

ORIGINAL RESEARCH

Study of care giver burden in persons living with HIV-A cross sectional study

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ABSTRACT

Background: The main aim of the present study was to assess the prevalence of caregiver burden among the family members of persons living with HIV.

Methods: A cross sectional hospital based study was conducted at ART PLUS centre GMC Jammu, over a period of 1 year from November 2018 to October 2019 after IEC permission. Written and Informed consent was obtained from each participant and predesigned and valid questionnaire was administered to each participant. During the interview, caregivers were asked about their demographics, including gender, age, educational status, employment status, marital status and annual income. Caregivers were asked about their level of caregiver burden through ZARIT QUESTIONNAIRE.

Results: There were a total of 100 caregivers participated in the study done over a period of 1 year conducted in GMC JAMMU. The majority were females (56%). 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. %). The mean caregiver burden score for the caregivers of PLHIV in this study was 51.85 (SD=17.5), range 0-88. The largest group of the participants (59%) reported “moderate to severe” caregiver burden. 29% caregivers living with HIV positive patients experience severe burden. 12% had only mild to moderate burden. Out of 100 caregivers, 91 were married (91%). 26 out of 91 (28.8%) suffered severe burden and 54 (59.3%) suffered moderate to severe burden where as 3 of 9 (33.3%) unmarried caregivers suffered from severe burden and 5(55.6%) of them had moderate to severe burden. Mild burden is noted in 12.1 % married caregivers and 11.1% of unmarried caregivers.

Conclusion: Majority caregivers of PLHIV experience caregiver burden. Intervention including care plan should be given to caregivers to minimize risk of burden and depression and increase their quality of life. This study also emphasizes that correct interventions at the right time will give the caregiver a better quality of life with lower stress and higher wellbeing of a caregiver.

INTRODUCTION

Human immunodeficiency virus (HIV) is a lentivirus, a member of the retrovirus family¹. 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 tuberculosis, herpes simplex viruses and pneumonia². Mutation of the virus is

common and due to this the retroviruses make it able to avoid the host cell's immune response and resist many antiretroviral drugs³. The number of newly infected individuals 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 persons living with HIV (PLHIV)⁴. In 2010 an estimated 34 million people were living with HIV, 30 million PLHIV were living in low and middle income countries. About 15 million PLHIV were in need of ART in 2010⁵. 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 virus⁶. Over the past decade, many studies have focused on the negative consequences of care giving, generally referred to as caregiver burden⁷, caregiver stress⁸ and caregiver strain⁹. Previous work among caregivers for those with HIV or AIDS has illustrated that the burdens of care giving are of great concern. Caregiver burden, which is the negative impact of care giving on the caregiver's life, has been associated with depressive symptoms and suicidal ideation. Care giver burden has not been studied much in this part of the world. This study will focus on accessing care giver burden and its impact on life of caregivers and possible ways to overcome their inadequate resources and insufficient support

AIMS AND OBJECTIVES

The main aim of our study is to assess the prevalence of caregiver burden among the family members of persons living with HIV

MATERIALS AND METHODS

This one year prospective cross sectional hospital based study was conducted at ART PLUS centre GMC Jammu, from November 2018 to October 2019, after obtaining the ethical clearance from Institutional Ethical committee (Certificate No. IEC/GMC/2019/793). Written informed consent was obtained, once the caregivers were screened. Caregivers were asked about their level of caregiver burden through ZARIT QUESTIONNAIRE.

INCLUSION CRITERIA

1. Care givers of people living with HIV.
2. Who gave written informed consent to participate in the study.
3. Age more than 14 years and less than 65 years.

EXCLUSION CRITERIA

1. Caregivers who suffered from Chronic ailments viz. Chronic Liver Disease, Chronic Kidney Disease etc.

MEASURES

Caregiver burden was a 22-item scale adapted from the Caregiver Burden Scale (ZARIT SCALE). Responses to individual items ranged from 0 (never) to nearly always (4). The scale was composed of five domains to assess the level of burden among caregivers of PLH: (1) General feelings, (2) feelings regarding caring for PLH, (3) sense of responsibility, (4) feelings when with impaired PLH, and (5) impact of PLH on caregivers' relationship. The adapted scale had a satisfactory internal consistency (Cronbach's $\alpha = 0.82$). This summative composite score ranged from 0 to 88. Sociodemographic characteristics include: gender, age in years, education, employment status, marital status and type of relation. Data collected was analysed using SPSS Version 11.5 statistical software. For continuous variables, the mean and standard deviation were calculated while for categorical variables, we calculated

proportions. For comparison of Zarrit Score in each domain with caregiver burden, statistical test ANOVA was used. The p-value<0.05 was considered to be significant.

OBSERVATIONS

There were a total of 100 caregivers participated in the study from November 2018 to October 2019.

The majority were females (56%), Most of them was in the age groups 20-60 years.

TABLE 1: DEMOGRAPHIC CHARACTER OF CAREGIVERS

DEMOGRAPHIC CHARECTERS	N	%
Gender		
Male	27	8
Female	44	2
Age (years)		
Less than 20	1	1
20-40	46	46
41-60	46	46
More than 60	7	7
Education		
Spouse	63	63
Parents	35	35
Others	2	2
Marital status		
Unmarried	9	9
Married	91	91
Occupation		
Govt. Employee	46	46
Farmer	14	14
House wife	30	30
Student	7	7
Others	3	3
Education		
Illiterate	26	26
Below Metric	47	47
Under-Graduate	9	9
Post-Graduate	18	18

Table 2: Age Distribution Among Caregivers

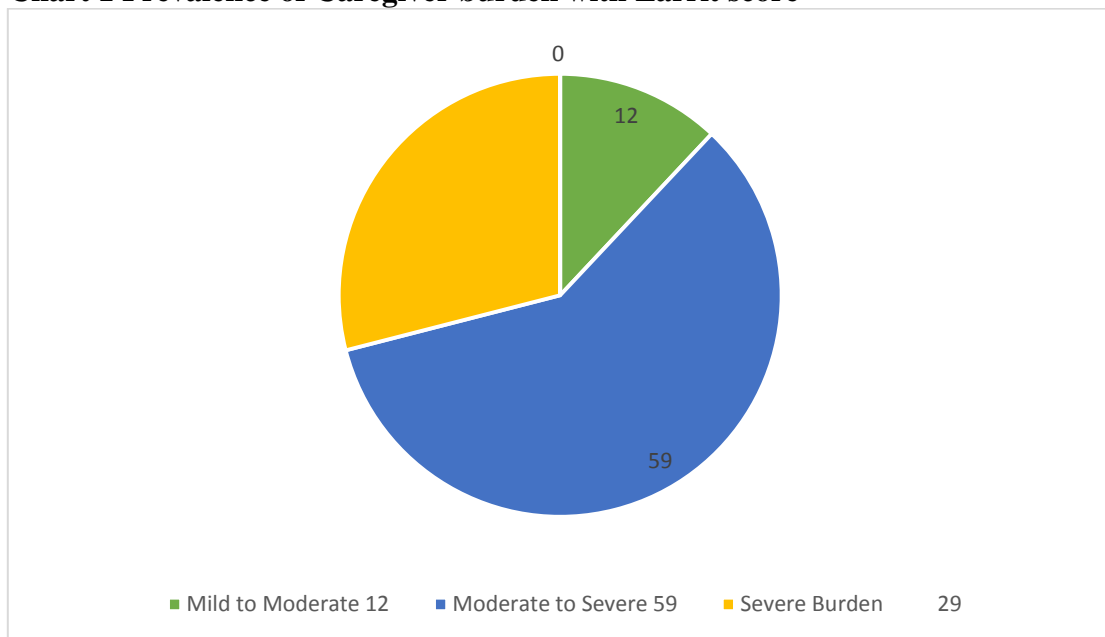
Age Distribution	Frequency	Percent
Less than 20	1	1.0
20-40	46	46.0
41-60	46	46.0
More than 60	7	7.0
Total	100	100.0

The mean caregiver burden score for the caregivers of PLHIV in this study was 51.85 (SD=17.5), range 0-88. The largest group of the participants (59%) reported “moderate to severe” caregiver burden. 29% caregivers living with HIV positive patients experience severe burden. 12% had only mild to moderate burden.

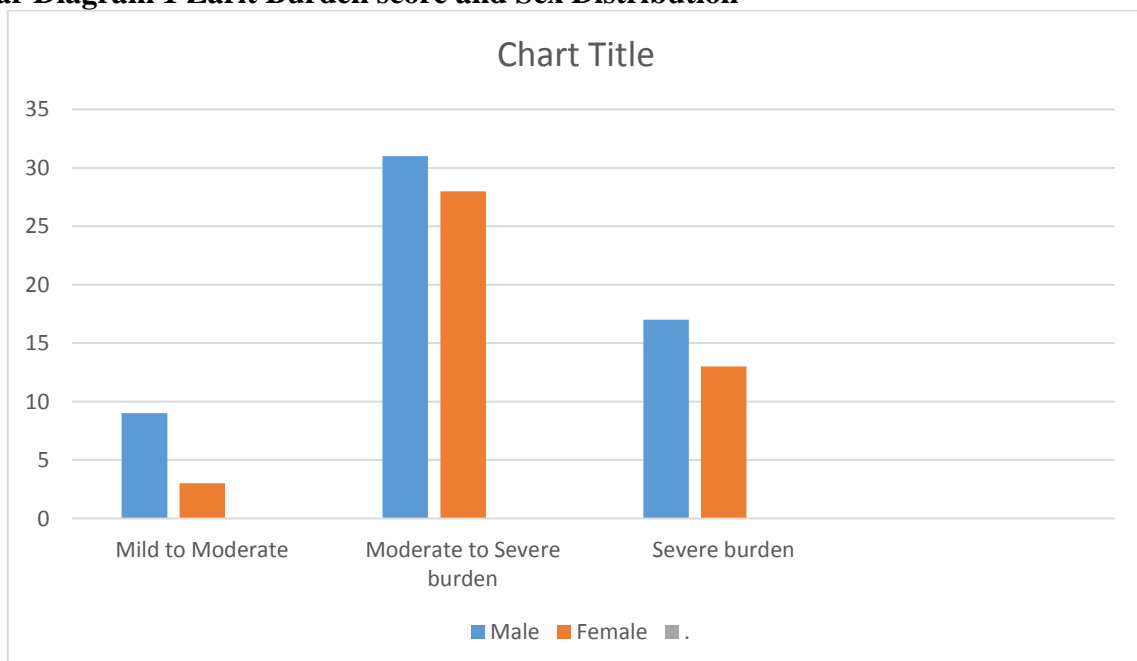
Table 3: Table Showing Frequency Distribution Of Caregiver Burden

Zarrit Score	Frequency	Percent
Mild to Moderate Burden	12	12.0
Moderate to Severe Burden	59	59.0
Severe Burden	29	29.0
Total	100	100.0

Pie Chart 1 Prevalence of Caregiver burden with Zarrit score



Bar Diagram 1 Zarit Burden score and Sex Distribution



Out of 56 females 16(28.6%) were noted to have severe burden and 31(55.4%) were having moderate to severe burden.13 out of 44 males(29.5%) suffered severe depression and 28 of 44(63.6%) had moderate to severe depression

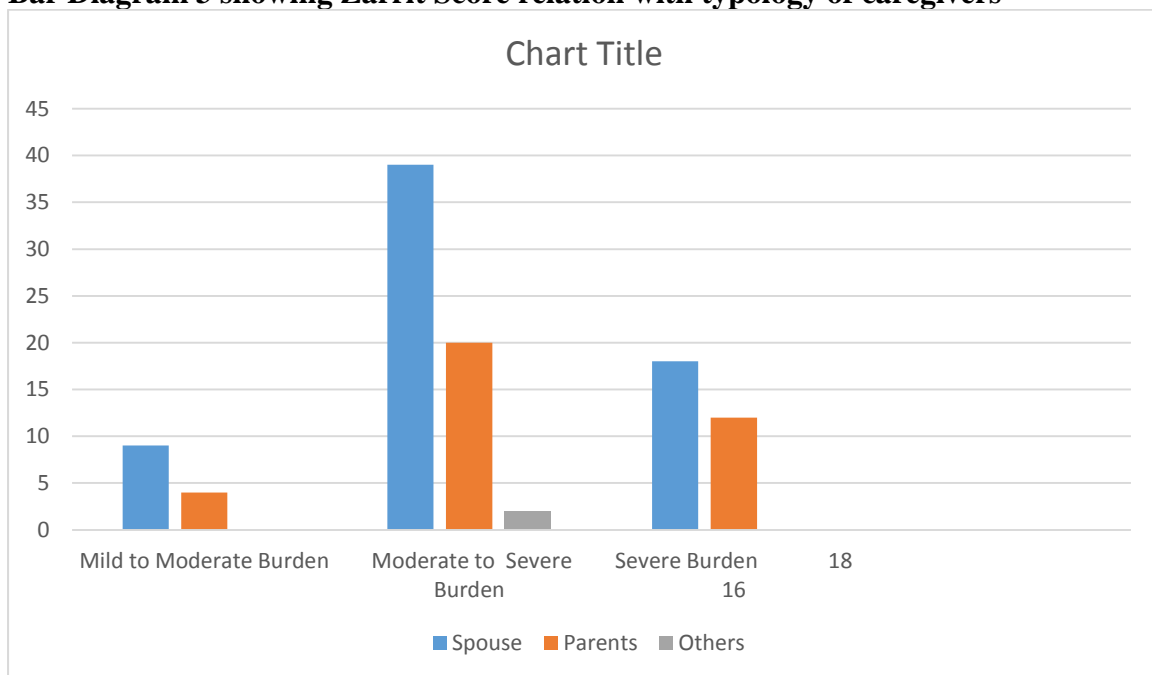
Table 4: Table Showing Age And Zarrit Score Cross Tabulation

		Zarrit score			P value	
		Mild to Moderate Burden	Moderate to Severe Burden	Severe Burden		
Age Category	<20	Count	0	0	1	
		% within Age category	0.0%	0.0%	100.0%	
	21-40	Count	6	23	17	
		% within Age category	13.0%	50.0%	37.0%	
	41-60	Count	6	30	10	0.276*
		% within Age category	13.0%	65.2%	21.7%	
	>60	Count	0	6	1	
		% within Age category	0.0%	85.7%	14.3%	
Total		Count	12	59	29	
		% within Age category	12.0%	59.0%	29.0%	

*Statistically insignificant.

Out of 7 caregivers above 60 years of age 6 of them(85.7%) had moderate to severe caregiver burden while 1 had severe caregiver burden(14.3%)(P value 0.276). 37% of caregivers in age category 21-40 years suffered severe caregiver burden and 50% of them had moderate to severe burden. The only teen caregiver in our study suffered severe burden.

Bar Diagram 3 showing Zarrit Score relation with typology of caregivers



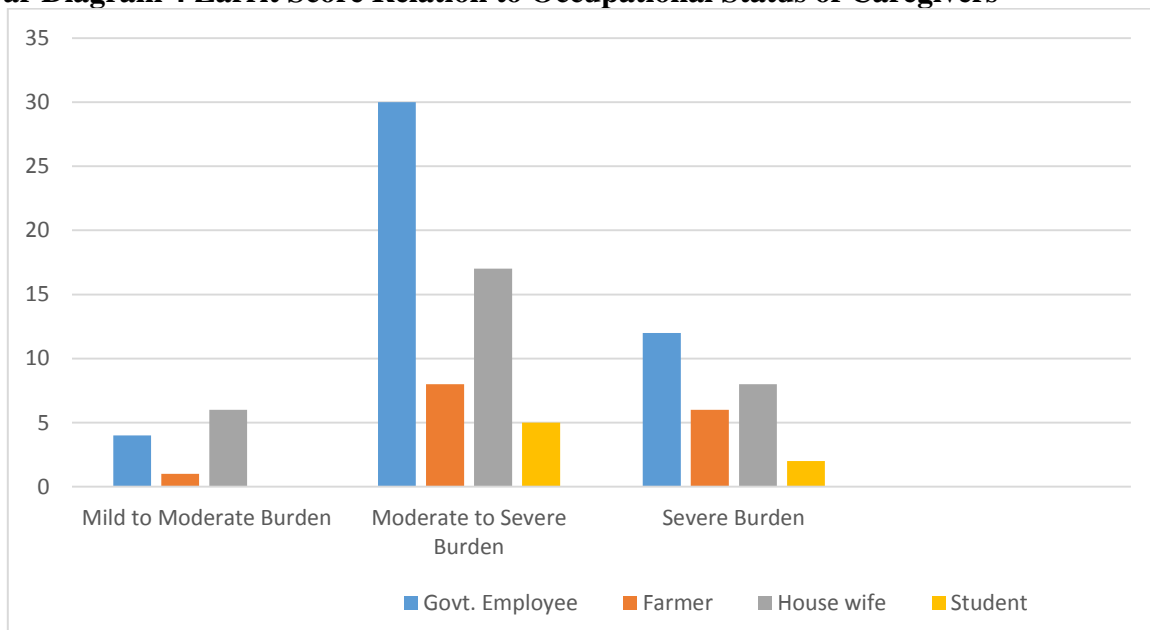
17 of 63 spouse (17% of total) were noted to have severe burden whereas 12 of 35 parents (12% of total) were noted to have severe burden. 37 of 63 spouse (37% of total) and 20 of 35 parents (20% of total) were noted to be having moderate to severe depression.

Out of 100 caregivers, 91 were married (91%). 26 out of 91 (28.8%) suffered severe burden and 54 (59.3%) suffered moderate to severe burden whereas 3 of 9 (33.3%) unmarried caregivers suffered from severe burden and 5 (55.6%) of them had moderate to severe burden. Mild burden is noted in 12.1% married caregivers and 11.1% of unmarried caregivers

Table 5: Zarrit Score Distribution With Educational Status

			Education Status		
			Illiterate	Below Matric	P value
Zarrit Score	Mild to Moderate Burden	Count	1	8	0.065*
		% within education status	3.8%	17.0%	
		% of Total	1.0	8.0	
	Moderate to Severe Burden	Count	19	25	
		% within education status	73.1%	53.2%	
		% of Total	19.0%	25.0%	
	Severe Burden	Count	6	14	
		% within education status	23.1%	29.8%	
		% of Total	6.0%	14.0%	
Total		Count	26	47	
		% within education status	100.0%	100.0%	
		% of Total	26.0%	47.0%	

Bar Diagram 4 Zarrit Score Relation to Occupational Status of Caregivers



6 out of 14 farmers (42.9%) suffered severe depression whereas 12 out of 46 govt. employees (26%) had severe burden. 8 out of 30(26.7%) housewives had severe burden. 2 out of 7 students (28.6%) had severe burden. 30 out of 46 Govt. employees (65.2%), 7 out of 14 farmers (50%), 16 out of 30 housewives and 5 out of 7 students (71.4%) had moderate to severe depression.

DISCUSSION

All family caregivers of PLHIV experienced some level of burden. The largest groups reported “moderate to severe” (59%) caregiver burden. Most of the caregivers were female (56%) and the most common relationship was spouse (63%). 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 ($p=0.026$). In our study 29% caregivers living with HIV positive patients experience severe burden. The mean caregiver burden score for the caregivers of PLHIV in this study was 51.85 (SD=17.5). The largest group of the participants (59%) reported “moderate to severe” caregiver burden. 12% had only mild to moderate burden. Caregiver burden is high in our setup because caregiver burden is a multidimensional problem. Its variables are dependent on sociodemographic characters of caregivers. Furthermore, HIV has still got stigma in our society and caregivers of PLHIV are socially not provided with adequate support.

A RCT done in Thailand¹⁰ came to outcome that a majority of the sample 66.6%, was female. Age ranged 19–80 years. The mean age of the participants was 44.3 years (standard deviation (SD) = 13.4). Most participants (86.6%) received less than high school education. A majority of the caregivers were employed (86.5%) and married/living with someone (79%). The mean caregiver burden score was 46.8 (SD = 12.12). A majority of the caregivers in the study reported either ‘moderate to severe’ or ‘severe’ burden (66.5%). This is consistent with our study as sociodemographic characters of caregivers matched in both studies as HIV is predominantly a disease of lower economic strata.

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. 64.7% 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 ART Centers. This is a good way to reach out to the caregivers and give them the information that they need for basic home care. A study¹¹ 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. The majority of caregivers expressed that they felt depressed. 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.¹² To reduce the caregiver burden and the negative health effects 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 caregiver is not enough or the caregiver’s well being is affected. 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 PLHIV¹³. The result can be used as a base for interventions for caregivers of PLHIV. The caregivers are a vulnerable group and most of them had moderate to severe burden. To be aware of what kind of support they need, it is easier to provide the correct interventions and that they are implemented 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 wellbeing, which would benefit both themselves and the person for whom they are caring.

CONCLUSION

Majority caregivers of PLHIV experience caregiver burden. 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. Correct interventions at the right time will give the caregiver a better quality of life with lower stress and higher wellbeing, which would benefit both themselves and the person for whom they are caring.

REFERENCES

1. **National encyklopedin (2012)**. HIV. Retrieved 16th of March 2012, from <http://www.ne.se/hiv>
2. **Gisslén, M.** Hiv and Aids. Retrieved 20th of March 2012, from <http://www.1177.se/Fakta-och-rad/Sjukdomar/Hiv-och-aids/>
3. **Svarovskia ES, Cheslock SR, Zhang et al.** Retroviral mutation rates and reverse transcriptase fidelity. *Frontiers in Bioscience* 2013 1(8), 117-34
4. **UNAIDS (2010a)**. Global report: UNAIDS report on the global AIDS epidemic 2010. Retrieved, 20th October 2011 from, http://www.unaids.org/documents/20101123_GlobalReport_Chap2_em.pdf
5. **WHO (2012)**. Antiretroviral therapy. Retrieved, 9th of March 2012, from <http://www.who.int/hiv/topics/treatment/en/index.html>
6. **Smittskyddsinstitutet**. Sjukdomsinformationonhivinfektion 2010. Retrieved 9th of March 2012, <http://www.smittskyddsinstitutet.se/sjukdomar/hivinfektion>
7. **Zarit SH, Reever KE, Bach-Peterson J.** Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; 20:649-55.
8. **Pearlin LI, Mullan JT, Semple S et al.** Care giving and stress process: An overview of concepts and their measures. *Gerontologist* 1990; 30:583-99.
9. **Given CW, Given B, Stommel M et al.** The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health* 1992; 15:271-83.
10. **Lee SJ, Li L, Jiraphongsa C et al.** Caregiver burden of family members of persons living with HIV in Thailand. *Int J Nurs Pract* 2010; 16:57-63.
11. **Walter K, Tindyebwa D, Rubaale et al.** Family Caregivers in Rural Uganda: The Hidden Reality. *Health Care for Women International* 2007; 28(10):856-71.
12. **Pirraglia PA, Bishop D, Herman DS et al.** Caregiver burden and depression among informal caregivers of HIV-infected individuals. *MD Gen Intern Med* 2005; 20(6):510-14.

13. **Socialstyrelsen.** Kompetensbeskrivning för legitimerad sjuksköterska. Retrieved 22nd of April 2012, from <http://www.socialstyrelsen.se/publikationer2005/2005-105-1>.