies and tonics, but not names of herbs or where to buy them.	Covered in volume I.	Azidothymidine mentioned in section on preventing mother-to-child transmission. Section on medications for symptoms and illnesses written for health care worker, includes avoiding steroids and recommended medications and dosage for various conditions.
Practical skills needed to care for ill people	Health care skills: taking a temperature, measuring breathing rate and pulse, use of ORS and salt-rice soup	Covered in volume I.	Not covered.
Emotional support and care for PLWHA and caregivers	Discusses emotional responses, importance of family love and support and other support networks. Emotional support for caregivers. Behavior change section for reducing high-risk activities.	Detailed discussion in section on counseling skills.	Anxiety and boredom are discussed in the section on common symptoms; lists emotional responses, and recommends exercise, work, rest, and maintaining contact with family and friends. No specific suggestions for support in Vietnam.
Available services	Mentions Friend-Help-Friend and Hai Au clubs and social services, but not how to find these groups, except that they exist in Ho Chi Minh City, Chanh	Information to help health care and social workers provide services, but no details on where to find services.	Not covered.

Characteristic	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume I</i>	<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume II</i>	<i>Care for People Living with HIV/AIDS</i>
	Hoa, Ha Noi, and Hai Phong.		
Presentation			
Format (e.g., chapters, story, headings)	Medium-sized (15 by 21 cm) booklet, with chapters and subheadings.	Medium-sized (15 by 21 cm) booklet, with chapters and subheadings.	Medium-sized (13 by 19 cm) booklet. Bound with card-stock cover.
Identification of subjects	Chapters with subheadings.	Chapters with subheadings.	In two parts, with subheadings.
Sequence	Logical flow from subject to subject; however, HIV transmission section addresses blood and mother-to-child transmission and then a detailed section on STIs, followed by sexual transmission and prevention of HIV.	Logical flow from subject to subject.	Logical flow from subject to subject.
Illustrations: type, relevance to text	Appropriate (familiar) illustrations. Some enhance and clarify text; others serve as visual appeal.	Very few illustrations used.	No illustrations.
Text: clarity, difficulty	Clear, detailed descriptions using local measurements; however, some technical/clinical terms used.	Clear, nontechnical text.	Liberal use of technical/clinical terms. Written for health care professionals.
Tone			
Tone of text and illustrations	Supportive.	Supportive and compassionate.	Neutral.
Is a particular group singled out for blame/fear?	No.	No.	No.
Suggestions for prevention and positive living	Practical alternatives offered for prevention. Positive living information includes some practical suggestions, but needs more detail about how, when, and where.	Not applicable.	Recommends that HIV-positive young women not get married, have babies, or have abortions.
Other comments	Developed with significant involvement of PLWHA and caregivers through questionnaires and three workshops. STI and behavior change sections were helpful, but clinical terms were overused.	Good sections on counseling, including specific needs of PLWHA and general counseling skills. The chapter on gender issues addresses the increased risk, greater burden of care and support, and stigmatization of women.	

Characteristic	<i>With Hope and Support</i>	<i>HIV/AIDS Prevention in the Community</i>	<i>Stay Fit—Feel Good</i>
Organization or agency	National AIDS Standing Bureau	National AIDS Standing Bureau, Ha Noi School of Medicine	PATH
Year	2001	2001	2001
Objective	Basic information on caregiving for PLWHA.	To help health care workers implement AIDS prevention activities.	To provide guidelines on community-based care for community volunteers, PLWHA, family members, and caregivers.
Target group	PLWHA, family, and caregivers.	Health care workers at the grassroots level.	PLWHA (PLWHA, community volunteers, family members, and caregivers).
Information supplied			
General			
Explanation of HIV/AIDS	Cursory explanation of virus, HIV stage, AIDS stage and role of opportunistic infections.	Thorough, highly technical description of the biology of HIV, progression of the disease, and guidelines for clinical diagnosis of AIDS.	Not covered.
Modes of transmission and nontransmission	Section on transmission explains the three modes of transmission (sex, blood, and mother-to-child). Nontransmission explained in home care section.	Missing pages. Includes information about safe blood transfusion.	Not covered.
Methods of prevention	Multiple alternatives offered for each mode of transmission (sex, blood, and mother-to-child). Covered in section about transmission.	Detailed section on prevention in the medical setting. Cursory discussion of prevention in the home setting, but does include condom use and sterilizing needles.	Not covered.
Financial planning and assistance	Not covered.	Discusses planning for the future, death, and care for children after death. Financial planning and assistance is not covered.	Not covered.
HIV testing	Not covered.	Clinical description of tests and testing for newborns.	Not covered.
Definition of home care	Advantages discussed in first section.	Lists the advantages of home care.	Not covered.
Care for PLWHA			
Staying healthy	Discussed in section about leading a positive life, including emotional support, hygiene, exercise, sanitation.	Limited discussion of household items to be separated.	Addresses opportunistic infections associated with HIV/AIDS, symptom-based care, useful medicinal plants, drug use, recommendations for over-the-counter drugs and healthy and unhealthy practices. Addresses psychological aspects of living with HIV/AIDS, including how to deal with psychological problems and how to assist

Characteristic	<i>With Hope and Support</i>	<i>HIV/AIDS Prevention in the Community</i>	<i>Stay Fit—Feel Good</i>
Sanitation	Detailed description of how to clean and/or dispose of items soiled by blood and body fluids.	Detailed section on sterilization in the medical setting.	PLWHA. Description of how to clean body and wounds, sterilize and/or dispose of items soiled by blood and body fluids by burning or burying.
Preparation of sanitation solutions	Recommends soaking soiled items in 1.0-percent chlorine solution, no information about how to prepare solution.	Recommends use of 0.05- to 0.1-percent chlorine solution.	Recommends use of Lysol when handling sputum; soaking in warm water mixed with salt after defecation; drying and applying body lotion; using soap to keep hands and body clean.
Hygiene	Covers hand washing, toilet cleaning, and food hygiene.	Discusses hand washing and food hygiene.	Discusses hand washing, burning or burying for proper disposal; keeping the living area clean and well-ventilated and allowing direct sunlight to shine in. Recommends that food be cooked and clean.
Diet and nutrition	Recommends eating nutritious food with a list of five specific food suggestions. No other details.	Daily requirement defined in calories, some specific food recommendations that are appropriate to Vietnam.	Recommends taking supplemental food regularly with detailed types of food and multivitamins. Some specific food is recommended in section on dealing with opportunistic infections.
Exercise	Recommends daily morning exercise, but not duration of exercise or suggested activities.	Not covered.	Recommends daily exercise within personal physical limits.
Information about common symptoms: treatment, prevention, when to seek help	Detailed section on symptoms, treatment, and seeking help. Advice for preventing illness is covered in section on positive living.	In section on home-based care, provides description, treatment advice, and information about when to seek medical attention for common symptoms and illnesses.	Detailed descriptions of symptoms, treatment, drug use, prevention, eating food and when to seek help.
Medicines: Western and traditional	Mentions some Western medicines and dosages for treatment of specific illnesses or symptoms. Recommends traditional remedies but offers no specific suggestions or where to find them.	Covers guidelines for antiretroviral therapy, with dosage instruction in annex 1. Guidelines and dosage for use of azidothymidine and nevirapine in pregnancy. Annex 2 lists common illnesses, recommended medications, and dosages.	Detailed recommendations for over-the-counter drugs to treat or relieve specific opportunistic infections, with dosage instructions and descriptions of drug and its brand name. Recommends traditional remedies with common and scientific names and photographs. Suggests an address for additional information and medicinal plant seedling contact.
Practical skills needed to care for ill people	Practical skills included in section on illnesses, including taking temperature, preparing ORS, moving bedridden patients.	ORS preparation only.	Includes practical skills for each section on opportunistic infections, such as specific steps for care during seizures/spasms, vision loss, fever, diarrhea, and vomiting.

Characteristic	<i>With Hope and Support</i>	<i>HIV/AIDS Prevention in the Community</i>	<i>Stay Fit—Feel Good</i>
Emotional support and care for PLWHA and caregivers	Explains emotional responses and how family can provide emotional support.	Limited discussion of emotional responses to HIV diagnosis.	Explains psychological problems common to PLWHA. Provides basic approaches in dealing with emotional problems. Provides guidelines for assisting dying PLWHA and bereaved families.
Available services	Not covered.	Mentions Friend-Help-Friend groups.	Gives contact address for finding medicinal plants.
Presentation			
Format (e.g., chapters, story, headings)	Medium-sized (15.5 by 20.5 cm), bound, card-stock-covered booklet.	Medium-sized (16 by 24 cm) textbook. Bound with card-stock cover.	Large-sized (21 by 28 cm) bound book, with heavy, durable plastic-coated pages.
Identification of subjects	Chapter titles and headings. Table of contents is limited to chapter titles.	Includes a table of contents and subject headings.	Manual is divided into two sections, and subjects are conveniently laid out on both sides of the manual.
Sequence	Subjects follow a logical sequence: (1) home care, (2) transmission/prevention, (3) positive living, (4) common illnesses.	Information has a logical flow.	Subjects follow a logical flow: In "Stay Fit": (1) common symptoms of specific opportunistic infections, (2) home care, (3) care during and after symptoms, (4) when to seek a doctor, (5) reminders. In "Feel Good": (1) home visits, (2) understanding psychological problems of PLWHA, (3) basic approaches to emotional problems, (4) guidelines for assisting dying PLWHA, (5) guidelines for assisting bereaved families.
Illustrations: type, relevance to text	Good use of illustrations; images are appropriate (familiar to readers); illustrations add clarity to text.	Limited use of illustrations; a few charts and medical illustrations.	Good illustrations with simple text; good medical illustrations and photographs of traditional medicinal plants. However, illustrations are overused, cluttering the pages.
Text: clarity, difficulty	Mostly simplified language. Limited use of technical terms in section on common illnesses. No colloquial expressions used.	Highly technical writing. Written for a medical professional.	Mostly simplified language; no use of medical terms; large type is easy to read.
Tone			
Tone of text and illustrations	Supportive tone; exhibits compassion for PLWHA.	Supportive tone.	Supportive tone, exhibits compassion for PLWHA.
Is a particular group singled out for blame/fear?	No.	No.	No.

Characteristic	<i>With Hope and Support</i>	<i>HIV/AIDS Prevention in the Community</i>	<i>Stay Fit—Feel Good</i>
Suggestions for prevention and positive living	Range of options provided.	Does not offer many prevention options for individuals. Prevention directed at the medical setting.	Offers few prevention options for caregivers and good suggestions for leading a positive life.
Other comments	None.	Contains pieces of useful information, but this information can be difficult to find. Reader must sort through a great deal of technical, policy, and epidemiological surveillance material. Technical/clinical nature makes book not effective for PLWHA and family caregivers. Good information contained in sections on HIV infection in pregnancy, obstetrics, and care for newborns; relationship between HIV and STIs; and guidelines for counseling.	Contains good illustrations, with photographs of traditional medicinal plants; detailed description of drugs and dosage instructions; provision of useful caring steps during and after opportunistic symptoms. Simple manual, useful to PLWHA. Contains information on both physical and psychological care that is conveniently laid out on both sides of the manual. A little heavy for ill people to carry.

Characteristic	<i>Family and People Living with AIDS</i>	<i>A Green Candle</i>	<i>When We Are Together</i>
Organization or agency	Ho Chi Minh City AIDS Prevention Committee	Le Chan AIDS Bureau and World Vision International	Le Chan AIDS Bureau and World Vision International
Year	1995	2002	2002
Objective	Not stated.	Not stated.	Not stated.
Target group	Not stated.	Not stated.	Not stated.
Information supplied			
General			
Explanation of HIV/AIDS	Explanation of HIV/AIDS, progression of the disease, and signs that AIDS has developed. AIDS are not covered.	Not covered.	Not covered.
Modes of transmission and nontransmission	Accurately describes how HIV is and is not transmitted.	Not covered.	Explains that HIV is not transmitted through ordinary social contact. Does not cover how HIV is transmitted.
Methods of prevention	Mentions condom use. No other preventions are covered.	Not covered.	Explains how to sterilize syringes. No other modes of transmission covered.
Financial planning and assistance	Lists address and telephone number of the Labor League in Ho Chi Minh City.	Mentions that Hung was sponsored by the Le Chan District AIDS Bureau and World Vision International to buy a cyclo.	Not covered.
HIV testing	Not covered.	Not covered.	Not covered.
Definition of home care	Describes advantages of home care.	Not covered.	Lists advantages.
Care for PLWHA			
Staying healthy	Lists things to avoid (e.g., malnutrition, drug use, anxiety, STIs) but gives no details about how to achieve these recommendations.	Not covered.	Section on sanitizing home.
Sanitation	Includes information about household utensils that can be shared and those that should be separated, cleaning and disinfecting items soiled with blood and bodily fluids, and disposal of soiled items. Recommends placing needles and syringes in a double plastic bag.	Not covered.	Includes information about household utensils that can be shared and those that should be separated, cleaning and disinfecting items soiled with blood and bodily fluids, and disposal of soiled items and used syringes. Warns against using hands to cover used needles. Recommends using pincers instead.
Preparation of sanitation	Includes information about how to mix chlorine	Not covered.	Recommends use of 0.5-percent

Characteristic	<i>Family and People Living with AIDS</i>	<i>A Green Candle</i>	<i>When We Are Together</i>
solutions	and alcohol solution and where to purchase.		chlorine solution, with instructions for how to mix.
Hygiene	Not covered.	Not covered.	Hand washing and food hygiene mentioned in section on diarrhea.
Diet and nutrition	Not covered.	Not covered.	Not covered.
Exercise	Not covered.	Not covered.	Not covered.
Information about common symptoms: treatment, prevention, when to seek help	Detailed description of common illnesses/symptoms, treatments, and when to seek medical assistance. Liberal use of clinical terms (e.g., "dermatic," "zona," "candidiasis," "dyspnoea")	Not covered.	Detailed description of common illnesses/symptoms, treatment and when to seek medical assistance. Closely resembles common illnesses sections in book 7 and book 10. Includes some clinical terms (e.g., "dermatosis," "zona," and "blain") but also uses local expressions (measurements using rice bowls, stool mixed with "white seeds like hogwash").
Medicines: Western and traditional	Describes some medications in the treatment sections for the various illnesses/symptoms but no dosage information. Has a heading for dangerous Western medications but does not explain when PLWHA might have contact with these medications.	Not covered.	Detailed section about traditional remedies, including recommended herbs and 8 recipes for relief from fever, diarrhea, itching skin and cough. A table on the back cover of the pamphlet lists 9 commonly used medicines by name, price, indication, dosage and instructions. Antiretrovirals are not covered.
Practical skills needed to care for ill people	Includes preparation of ORS.	Not covered.	Pamphlet includes a section on practical guidelines for caring for ill people, including use of ORS, salt-rice soup, chlorine solution, alcohol solution, potassium permanganate, gentian violet, salt water for washing wounds, salt water for rinsing mouths; taking a temperature; sterilizing syringes/needles; and making gloves.
Emotional support and care for PLWHA and caregivers	Cursory recommendations (do not abandon, do not stigmatize, treat with compassion and respect).	Mentions possible emotional responses to an HIV diagnosis and suggests that active participation in support groups and unconditional love of families can help PLWHA to lead a positive life.	Not covered.
Available services	Lists names, addresses, and telephone numbers	Le Chan AIDS Bureau, World Vision	Not covered.

Characteristic	<i>Family and People Living with AIDS</i>	<i>A Green Candle</i>	<i>When We Are Together</i>
	for seven medical centers and social support organizations in Ho Chi Minh City.	International, Friend-Help-Friend groups	
Presentation			
Format (e.g., chapters, story, headings)	Medium-sized (14 by 19.5 cm) pamphlet with subject headings.	Small (15 by 10.5 cm) pamphlet telling story of young man with HIV. Photo novella.	Small (15 x 10.5 cm) pamphlet with card-stock cover.
Identification of subjects	Subject headings only; no table of contents or index.	Story, no subject headings.	Subject headings.
Sequence	Follows a logical sequence: (1) reasons for home care, (2) sanitation, (3) symptoms and illnesses.	Progression of man's life from good job to first injection drug use to addiction to HIV infection to turning life around with support of family.	Information flows logically.
Illustrations: type, relevance to text	Illustrations used to clarify text; one negative photo of downcast, emaciated individual with AIDS. One dated and dangerous photo showing use of two hands to cover an injection needle.	Cartoon-type illustrations are integral part of the story.	Appropriate, familiar illustrations used. Illustrations are upbeat and clarify/highlight the text.
Text: clarity, difficulty	Very small type used. Liberal use of technical terms; some confusing descriptions.	Clear, simple text.	Limited use of technical language in descriptions of symptoms and medications. Two methods for needle sterilization described, boiling and the 2-2-2 method. The recommendation for the 2-2-2 method is confusing, because it states this should not be used for patients.
Tone			
Tone of text and illustrations	Neutral.	Supportive, compassionate.	Neutral to supportive.
Is a particular group singled out for blame/fear?	No.	No; demonstrates how good people can fall into drug addiction.	No.
Suggestions for prevention and positive living	Recommends condom use. Also suggests avoidance of drug use and anxiety, but no detail is provided on how to achieve these suggestions.	Not covered.	Not covered.
Other comments	Text is identical to that of <i>Taking Care of HIV/AIDS Infected People at Home</i> .	Story about positive living and turning life around after drug addiction. Helps to destigmatize injection drug use by demonstrating how a good person can fall into drug addiction.	None.

Characteristic	<i>Handbook: Taking Care of HIV/AIDS Infected People at Home</i>	<i>Taking Care of Your Loved Ones at Home</i>	<i>Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home care</i>
Organization or agency	Ho Chi Minh AIDS Committee	Ho Chi Minh City AIDS Committee, Medecins du Monde, UNICEF	Ho Chi Minh City AIDS Committee, Medecins du Monde, UNICEF
Year	2000	1999	1999
Objective	Not stated.	To give people information on taking care of people with AIDS in the home.	To help medical works to provide good, safe, compassionate care in the home.
Target group	Not stated.	Family caregivers and PLWHA.	Medical workers.
Information supplied			
General			
Explanation of HIV/AIDS	Explanation of HIV/AIDS, progression of the disease and signs that AIDS has developed are not covered.	Fully described in easy-to-understand terms in chapter 2. Includes progression of disease and development of AIDS.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Modes of transmission and nontransmission	Accurately describes how HIV is and is not transmitted.	Clearly defines transmission through sex, blood, and mother-to-child. Describes how HIV is not spread. Contradicting statements about kissing on lips.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Methods of prevention	Mentions condom use. No other preventions are covered.	Describes prevention of sexual transmission, including diagram showing proper condom use. Does not describe preventive measures for injection drug users. Appendix B describes home childbirth, but does not describe how to prevent transmission to baby.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Financial planning and assistance	Lists address and telephone number of the Labor League in Ho Chi Minh City.	Discusses planning for the future (death and care for orphaned children) but not concrete steps—no financial information.	Not covered.
HIV testing	Not covered.	Not covered.	Not covered.
Definition of home care	Describes advantages of home care.	Chapter 1 addresses home care and its advantages.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .

Characteristic	Handbook: Taking Care of HIV/AIDS Infected People at Home	Taking Care of Your Loved Ones at Home	Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home care
Care for PLWHA			
Staying healthy	Lists things to avoid (e.g., malnutrition, drug use, anxiety, STIs) but gives no details about how to achieve these recommendations	Described in chapter 3.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Sanitation	Includes information about household utensils that can be shared and those that should be separated, cleaning and disinfecting items soiled with blood and bodily fluids, and disposal of soiled items. Recommends placing needles and syringes in a double plastic bag.	How to clean items soiled with blood and body fluids is mentioned in chapter 3.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Preparation of sanitation solutions	Includes information about how to mix chlorine and alcohol solution and where to purchase materials.	Not covered.	Not covered.
Hygiene	Not covered.	Hand washing, bathing, and food hygiene.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Diet and nutrition	Not covered.	Includes a list of food groups and specific suggestions but not daily recommendations or tips for time and cost savings.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Exercise	Not covered.	Limited coverage in chapter 4, which focuses on stress management.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Information about common symptoms: treatment, prevention, when to seek help	Detailed description of common illnesses/symptoms, treatment and when to seek medical assistance. Liberal use of clinical terms (e.g., "dermatic," "zona," "candidiasis," "dyspnea")	Describes common problems in chapter 8, including treatment and when to seek medical help.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Medicines: Western and traditional	Describes some medications in the sections on treatment of various illnesses/symptoms but gives no dosage information. Has a heading for dangerous Western medications but does not explain when PLWHA might have contact with these medications.	Describes some traditional medicines in treatment of specific conditions. Chapter 6 mentions taking full course of prescribed medications. Confusing statement that traditional remedies are useful as long as they are not dangerous, without elaboration. Antiretroviral drugs are not covered.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Practical skills needed to care for ill people	Includes preparation of ORS.		
Emotional support and care for PLWHA and caregivers	Cursory recommendations (do not abandon, do not stigmatize, treat with compassion and respect).	Full coverage of emotional care for PLWHA (chapter 4) and caregivers	Covered in <i>Taking Care of Your Loved Ones at Home</i> .

Characteristic	<i>Handbook: Taking Care of HIV/AIDS Infected People at Home</i>	<i>Taking Care of Your Loved Ones at Home</i>	<i>Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home care</i>
Available services	Lists names, addresses, and telephone numbers for seven medical centers and social support organizations in Ho Chi Minh City.	(chapter 5), with practical suggestions. Mentions social workers and support groups but not where to find these. Not covered.	Not covered.
Presentation			
Format (e.g., chapters, story, headings)	Medium-sized (14 by 19.5 cm) pamphlet with subject headings.	Large (8.5 by 11 inch) chapter booklet with tape binding and plastic cover.	Large (8.5 by 11 inch) book.
Identification of subjects	Subject headings only, no table of contents or index.	Detailed table of contents with chapters and subject headings.	Subject headings.
Sequence	Follows a logical sequence: (1) reasons for home care, (2) sanitation, (3) symptoms and illnesses.	Logical flow of information, clearly divided into chapters.	Logical flow.
Illustrations: type, relevance to text	Illustrations used to clarify text; one negative photo of downcast, emaciated individual with AIDS. One dated and dangerous photo showing use of two hands to cover an injection needle.	Limited use of cartoon drawings, most of which do not clarify text and many of which portray suffering.	No illustrations.
Text: clarity, difficulty	Very small type used. Liberal use of technical terms; some confusing descriptions.	Clear, nontechnical text. Simplified and informative descriptions of medical terms and conditions. No colloquial expressions.	Clear, nontechnical text.
Tone			
Tone of text and illustrations	Neutral.	Supportive, compassionate, and helpful.	Supportive, compassionate, and helpful.
Is a particular group singled out for blame/fear?	No.	No.	No.
Suggestions for prevention and positive living	Recommends condom use. Also suggests avoidance of drug use and anxiety, but no detail is provided on how to achieve these suggestions.	Practical preventive information, but incomplete. Needle sharing not covered, no specific suggestions for assistance.	Covered in <i>Taking Care of Your Loved Ones at Home</i> .
Other comments	Text is identical to that in <i>Family and People Living with AIDS</i> .	Includes a chapter on care of the	This is a companion to <i>Taking</i>

Characteristic	Handbook: Taking Care of HIV/AIDS Infected People at Home	Taking Care of Your Loved Ones at Home	Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home care
	<i>Taking Care of HIV/AIDS Infected People at Home</i> has been improved by the use of a larger type, and the dated/inaccurate picture on the front of two hands covering an injection needle has been replaced with a picture of the single-hand method for covering needles.	dying and an appendix on body lifts for bedridden people.	<i>Care of Your Loved Ones at Home</i> .

NOTE. ORS, oral rehydration salts; STIs, sexually transmitted infections.

Appendix E. Care and support stakeholder semi-structured questionnaire

PATH is gathering information from different NGOs practice in Viet Nam about program and IEC material regarding caring for PLWHA. We want to take a few minute to talk with you about program you have in caring for PLWHA.

Your information is very helpful for determine the gap in services and IEC material available for caring PLWHA.

Organization

Name:

Address:

Telephone:

Do you have any program or IEC materials related to caring for PLWHA or caregiver? If Yes. Please ask questions 101 to 103

Contact person:

Make the appointment

Can we have a copy of your material when we will meet together?

Project information

101. Name:

102. Duration:

103. Project site:

104. Donor:

105. Local partner:

106. Brief description of project:

IEC/BCC information

201. What are the aims of using IEC/BCC materials in your project?
Please give three reasons.

- 1.
- 2.
- 3.

202. Name, type of IEC/BCC materials used in your project?

Name	Type (leaflet, flipchart, poster, banner, video, cassette tape, CD, radio, TV program, internet, etc)
1.	
2.	

203. Source of materials? (There maybe different kinds of materials are used, in your project. Please take the number you used in the above table to indicate each materials)

Material 1:

1. Adapted from materials of other organizations/project
Source of material

2. Self-developed
Process to develop
Lesson learned

Material 2:

1. Adapted from materials of other organizations/project
Source of material

2. Self-developed
Process to develop
Lesson learned

Material 3:

1. Adapted from materials of other organizations/project
Source of material

2. Self-developed
Process to develop
Lesson learned

Please state why you adapted from other organization or why you developed the materials by your-self?

204. Can you briefly describe the process of developing these materials? (If you use different process for different materials, please describe separately for each materials. The number of material below refers to number mentioned in question 203)

Material 1:

Material 2:

205. Why did you choose to develop it that way?

206. Did you have any guideline to develop these materials?

Yes

No

If yes, please specify the form of guideline used:

Training/workshop
Manuals
Supervision/technical assistance
FGDs/ IDIs
Inspiration from other projects
Other (please specify)

Human resources

301. Do you have a communication specialist in your office?

Yes

No

302. Was she/he involved in the development of the materials?

Yes

No

303. Did you involve any communication-trained persons in the IEC/BCC development process?

Yes

No

304. Drawing on your experience and your organization, how do you think IEC/BCC on HIV/AIDS could be improved in Vietnam?

I. General information

401. Contact address and email:

402. If needed, may we contact you again later for further information about your work in this field?

Yes

No

403. Will you be available for 1 day in August/September to take part in this consultation

Thank you very much for your consideration and for taking time to share with us. We wish you a good career and success in your projects.

Appendix F. Guidelines for discussion for persons living with HIV/AIDS (PLWHA) and caregivers

The purpose of these discussions is to identify the needs of PLWHA and their caregivers for information and education materials related to home care and community care. The objective is to determine the needs of PLWHA as they see them and the gaps in meeting those needs. We are looking to prioritize the information that is most important to PLWHA and the sources of information that are accessed by PLWHA.

General topics for discussion of home care in HIV infection period and in AIDS:

What are the home care needs of PLWHA during HIV infection period and in AIDS?

From the perspective of PLWHA, what are the needs of family members? What do PLWHA want family members to know about their care and support?

From the perspective of PLWHA, what are the needs of health workers? What do PLWHA want health workers to know about their care and support?

Suggested discussion topics for PLWHA:

Health care: What are the health care needs of PLWHA? Who provides care? How do PLWHA access care? Where do PLWHA find care?

Health Facilities: Are healthcare facilities available to PLWHA? Do PLWHA know where to find healthcare facilities and do they have transportation? What is the quality of services provided? Do PLWHA experience stigma or discrimination in healthcare facilities? By health workers?

Nutrition: Do PLWHA know the fundamentals of adequate nutrition? Do PLWHA know which food will provide the best nutrition? Do PLWHA understand how nutrition can affect their long-term health? Do PLWHA understand the effects of nutrition on prevention of opportunistic infections?

Infection prevention in home settings: Do PLWHA know how to maintain hygiene? Do PLWHA know how HIV is spread? Do PLWHA and their families know how to prepare sterilizing solutions? Do PLWHA have access to sterilizing products?

Disease progression: Do PLWHA understand the progression of HIV/AIDS?

Opportunistic infections: Do PLWHA know the common types of opportunistic infections to watch for? Do PLWHA know how to avoid opportunistic infections? Do PLWHA know how to treat opportunistic infections? Who provides treatment? Are treatments affordable? Are PLWHA or their family members knowledgeable about home remedies? Do PLWHA or family members know how to prepare ORT?

Anti-Retrovirals: Are ARs available? What do PLWHA think that ARs can do for them? Is it affordable? Do PLWHA think it is beneficial or effective?

Traditional medicine options: Are traditional medicines available? What do PLWHA think that traditional medicines can do for them? Do PLWHA think that traditional medicines are beneficial or effective? How much do the traditional medicines cost?

Pain Management: Is pain management available? Is it affordable? Where do PLWHA obtain pain medications?

Harm reduction: Are IDUs knowledgeable about the harmful effects of continued drug use for PLWHA? Do IDUs understand how to avoid spreading HIV? Do IDUs follow the practices to avoid spreading HIV? Do PLWHA know the risks of unprotected sex with both HIV- and HIV+ partners? Do PLWHA follow safer sex practices?

Family planning and reproductive health needs: Do PLWHA have access to contraceptives? Condoms? Do PLWHA know the issues/risks associated with pregnancy and breastfeeding for HIV+ women?

Access to welfare/social services: Are welfare/social service facilities available to PLWHA? Do PLWHA know where to find welfare/social service facilities and do they have transportation? What is the quality of services provided? Do PLWHA experience stigma or discrimination in welfare/social service facilities? By social workers?

Mental care and stress management: What do PLWHA need to know about their mental care? What do PLWHA need family members to know about their stress and mental health? What do PLWHA need health workers and social workers to know about their stress and mental health?

Healthcare planning: Who will provide care as the disease progresses? Where will care be obtained? What are the financial concerns of PLWHA as the disease progresses? If PLWHA have children, how will the children be cared for when the disease is advanced?

Dying and planning for death: Who do PLWHA talk with about dying? Have PLWHA made any plans for death? If PLWHA have children, who will care and provide for their children after their death? What are their financial concerns about dying? Do PLWHA know where they can seek assistance in planning for death?

Aspects of daily living with HIV/AIDS: Are there any other topics of daily living that PLWHA would find helpful?

Prioritize the most important information needed.

IEC Sources:

How do PLWHA get their information (e.g. TV., radio, newspaper, books, internet, booklets, leaflets, public announcements)? What are the sources of information PLWHA find most informative? Are there any sources of information that are more or less trustworthy?

Who do PLWHA talk with about their health care and emotions (e.g. friends, family, peers, other PLWHA, support groups, health workers, social workers, NGO service center staff, traditional healer)? Why these people? Are there people who PLWHA would not talk with about their health care and emotions? Who and why?

Written IEC Material: For written material, what is the best format (e.g. large book, booklet/size of booklet, leaflet)? Should the written material be fully comprehensive with plenty of detail or should it highlight the most important information? Should it have large or small print? Should it have photos, drawings or diagrams?

Have PLWHA found sources of information that answer most of their questions or that are particularly useful or effective? What are they? Have PLWHA found sources of information that are particularly unhelpful? What are they?

Appendix G. Information, education, and communication materials that have been collected in English and Vietnamese for people living with HIV/AIDS

Title	Source	Date
<i>Training Curriculum to Teach Health Workers How to Work with Families Providing AIDS Home Care</i>	Medecins du Monde, Ho Chi Minh City AIDS Committee, UNICEF	1999
<i>Taking Care of Your Loved Ones at Home</i> (a manual for AIDS home care)	Medecins du Monde, Ho Chi Minh city AIDS Committee, UNICEF	1999
<i>With the Remaining Days</i>	Binh Thanh AIDS Committee, Ho Chi Minh City	February 1998 (no publication)
<i>HIV/AIDS Prevention in the Community</i> (material for AIDS staff at grassroots level)	Ha Noi Medical School	2001 (medical publisher)
<i>With Hope and Support</i>	Vietnam Ministry of Health, National AIDS Standing Bureau	2001 (medical publisher)
<i>Training Manual: Home Care for PLWHA IV/AIDS</i> (information on HIV/AIDS for labor)	NCDPA, GTZ Care International in Vietnam	2002 (transportation publisher)
<i>Taking Care of HIV/AIDS Infected People at Home</i>	Ho Chi Minh City AIDS Committee, Health Education Center	2000
<i>Family and People Living with AIDS</i>	Ho Chi Minh City AIDS Committee	1995
<i>Taking Care of AIDS Patients at Home</i>	Ministry of Health	1991
<i>When We Are Together</i>	Le Chan AIDS Committee, WVI	2002
<i>A Green Candle</i>	Le Chan AIDS Committee, WVI	2002
<i>Home-Based Care and Support for People Living with HIV/AIDS, Volume I and Volume II</i>	Le Chan AIDS Committee—Hai Phong, WVI, AusAID	2002
<i>Handbook: Care for PLWHA</i>	Ministry of Health, AIDS Division	2001 (Ha Noi publisher)
<i>Stay Fit—Feel Good</i>	PATH Mekong	
<i>With Hope and Help, Manual for PLWHA/Manual on Self-Care, and Manual for Communities</i>	UNICEF	
<i>AIDS Home Care Handbook</i>	World Health Organization	
<i>Conducting a Training Course on Caring for HIV/AIDS at Home</i>	NCDPA, National AIDS Standing Bureau	April 2001
<i>Tuberculosis and HIV/AIDS</i>	Associate Professor Hoang Minh	2000 (medical publisher)
<i>Question and Answer about SIDA—AIDS</i>	Dr Nguyen Duc Toan	2001 (medical publisher)
<i>Basic Health Care Skills for Health Staff</i>	Ministry of Health, Scientific and Training Department	2001 (medical publisher)
<i>Guideline the Process to Take Care Patient</i>	Ministry of Health	2002 (medical publisher)
<i>Guide Families to Care for PLWHA</i>	National AIDS Standing Bureau	1999

Note. GTZ, Gesellschaft für Technische Zusammenarbeit; NCDPA, National Committee for AIDS Prevention and Drug and Prostitution Control; WVI, World Vision International.

Appendix H. Consultation participants and agenda

1. Consultation participants

26–27 August 2002

Ha Noi

Nine people living with HIV/AIDS (PLWHA) and five caregivers from Ha Noi and Hai Phong participated.

Dr. Tran Thu Hoa	Le Chan AIDS Committee, Hai Phong
Mr. Duong Minh Hung	Ba Dinh district AIDS Committee, Ha Noi
Mr. Nguyen Ngoc Tuan	Ba Dinh district AIDS Committee, Ha Noi
Mr. Hoang Huy Thiem	Ba Dinh district AIDS Committee, Ha Noi
Mr. Nguyen Van Qui	Ba Dinh district AIDS Committee, Ha Noi
Dr. Thomas Kane	Family Health International
Ms. Nancy Jamieson	Family Health International
Ms. Deborah Lawrence	Gesellschaft für Technische Zusammenarbeit
Ms. Le Thu Ha	Gesellschaft für Technische Zusammenarbeit
Ms. Tussnai Kantayaporn	PATH Mekong
Ms. Somporn Kritsuwannaratana	Lampang Province, Thailand field staff
Mr. Chris Herink	World Vision International
Dr. Laurent Zessler	Joint United Nations Programme on HIV/AIDS
Ms. Duong Hoang Quyen	Joint United Nations Programme on HIV/AIDS
Ms. Fran Murphy	Australian Red Cross
Ms. Huynh Lan Phuong	Australia Red Cross
Ms. Vu Thi Du	World Vision
Mr. Pham Tien Dung	World Vision International
Ms. Dao Thi Mai Hoa	Family Health International
Ms. Nguyen Thi Phuong Mai	Consultant for Family Health International
Ms. Le Viet Hoa	PATH
Ms. Ngo Thi Thanh Thuy	PATH
Ms. Nguyen Hoang Diep	PATH
Ms. Nguyen Thanh Binh	PATH
Ms. Bui To Van	PATH
Ms. Trinh Thu Huong	PATH
Dr. Tran Tuan Anh	Centre for Health Education, Ministry of Health
Dr. Bui Hong Son	Cooperative for Assistance and Relief
Everywhere	
Ms. Nguyen Thi Y Duyen	UNICEF
Serge Doussantousse	Independent consultant

2. Consultation agenda

Monday, 26 August 2002

8:00–8:30 Welcome and introduction
Explanation of consultation objective
Agreement of group discussion objectives and guidelines

8:30–10:00 Functional group discussions
People living with HIV/AIDS
Caregivers
Programme Staff
Experts

10:00–10:15 Break
10:15–10:45 Functional group discussions (continue)
10:45–12:00 Group presentations

12:00–13:00 Lunch
13:00–14:00 Thai experience presentation
14:00–15:00 Group discussion
15:00–15:15 Break
15:00–17:00 Continued group discussion and presentation

Tuesday, 27 August 2002

13:30–14:15 Summary of previous day's results
14:15–15:15 Question and answer session
15:15–15:30 Break
15:30–16:30 Thai experience presentation
16:30–17:00 Final summary