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Caregiver burden and need of support among family members of
persons living with HIV
- A quantitative study

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Sammanfattning

Introduktion: Vietnam har en av de snabbaste växande HIV-epidemierna i världen. De primära vårdgivarna vid sjukdom är familjemedlemmar.

Syfte: Syftet med studien var att undersöka känslan av vårdgivarbelastning hos familjemedlemmar till personer som lever med HIV när de vårdar sin anhörig och vilka stödinsatser de behöver. Vidare var syftet att se om några skillnader mellan män och kvinnor föreligger.

Metod: En deskriptiv tvärsnittsstudie med en kvantitativ metod användes. Studien genomfördes på Hospital of Tropical Diseases i Ho Chi Minh City, Vietnam. Ett bekvämlighetsurval användes. Sjuttioen av 87 enkäter var fullständigt ifyllda och användes för analys.

Resultat: Den största delen av deltagarna upplevde ”mild till lindrig” (35%) och ”lindrig till svår” (42%) belastning. Familjevårdgivarna kände att de skulle vilja göra mer för sin anhörig och vårda dem på ett bättre sätt. De uttryckte också att den svåra ekonomiska situationen ökade belastningen. Stödinsatser som efterfrågades mest var ekonomiskt stöd, kunskap om hur man vårdar och mentalt stöd för att klara av situationen som vårdgivare. Gällande vårdgivarbelastning fanns en signifikant skillnad, män var mer generade än kvinnor när de hade besök av vänner. Hög vårdgivarbelastning var starkt associerad med känslan av depression ($p=0.000$).

Slutsats: Hög vårdgivarbelastning och känslan av depression var starkt associerade. Vårdgivarna är i behov av stödinsatser av olika slag för att klara av sin situation. Åtgärder som inkluderar en omvårdnadsplan skulle kunna erbjudas till vårdgivarna för att minimera risken av vårdgivarbelastning, depression och öka deras livskvalité.

Nyckelord: HIV, familjemedlemmar, stödinsatser, vårdgivarbelastning, Vietnam

Abstract

Introduction: Vietnam has one of the fastest growing HIV- epidemics in the world. In Vietnam the primary caregivers are the family.

Aim: The aim was to examine caregiver burden and need of support among family members of persons living with HIV [PLHIV] in Ho Chi Minh City, and also to investigate the differences in these matters between genders.

Method: A descriptive cross-sectional study with quantitative method was used. The study was carried out at the Hospital of Tropical Diseases, Ho Chi Minh City, Vietnam where people living with HIV are treated. A convenience sample was used. Seventy one of 87 questionnaires were completed.

Result: The largest groups reported “mild to moderate” (35%) and moderate to severe” (42%) caregiver burden. The caregivers felt that they should do more for their relative and a better job in caring for them. They also expressed that the financial situation added to the burden. The needs of support most requested were economic support, knowledge about caring, and mental support to cope. Concerning caregiver burden scale only one significant difference was found, male participants found it more embarrassing to have friends over than female participants. High caregiver burden was strongly associated with depression ($p=0.00$).

Conclusion: High caregiver burden and feeling of depression was strongly associated. The caregivers of PLHIV are in need of different kinds of support to cope with their situation. Intervention including care plan should be given to caregivers to minimize risk of burden and depression and increase their quality of life.

Key words: HIV, family members, needs of support caregiver burden, Vietnam

Acronyms

AIDS = Acquired immunodeficiency syndrome

ART = Antiretroviral therapy

CBS= Caregiver burden Scale

HIV = Human immunodeficiency virus

MSM = Men who have sex with men

PLHIV = People living with human immunodeficiency virus

PWID = People who inject drugs

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1. INTRODUCTION

1.1. Human Immunodeficiency Virus

Human immunodeficiency virus [HIV] is a lent virus, a member of the retrovirus family (Nationalencyklopedin, 2012). The virus uses the host's T- lymphocytes, which are a group of white blood cells that play a central role in the cell-mediated immunity. As the HIV- infection progresses, a reduction of these cells leads to an impaired immune defence and greater risks of opportunistic infections, for example tuberculoses, herpes simplex viruses and pneumonia (Gisslén, 2011; AIDS.org, 2012). The HIV- infection eventually develops to acquired immunodeficiency syndrome [AIDS] when the level of T-lymphocytes reaches a certain limit (Gisslén, 2011). Mutation of the virus is common and due to this the retroviruses makes it able to avoid the host cell's immune response and resist many antiretroviral drugs (Svarovskia, Cheslock, Zhang, Hu & Pathak, 2003). Because of the high level of mutation no vaccine has yet been developed against HIV, however, antiretroviral therapy [ART] can decrease the concentration of HIV in blood which makes the destruction of the immune defence progress slower and it also results in lower transmission risk (AETC, 2011). ART is a combination of at least three antiretroviral drugs (WHO, 2012).

1.2. History to present

The first case of HIV was diagnosed 1981. Since then about 25 million people has died from the disease. The number of newly infected has stabilized in most parts of the world and since the late 1990's the AIDS-related deaths have decreased. This is largely due to the increased availability of ART and the improvement of care and support offered to the person living with HIV [PLHIV] (UNAIDS, 2010a).

In 2010 an estimated 34 million people was living with HIV, 30 million of the PLHIV were living in low- and middle-income countries. About 15 million PLHIV were in need of ART in 2010 (WHO, 2012). The majority of new infections occur in developing countries. An estimated 4.9 million people in Asia were living with HIV in 2009 (UNAIDS, 2012).

1.3. Ways of contamination and risk prevention

PLHIV will carry the virus for the rest of their life and cannot be cured. The contagiousness is relatively low but one shall always be aware of the transmission risk and the ways of transmission due to the fact that the only guard to not be infected is to avoid exposure of the virus (Smittskyddsinstitutet, 2010). HIV can be transmitted through blood, semen, vaginal secretions and breast milk. Blood is the fluid with the highest concentrations of the virus followed by semen, vaginal fluids and breast milk contains the lowest. Activities considered as high-risk transmission ways are unprotected sexual contact, direct blood contact, childbirth and breastfeeding. HIV is not transmitted through body fluids as saliva, tears, sweat, feces and urine nor by social contact in daily life (AIDS.org, 2012). Preventive interventions are use of condoms during sexual intercourse and oral sex, use of plastic gloves when exposed to blood and dress wounds. Another preventive intervention is that PLHIV are not allowed blood donors (Smittskyddsinstitutet, 2010). To prevent mother to child transmission the mother should take ART during the pregnancy, delivery and breastfeeding. The child should be delivered with the help of trained health care personal. The child should be 100% breastfed for 6 months with the condition that the mother has access to ART (Dalekant, 2012). To decrease the transmission between people who inject drugs [PWID] they should use new, clean needles and not chare needles with each other (Red cross, 2012).

1.4. HIV- situation in Vietnam

In 2012 an estimated number of 280 000 are believed to live with HIV in Vietnam. In the end of 2009 the number of PLHIV was 160,019 and until then 44,050 deaths had been AIDS-related in Vietnam (UNAIDS, 2010b). Less than one percent of the population is HIV-positive, which is defined as a non-generalized epidemic (Unicef, 2008). The prevalence varies in the different regions and is concentrated among PWID, men who have sex with men [MSM] and sex workers (UNAIDS, 2012). It was reported in 2004 that approximately 65 % of PLHIV were PWID (Gaudine, Gien, Thuan & Dung, 2009).

The drug abuse in Vietnam has approximately been threefold the past ten years and has now spread to urban areas as it before was a dominant phenomenon in the rural districts. Heroin is currently the predominant drug, having surpassed opium. Due to the type of the drug have changed the way of administration also changed to injecting instead of smoking which was the main route before (Nguyen & Scannapieco, 2007). This change of drug administration and sharing of injecting needles has lead to increased cases of HIV- infections and has made Vietnam has one of the fastest growing HIV epidemics in Asia (Xuan Tran, Ohinmaa, Thanh Nguyen, Anh Nguyen

& Huong Nguyen, 2011). From 1997 to 2002 the prevalence of HIV- infections among PWID in the country has tripled, from 9.23% to 32.08%. Financial struggles are a big problem among PWID because of their expenditures for drugs which results in criminality and prostitution for some. The majority of PWID are financially dependent on their families (Nguyen & Scannapieco, 2007).

The majority of PLHIV and their families experience stigma and discrimination. Fear and misperceptions about the transmission ways of HIV are the main causes of discrimination and stigma. The widespread lack of knowledge about the disease has contributed to unfriendly attitude from nurses towards PLHIV, difficulties in getting employment and family members felt expulsion by for example neighbours. The stigma also led to family members feel ashamed, forced to behave differently, fear of transmission and a financial burden due to their association with PLHIV (Thi et al., 2008). Family members of PLHIV has also expressed that even they feel discriminated by healthcare professionals, their questions were unanswered and the treatment of their relative was inadequate. The difficult financial situation in these families are also linked to the PLHIV's great risk of losing their job and because the caregiving family member has to leave the work place to take care of the sick family member (Gaudine et al., 2009).

The Vietnamese government contributed to stigma and discrimination against PLHIV. For several years a campaign displayed public health posters linking HIV and AIDS with drug use and sex work. As a result of this campaign it was believed that all PLHIV were involved in illegal and immoral behaviour. The PLHIV who were not included in the groups of PWID, MSM and sex workers had difficulties being open with their HIV status in fear of being connected to the groups mentioned in the campaign. This still remains in the minds of the population despite new campaigns encouraging people to show compassion for PLHIV (Thi et al., 2008).

1.5. Caregiver situation

A study in the USA shows that caregiving family members are at risk of developing depression. The study found that the heavy burden of caregiving led to significantly greater odds of caregiver depression. About 27 % of the care-giving family members had a heavy caregiver burden and 50 % were depressed (Pirraglia et al., 2005).

In Tanzania the caregiver is often a woman. Mothers were the most common caregiver and non-maternal caregivers often siblings expressed that they took the responsibility because the mother

of the patient was incapable of doing it. Physical, social and economic problems were reported from the caregivers. The physical problems included doing laundry, getting water and lifting the patient. Stigma was experienced directly towards the family. This sometimes leads to exclusion of the PLHIV and the caregiver by the family. The caregivers relied on economic support from neighbours and relatives because all their time was spent on taking care of the patient (Tarimo, Kohi, Outwater & Blystad, 2009). The caregiver situation in rural Uganda was similar to the one in Tanzania. The patients' care remains home-based, sometimes with addition of health care services. The main burden is almost always carried by women who are already overburdened with responsibilities for their families. The caregivers are not trained in basic care of PLHIV which worries them and they all claim that the provision of care has a negative impact on their well-being. They feel weak and some of their income has greatly been affected due to the every-day demands. The financial situation and the stigma surrounding PLHIV and their families result in isolation and pain for the caregiver. The financial status and the position of the ill family member (dependent or provider) were major factors in determining the family caregiver ability to cope with the burden of care (Walter et al., 2007). Other factors that have been found to cause depression among informal caregivers are spending all day together, having to help others besides the PLHIV and the time the HIV diagnosis has been known to the patient and caregiver (Pirraglia et al., 2005). Caregivers' responses about their ways of coping with the burden vary. Some of them change their work schedules and some relocate resources from other needs, for example children's education or selling family properties. In some cases the children stop going to school to work instead to provide financial means (Walter et al., 2007).

Caregivers' depressive symptoms have been shown to be greater if the caregiver was young, was female, was low educated, or used drugs in the last 6 months, and if the caregiver burden was high. Caregivers have also reported that high level of stigma was connected to increased depressive symptoms. If the caregivers share their problems with someone else the level of depressive symptoms was lower (Mitchell & Knowlton, 2009). Because of the stigma caregivers claim the PLHIV does not want them to talk with other people about their situation and need of help, because they feel shamed. This gives the caregivers even less chance to get support which leads to no relief and increases the stress. The caregivers develop deep sense of exhaustion, discouragement and helplessness. Some caregivers cope with their situation and find support from the church and by informal networking with other caregivers of PLHIV (Pallangyo & Mayers, 2009). Even if some of the caregivers find support in new established friendships the support from the government and nongovernmental organizations are limited

which also is a source to increased stress for the caregiver. There are available programs for home-based care but these are viewed as largely dysfunctional (Pallangyo & Mayers, 2009; Walter et al., 2007).

The needs of support can be divided into different levels. Basic-, practical- and emotional-level. Basic needs included lack of food and affordable transport to the hospital. These expenses were difficult to cover due to that many of the households did not have any income at all. On the practical level many caregivers did not have gloves, sheets and clean water. On an emotional level the caregivers expressed that they felt isolated because they did not want to disclose their status due to stigma in the community. The fear of disclosure also made the caregivers not able to take the help that was offered to PLHIV and their caregivers (Campell, Nair, Maimane & Sibiya, 2008; Pallangyo & Mayers, 2009).

Lack of knowledge about HIV, ways of transmission and the correct treatment makes family members frustrated. They feared that sharing living area or utensils could infect the other members of the family. The lack of knowledge also led to misconceptions about the disease, some caregivers associated HIV with witchcraft. Some also considered taking their relatives to traditional healers (Tshilio & Davhana-Maselesele, 2009).

1.6. Caregiver situation in Vietnam

In Vietnamese culture, the majority of the population is Buddhist, the family is very important and most of the health decisions are family based and not made individually (Gordon, Bernadett, Evans, Bernadett Shapiro & Dang, 2006). Therefore, the family carries out a great part of the care given to the person diagnosed with HIV. It is shown in a study that the caregivers of PLHIV face a great burden and as the number of PLHIV is increasing the number of caregivers follow. Caregiver burden, the negative consequence of care giving, is a multidimensional problem. It affects the caregiver physically, emotionally, socially and environmentally. The demands of caregiving can force the caregiver into social isolation. This stress is even greater if the caregivers themselves are infected with HIV. Understanding this phenomenon and being able to provide the caregivers the support and help they need, will improve the health and wellbeing of both the caregivers and the PLHIV (Lee, Li, Jairaphongsa & Rotheram-Borus, 2010).

PLHIV feels responsibility and expresses great concern about how their family will be treated after their HIV-status is known. Some expressed fear about their children who will not be able to go to school or the emotional burden that is placed on the family. The fear of their family being

mistreated because of them made some PLHIV consider suicide. The PLHIV who disclosed to their families had a greater chance to overcome depression, reduce their high-risk behaviours and seek medical treatment (Salter et al., 2010).

In Vietnam the family members take great responsibility for their sick relatives. The family members care for them at home and also accompany them to the hospital if further medical care is needed. They provide the natural care needed such as hygiene, providing food and mobilization. Little has been studied about caregiver burden among family members of PLHIV in Vietnam. Due to the increasing number of PLHIV and hence family caregivers it is important to explore how the caregivers experience the situation and the burden. The study elucidates the burden that family caregivers of PLHIV experience and identify what help and support they need. The results can be used as basic data for future studies with specific interventions for family members who give care to PLHIV. This study in Ho Chi Minh City will examine and illustrate the problem in order to facilitate the provision of adequate support to the caregivers.

2. THEORETICAL FRAMEWORK

In this study Katie Eriksson's theories of nursing was used as the theoretical framework.

The theory is based on caring as a relation between two equal parts. The professional care (nurses) replaces the natural care (care given from family members) in situations when the natural care is not enough to improve human integrity, health and development. This can be applied to the caregivers who also need support and care. Their health is affected by the burden from the care of their family member. The nursing goal is an interaction in which both parts share and participate (Kristoffersen, 2006).

3. AIM

The aim of this study was to examine caregiver burden and need of support among family members of persons living with HIV in Ho Chi Minh City. The aim was also to investigate differences between genders in caregiver burden and need of support.

4. RESEARCH QUESTIONS

What do family members experience as a burden while caring for a relative with HIV?

What kind of support do the caregivers need?

Are there any differences or similarities between genders in caregiver burden and need of support?

5. METHODOLOGY

5.1. Design

A descriptive cross-sectional study with quantitative method was used.

5.2. Setting

The study was carried out at the Hospital of Tropical Diseases, Ho Chi Minh City, Vietnam. PLHIV are treated at this hospital. The data was collected during three weeks in March and April 2012.

5.3. Procedure

The project was a collaboration between the Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy in Ho Chi Minh City, Vietnam, and the Department of Public Health and Caring Sciences at Uppsala University, Sweden.

The ethics committee at the Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy in Ho Chi Minh City and the Director of the Hospital of Tropical Diseases approved the project.

The participants were recruited by the Vietnamese Co-supervisor together with the Vietnamese Lecturer in nursing and the authors at the hospital. The participants was also informed by this group, orally and in an accompanying letter of information (Appendix 1), about the aim of the study, what the questionnaire is going to be used for, and their rights. The participants who agreed to participate were asked to answer the questionnaire and hand it back after finishing. The questionnaire was distributed in a room at the hospital ward. If the participants had any problems while answering the questionnaire they received help from the Vietnamese Co-supervisor and

lecturers. The head nurse at the department distributed questionnaires to the relatives in the ward and the daily care centre. Due to a small number of answered questionnaires during the first two weeks of collecting data the method where changed for the third week. The third week the Vietnamese co-supervisor, lecturer and 4 students from the University of Medicine and Pharmacy collected data by approaching the caregivers in the ward and helping them answering the questionnaire.

5.4. Sample

A convenience sample of participants was used. Eighty seven participants took part in the study, 16 were excluded due to not completing the questionnaire correctly. The final sample consisted of 71 participants. The inclusion criteria were that they are family members of PLHIV being treated at the Hospital of Tropical Diseases. If the relative could not read and write the supervisor, lectures or head nurse read the questions for them.

5.5. Instrument

A questionnaire was developed for this study by the two supervisors, Pranee Lundberg, Associate Professor at the Department of Public Health and Caring Sciences, Uppsala University, and Mrs. Doan Thi Kim Thoa, lecturer at the Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy (Appendix 2). It was written in English and translated into Vietnamese. The questionnaire is based on a longitudinal study by Zarit, Todd and Zarit (1986). The questionnaire in English was translated into Vietnamese by Mrs. Doan Thi Kim Thoa and then translated back into English by Mrs. Phan Thi Thu Huong, lecturer at the Department of Nursing in order to increase validity of the questionnaire. The questionnaire is divided into three parts: demographic information; caregiver burden; need of support.

Part I of the questionnaire consists of ten questions: gender, age, religion, education, marital status, employment, personal income per month, relationship to the HIV- patient, duration of the relationship and time per day spent for care giving. The participants can choose from predetermined options.

Part II of the questionnaire is where the participants will reflect on their burden, caregiver burden scale [CBS]. It consists of 23 questions. 22 will be answered by using a scale 0-4, which

represents "never" to "nearly always". The participants will encircle the number of the option that is closest to their own experience. Question number 23 regarding depression has 3 options which are; "yes very much", "yes very little" and "no".

In Part III, the participants will mark one or several of nine options regarding their needs of support, eight which are predetermined and one where the participants can specify their need of support.

The questionnaire was tested on family members to PLHIV before the study started. Question seven in part I was changed from multiple choice answer to writing the answers. Two of the multiple choice answers in question eight regarding type of relationship were changed as well. Sibling and child were removed and replaced by friend and neighbour.

5.6. Ethical considerations

The ethics committee at the Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy in Ho Chi Minh City, Vietnam approved the project after submission by the Vietnamese co-supervisor. The Director of the Tropical Disease Hospital granted permission to carry out the project. A letter of information was distributed to potential participants confirming that participation is voluntary and anonymous. The data was analysed confidentially. The authors used the ICN Code of Ethics for Nurses for ethical considerations (International Council of Nurses, 2006).

5.7. Analysis of data

The data was analysed by using the SPSS- programme, The Statistical Package of Social Science. Answers in Part I was coded into numbers and registered. The scale used in Part II (caregiver burden scale) between 0-4 was converted into never (0), rarely (1), sometimes (2), frequently (3) and nearly always (4). Each questionnaire's answer from Part II was summarized and placed in one of the groups below (Zarit, Todd & Zarit, 1986).

0 to 20 = little or no burden

21 to 40 = mild to moderate burden

41 to 60 = moderate to severe burden

61 to 88 = severe burden

Part III was also coded and registered.

The questionnaire contains both nominal scale (Parts I and III) and ordinal scale (Part II). Median, mean and percentage will be used during the analysis. Mann Whitney U test was used to see differences between male and female mean values on the CBS. Pearson's Chi Square was used to compare male and female participants feeling of depression and level of caregiver burden. Spearman's ranking test was used to see correlation between caregiver burden and feeling of depression. A significant difference must have p-value less than or equal to 0.05. The results were presented in descriptive tables.

6. RESULT

In total 87 caregivers participated in the study. Of these caregivers, 16 did not complete the questionnaire and could therefore not participate in the study. This resulted in 71 caregivers included in this analysis. The response rate was 81.6 %.

6.1. Demographic characteristics

The demographic characteristics of the caregivers are presented in Table 1. The majority were women (62%). Their age ranged from 17- 77 years and the mean age of the participants was 44.89 years (SD= 15.035). Most of them was in the age groups 17-30 years old (22.5%) and more than 60 years old (22%). More than a half was Buddhist. About 71.8% were employed and the monthly income differed a lot among them. Most of the participants were married/cohabited (69%) and 36.6% had secondary school education. The type of relation with PLHIV was mostly a mother or father (38%).

6.2. Family members' caregiver burden

The mean caregiver burden score for the caregivers of PLHIV in this study was 43.85 (SD=17.5), range 0-88. The largest group of the participants (42.3%) reported "moderate to severe" caregiver burden. Figure 1 shows the distribution of the caregiver burden among the participants. The frequencies of the caregiver burden among the participants and gender are shown in Table 2. There was no significant difference in caregiver burden between male and female caregivers.

Table 1. Demographic characteristics of caregivers (N=71)

Demographic characteristics	Total	
	N	%
Gender		
Male	27	38.0
Female	44	62.0
Age (years)		
17-30	16	22.5
31-40	12	16.9
41-50	14	19.7
51-60	13	18.3
>60	16	22.5
Religion		
Catholic	9	12.7
Buddhist	47	66.2
Protestant	1	1.4
No religion	14	19.7
Education		
Illiterate	4	5.6
Literate	8	11.3
Elementary school	15	21.1
Secondary school	26	36.6
High school	12	16.9
College/University	6	8.5
Marital status		
Single	4	5.6
Married/cohabit	49	69
Divorced/separated	4	5.6
Widowed	9	12.7
Never married	5	7.0
Employment		
Yes	51	71.8
No	20	28.2
Income per month (USD)		
No income	16	22.5
1-50 USD	5	7.0
51-100 USD	16	22.5
101-150 USD	22	31
>150 USD	12	17
Type of relationship		
Wife/husband	16	22.5
Partner	1	1.4
Sibling	16	22.5
Mother/Father	27	38.0
Child	5	7.0
Other	6	8.5
Duration of relationship to live together		
Less than 5 years	24	33.8
5-20 years	19	26.8
>20 years	28	39.4
Time spend per day for caregiving		
Less than 6 hours	9	12.7
6-18 hours	15	21.1
All day	47	66.2

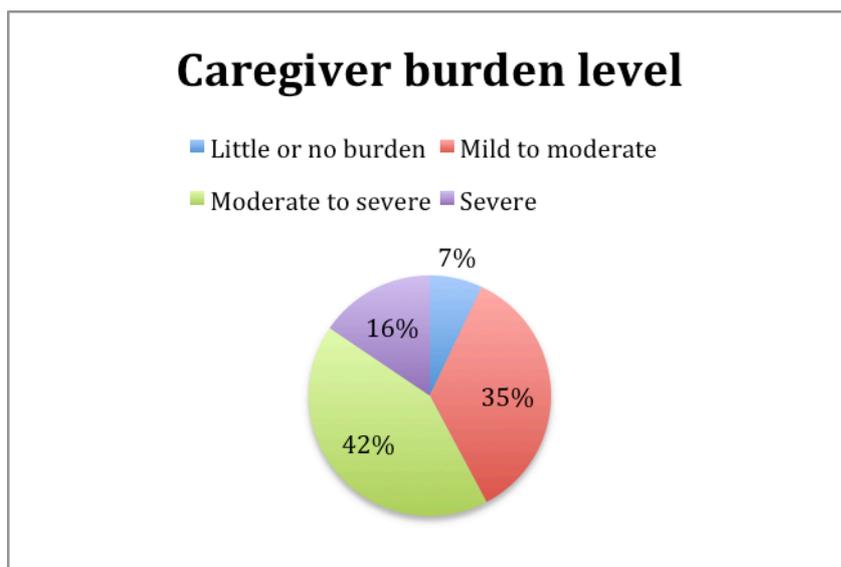


Figure 1. Caregiver Burden Scale (N=71)

Table 2. Experiences of burden among caregiver (N=71).

Caregiver burden	Total	Male	Female	χ^2	p-value
Little or no burden	5	1	4	0.742	0.389
Mild to moderate burden	25	12	13	1.628	0.202
Moderate to severe burden	30	9	21	1.421	0.233
Severe burden	11	5	6	0.305	0.581

Significant difference: $p \leq 0.05$

Table 3 shows the comparison between male and female caregivers in each question of caregiver burden scale. There was significant difference between the male and female caregivers in feeling uncomfortable about having friends over because of their relative ($p = 0.026$). More male than female caregivers felt uncomfortable having friends over because of their relative. The mean value for men was 1.7 and for the women it was 0.86. The mean values for the total CBS for the male participants was 44.52 (SD=16.442) and female participants 43.43 (SD=18.295). The participants expressed higher levels of caregiver burden specifically in questions 14, 15, 20 and 21 in the caregiver burden scale. These questions concern the caregiver's feeling of being the only one that the PLHIV could depend on and inadequate economy. Further the caregivers' answers implied feelings of being insufficient regarding doing a better job and doing more for the PLHIV while caring.

Table 3. Caregiver burden experienced by male and female caregiver.

Caregiver burden	Male Mean(SD) Median	Female Mean(SD) Median	Z	p-value
1. Do you feel that your relative asks for more help than he or she needs?	2.19 (1.210) 2.0	2.41 (1.436) 3.0	-0.94	0.347
2 Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	2.33 (1.468) 3.0	2.30 (1.488) 3.0	-0.061	0.951
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	2.59 (1.5) 3.0	2.14 (1.424) 2.0	-1.475	0.14
4. Do you feel embarrassed over your relative's behavior?	1.63 (1.275) 2.0	1.61 (1.45) 1.5	-0.171	0.864
5. Do you feel angry when you are around your relative?	0.93 (1.107) 1.0	1.11(1.083) 1.0	-0.88	0.379
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	1.0 (1.301) 0	0.91 (1.254) 0	-0.279	0.781
7. Are you afraid about what the future holds for your relative?	2.52 (1.282) 3.0	2.57 (1.421) 3.0	-0.342	0.732
8. Do you feel your relative is dependent on you?	2.44 (1.553) 3.0	2.57 (1.576) 3.0	-0.384	0.701
9. Do you feel strained when you are around your relative?	1.3 (1.353) 1.0	1.57 (1.388) 2.0	-0.817	0.414
10. Do you feel your health has suffered because of your involvement with your relative?	1.85 (1.292) 2.0	2.11 (1.351) 2.0	-0.904	0.361
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	1.63 (1.418) 2.0	1.59 (1.484) 1.0	-0.171	0.865
12. Do you feel that your social life has suffered because you are caring for your relative?	2.04 (1.372) 2.0	2.07 (1.453) 2.0	-0.152	0.879
13. Do you feel uncomfortable about having friends over, because of your relative?	1.7 (1.636) 2.0	0.86 (1.268) 0	-2.228	0.026
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	2.74 (1.483) 3.0	2.75 (1.644) 4.0	-0.504	0.615
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	2.89 (1.155) 3.0	2.86 (1.25) 3.0	-0.093	0.926
16. Do you feel that you will be unable to take care of your relative much longer?	2.07 (1.385) 2.0	1.80 (1.391) 2.0	-0.798	0.425
17. Do you feel you have lost control of your life since your relative's illness?	1.7 (1.382) 2.0	1.95 (1.478) 2.0	-0.742	0.458
18. Do you wish you could just leave the care of your relative to someone else?	1.11 (1.281) 1.0	0.66 (1.055) 0	-1.690	0.091
19. Do you feel uncertain about what to do about your relative?	1.52 (1.397) 1.0	1.41 (1.335) 1.5	-0.314	0.754
20. Do you feel you should be doing more for your relative	3.30 (0.953) 4.0	3.11 (1.039) 3.0	-0.782	0.434
21. Do you feel you could do a better job in caring for your relative?	2.74 (1.375) 3.0	2.98 (1.11) 3.0	-0.492	0.622
22. Overall, how burdened do you feel in caring for your relative?	2.3 (1.706) 3.0	2.07 (1.591) 2.0	-0.668	0.504

Significant difference: $p \leq 0.05$

6.3. Family members' feeling of depression

Concerning feeling of depression, 42% of the caregivers reported "yes, very little" while 34% experienced "yes, very much", see Figure 2. The comparison between genders shown a significant difference between male and female caregivers in the group that answered no feeling of

depression ($p=0.047$), see Table 4. More female than male caregivers reported no feeling of depression when giving care. High caregiver burden could be strongly associated with depression. Ninety one point six percent of those experiencing some level of depression reported a “moderate to severe” and “severe” caregiver burden. A significant correlation between high caregiver burden scores and great feeling of depression was found using Spearman’s ranking test, ($p=0.000$).

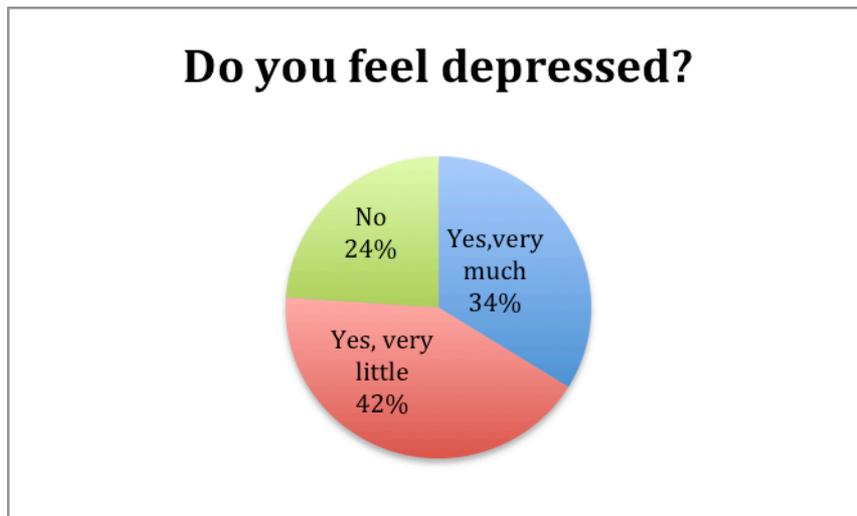


Figure 2. Feeling of depression (N=71).

Table 4. Feeling of depression between genders (N=71).

Feeling of depression	Total	Male	Female	χ^2	p-value
Yes, very much	24	10	14	0.204	0.652
Yes, very little	30	14	16	1.645	0.2
No	17	3	14	3.940	0.047

Significant difference: $p \leq 0.05$

6.4. Needs of support among caregivers

Table 5 shows the needs of support among caregivers. The type of support that was mostly reported as a need among the participated caregivers was “economic support”, “knowledge about giving care to persons with HIV/AIDS” and “mental support to cope with the situation”. There were no significant differences between the genders.

Table 5. Needs of support (N=71).

Need of support	Total	Male	Female	χ^2	p-value
Knowledge about HIV/AIDS	35	15	20	0.683	0.409
Knowledge about giving care to persons with HIV/AIDS	46	17	29	0.064	0.801
Mental support to cope with the situation	42	16	26	0	0.989
Communication support	20	7	13	0.108	0.742
Religious/spiritual support	18	7	11	0.008	0.931
Social support	35	15	20	0.683	0.409
Economic support	53	19	34	0.421	0.516
Support to relatives	35	16	19	1.730	0.188
Other support	13	7	6	1.690	0.194

Significant difference: $p \leq 0.05$

Eight caregivers specified that hospital and treatment fees should be lower to make it easier to follow long-term treatment. One caregiver was afraid of how the community would react and wrote:

“Don’t tell neighbor or local people because it can affect my relatives”

Two caregivers wrote about their situation and what kind of support they needed to handle the situation.

“Need someone to take my place so that I have time to relax”

“Support to make caregivers feel stronger”

Two caregivers mentioned that support was needed to make it easier to take care of patient, while one caregiver did not need any support at all.

7. DISCUSSION

All family caregivers of PLHIV experienced some level of burden. The largest groups reported “mild to moderate” (35%) and “moderate to severe” (42%) caregiver burden. Most of the caregivers were female and the most common relationship was mother/father to PLHIV. The caregivers felt that they should do more for their relative and a better job in caring for them. They also expressed that the financial situation added to the burden. Male caregivers were more likely to feel embarrassed when having friends over than female participants ($p=0.026$). A significant correlation between high caregiver burden and great feeling of depression ($p=0.000$) was found. The CBS answers reflected the needs of support, which were economic support, knowledge about caring, and mental support to cope. There was no significant difference between the genders regarding needs of support.

7.1. Result discussion

The majority of caregivers were women and 43% of all women were mothers to the PLHIV. This result reflects earlier studies that have shown that women, in particular mothers carry the main caregiver burden (Walter et al., 2007; Tarimo et al., 2009). Most of the caregivers were Buddhists,

which also is the largest religious group in Vietnam. The Buddhist has a family oriented mindset, which means that families often make health decisions together and care for one another if a family member gets sick (Gordon et al., 2006). This family oriented way of thinking has been seen in the answers to the questions which concerns that they feel their level of care is not enough. The questions concerning this are “Do you feel you should be doing more for your relative?” (M=3.18) and “Do you feel you could do a better job in caring for your relative?” (M=2.89). These two questions had the highest mean value in the CBS. The feeling of being inadequate regarding how the care is provided and the quality of the care shows that the caregiver wants to improve the care of the PLHIV but does not have right equipment, enough knowledge about doing it and about HIV in general. The caregiver provides the natural care but need to be replaced by professional caregivers alternative receive knowledge when the care exceeds their ability.

As shown by Pirraglia and co-workers (2005) spending all day together is a factor for depression, as 47 of the caregivers in this study answered that they did, they might be at greater risk of feeling depressed. Though was no statistical significance shown in that case in this study. The level of education among a greater part of the participants was equal with secondary school or lower, this may have contributed to that economic support and knowledge about caring for PLHIV was highly requested in this study. The caregivers with no or low education may have a job with a income that can not provide for their families needs and if the financial demands from the PLHIV are added on it makes the situation very difficult. 39 of the 53 participants who reported secondary school education or lower reported some feeling of depression in this study. An earlier study has shown that low education is a risk factor for greater depression (Mitchell & Knowlton, 2009).

The caregiver burden is a multidimensional problem. The caregivers in this study have experienced range from fear of the future and feeling of inadequacy to economic concerns. The needs of support reflect the different angles of caregiver burden and must therefore be adapted and cover all the dimensions to make sure all needs are met. Sixty four point seven percent of the participants in this study felt that they lacked knowledge about caring for a PLHIV. A way to provide this information to caregivers could be arranged courses by healthcare-professionals at the wards where PLHIV are being treated. This is a good way to reach out to the caregivers and give them the information that they need for basic home care. Walter and co-workers (2007) found that lack of training in basic care of PLHIV worries the caregivers a lot and this may have a negative impact on their wellbeing. Furthermore the courses can provide contacts with other caregivers in a similar situation where they can openly discuss their problems and concerns. Caregivers that share

their problems with someone have shown fewer depressive symptoms (Mitchell & Knowlton, 2009). Some caregivers find support and cope with their situation by joining informal networks of caregivers (Pallangyo & Mayers, 2009). This kind of mental- (59%) and social-support (49%) to cope with their caregiver burden was highly requested in our study. A part of the course could also include knowledge about HIV, for example ways of transmission and how to protect one self. This intervention is on a group-level. To target a wider section of the population the government must be involved. The Vietnamese government displayed public health posters linking HIV/AIDS with drug use and sex work. By this campaign they contributed to stigma and discrimination against PLHIV and their families (Thi et al., 2008). Due to the government's impact on the Vietnamese people they could use their position to provide knowledge and information about HIV/AIDS for example the transmission ways and how to protect one self. This would be a step in direction towards removing the misconceptions about HIV/AIDS, which is a result of the peoples' lack of knowledge (Tshilio & Davhana-Maselesele, 2009). This information should reach out to the whole population, not only the transmitted and their caregivers and give them all the same access to knowledge. If a campaign like this would be realized it may reduce the stigma and discrimination against PLHIV and their caregivers, which many of them experience. Previous studies have shown that the caregivers of PLHIV often felt stigma and discrimination from for example neighbours, co-workers, friends and sometimes even family members. Due to the stigma the PLHIV and its' family including the caregiver loose their social network and thereby their natural social support from relatives, neighbours, friends and co- workers who turn them their back. This and the fact that the caregiver needs to take care of the PLHIV almost all day leads to isolation, helplessness, exhaustion and higher risk of depression. If the stigma and discrimination decrease the caregivers and the PLHIV still would have their relative and friends (people surrounding them) around them for support and have a greater chance of a better life with less stress and feeling of depression (Gaudine et al., 2009; Pallangyo & Mayers, 2009; Tarimo et al., 2009; Thi et al., 2008).

The fact that the caregivers felt that they did not have enough money to take care of the PLHIV reflects the question about needs of support. Economic support was the need of support that most caregivers requested. Sixteen caregivers in our study reported that they had no income at all. The economic situation is often strained and if a family member needs medical attention this will affect the economy of the family greatly. Additional expenses, such as medicines, hospital fees and medical equipment (for example gloves), will have a big impact on the economy. Families with a PLHIV may also be extra vulnerable because of the discrimination and stigma directed towards them. The stigma and discrimination can lead to that the PLHIV and/or the family

caregiver loses their employment. Other causes of losing their employment might be that the PLHIV is too sick to work or because the caregiver needs to stay at home to care for the PLHIV (Gaudine et al., 2009). The economic situation also differs due to if the PLHIV was a dependent or a provider (Walter et al., 2007).

The majority of caregivers expressed that they felt depressed. Twenty two of 24 caregivers that answered “yes, very much” on the question about feeling of depression also reported “moderate to severe” or “severe” caregiver burden. These variables are associated with each other but based on this study it is not possible to say which variable that is dependent of the other. To answer this question a study with depth interviews and background information about medical status would be necessary. A previous study has shown that caregiving family members are at risk of developing depression, the study also found that the heavy burden of caregiving led to significantly greater odds of caregiver depression (Pirraglia et al., 2005).

Regarding Katie Eriksson’s nursing theory, the theory is based on caring as a relation between two equal parts, has been applied in the care of PLHIV when care is mostly given from a family member (Kristoffersen, 2006). As a family member that has to care of the PLHIV in every day life he/she sometimes has to be replaced to be able to take care of his/her own health. The caregiver provides the natural care and the nurse gives the professional care. The natural care cannot replace the professional care because the caregiver does not have enough knowledge and the right equipment to offer it. The level of care exceeds their knowledge, which might be a cause to the high caregiver burden and feelings of depressions. The caregivers experience different levels of caregiver burden and depending on how burdened they are their well being and health are affected. To reduce the caregiver burden and the negative health affects of the caregiver the nurse has to interact with the caregiver in the care of the PLHIV. The interaction implies that the nurse replace the caregiver at times when the care given from he/she is not enough and/or the caregiver’s well being are affected. One of the nurse’s elementary competence is a comprehensive view of the patient and his/hers family and also support and guide family members in their participation of caregiving. The nursing goal is to be open- minded, perceptive to be able to see when the caregiver has to be replaced and show respect, empathy, integrity and improved health, both for the caregiver and the PLHIV (Socialstyrelsen, 2005).

7.2. Methodology discussion

The use of a questionnaire was a good way to collect data in this study. A large amount of

information could be collected and it did not take a long time to answer the questionnaire. Information given to the participants before they filled in the questionnaire was not univocal at all time as some participants entered the room in the middle of the information. This may have affected that many questionnaires were incomplete because the participants did not hear that all questions must be answered for the questionnaire to be valid. Due to the amount of questions put forward by the participants while answering the questionnaire there should have been more people available to help them or the number of participants should have been restricted to eight people in the room at the same time, so the participants would have been given the attention they needed. The persons helped the participants should not be connected to the ward or the caregivers in any other way, they should have been impartial. The doors to the room where the study took place should have been closed as there were many persons standing outside the room looking and talking to the participants. This disturbed the participants and may have cause them to miss a question or answer differently because they thought that someone saw their answers. The third week of data collection the Vietnamese co-supervisor, lecturer and four students from the University of Medicine and Pharmacy collected data by approaching the caregivers in the ward and helping them answering the questionnaire. This was a more effective method as more than half of the completed questionnaires were collected that week. The incomplete questionnaire rate also decreased the third week; only three questionnaires were not completed that week. This may have been caused by the number of persons available to help the participants and answer their questions about the questionnaires.

Two questions could have been changed. Question 4 in Part 1 should have been split into two questions, one asking about the status of illiterate/literate the second one asking about their level of education. Some participants may have attended school but not have the ability to read and write. The answering alternative literate was probably not checked as much because level of education was checked instead. Question 9 “duration of relationship to live together” was misunderstood by many participants and could have been changed to “duration of the relationship” as some of the caregivers did not live together with the PLHIV.

All questionnaires that were not completed were removed. The data from the removed questionnaires were not studied so we do not know if they had any common denominators with each other. The removed questionnaires may have affected the result if completed but in what way

we can only assume.

In the ward that the study took place there were about 50 patients and there were not many new patients admitted. In effect this meant that no new caregivers came to the ward on a regular basis. The sample was too small for the result to be generalizable on the population of caregivers. Further studies with the same aim would be necessary before any intervention-studies begin. In depth interviews could clarify and specify what support is wanted from the caregivers for example what kind of knowledge they ask for or how much money they need.

8. NURSING IMPLICATION

The result can be used as a base for interventions for caregivers of PLHIV. The caregivers are a vulnerable group and that there are specific characteristics for the individuals most at risk regarding feelings of high caregiver burden and developing depression. This is important to have in mind and always pay attention when meeting these individuals in the healthcare system. To be aware of what kind of support they need it is easier to provide the correct interventions and that they are put in as soon as possible. The right interventions requested from the caregivers should be included in a care plan that is activated when somebody starts to care for a PLHIV. This might decrease the level of burden experienced by the caregivers and minimize the risk to develop depression from high caregiver burden. Correct interventions at the right time might give the caregiver a better quality of life with lower stress and higher well being, which would benefit both themselves and the person for whom they are caring.

9. CONCLUSION

Many caregivers of PLHIV experience caregiver burden and feelings of depression. They are in need of support in different ways. The most common supports that were requested were economic support, knowledge about caring for PLHIV and mental support to cope with their situation as caregiver. Therefore, intervention including care plan should be given to caregivers to minimize risk of burden and depression and increase their quality of life. The care plan for the caregiver should include needs of support that are available. The appropriate contacts are established with specific authorities that will enable the help fast. The goal with the care plan is that necessary information about possible interventions already has been collected and are therefore able to be and can be activated as soon as requested by the caregiver.

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12. Appendix 1

Letter of information for participants in the study *Caregiver burden and depression among family members of persons living with HIV*.

Conducted by Anna Grafström and Sofia Petersson, nursing students from Uppsala University. The study is a collaboration between the Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy in Ho Chi Minh City, Vietnam, and Department of Public Health and Caring Sciences at Uppsala University, Sweden.

The aim of the study is to examine how you as a caregiver, for a family member with HIV, experience this and what kind of support that you feel you need. If you choose to participate you will answer a questionnaire with predetermined alternative answers. The questionnaire consists of three parts. Part I are basic information for example gender, religion, marital status and questions about your relationship to the patient. Part II is where you answer the questions about how you experience the care giving of your family member, this part consists of 23 questions. Part III is where you mark one or more alternatives for what needs of support you experience. The results from this study may help us to better understand the situation for family caregivers to be able to give better support and help.

The questionnaire will take approximately 20 minutes to fill in. The questionnaire will be anonymous.

Your participation in this study is voluntary. You may refuse to participate, refuse to answer questions or withdraw from the study at any time. You have no obligation to participate in concurrent or future studies

If you have any questions about the study please email us at **vietnam2012thesis@gmail.com**

Best regards

Anna Grafström & Sofia Petersson

13. Appendix 2

Caregiver burden and depression among family members of persons living with HIV

The questionnaire is divided into 3 parts: demographic information, caregiver strain and needs of support. Please answer in every question.

Part I: Demographic information

1. Gender Male Female
2. Age years old
3. Religion
 Catholic Buddhist Protestant
 Islam No religion
4. Education
 Illiterate Literate Elementary
 Secondary school High school College/University
5. Marital status
 Single Married/cohabit Divorced/separated
 Widowed Never married
6. Employment: Yes No
7. Personal income per month(VND/month)
8. Type of relationship to the HIV patient
 Wife or husband Partner Friend
 Mother or father Neighbor Other, please specify
9. Duration of the relationship to live together
 Less than 5 years 5 to 20 years greater than 20 years
10. Time per day spent together for care giving
 Less than 6 hours a day 6 to 18 hours a day All day

Part II: Caregiver Burden (Caregiver Burden Scale, CBS)

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There is no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0	1	2	3	4
15. Do you feel that you do not have	0	1	2	3	4

enough money to care for your relative, in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

12. Do you feel depressed?

- Yes, very much Yes, very little No

Part III: Needs of support

13. What needs of support do you have when working with HIV patients? (You can mark (X) in several boxes)

- Knowledge about HIV/AIDS
- Knowledge about giving care to persons with HIV/AIDS
- Mental support to cope with the situation
- Communication support
- Religious/spiritual support
- Social support
- Economic support
- Support to relatives
- Other support, please specify

Thank you for your answers.