UISS International Journal of Health Sciences and Research ISSN: 2249-9571

Original Research Article

www.ijhsr.org

# Perceived Social Support and Burden among Family Caregivers of Cancer Patients

Maheshwari Preksha S<sup>1</sup>, Mahal Rajinder Kaur<sup>2</sup>

<sup>1</sup>Assistant Professor, University College of Nursing, BFUHS, Faridkot, Punjab. <sup>2</sup>Professor and Principal, M D Oswal College of Nursing, Ludhiana, Punjab.

Corresponding Author: Maheshwari Preksha S.

Received: 19/12/2015

Revised: 31/12/2015

Accepted: 31/12/2015

#### ABSTRACT

**Introduction:** The Punjab State of India has seen greater prevalence of cancer and a trend toward outpatient treatment, providing support and managing care has placed added responsibilities on family caregivers. Family caregivers receiving social support are likely to feel low burden, so the purpose of present study was to examine the relationship of perceived social support and burden among family caregivers of cancer patients.

**Methods:** In an exploratory, co-relational, cross sectional survey, 225 eligible family caregivers of cancer patients undergoing chemotherapy and radiation therapy in selected hospital of Punjab were enrolled conveniently and assessed using Socio demographic Data Sheet, Caregiver Reaction Assessment (CRA), and Multi-dimensional Scale for Perceived Social Support (MDSPSS). Data were analyzed using descriptive statistics and Independent t-test, ANOVA and Pearson's correlation.

**Results:** Perceived social support had large negative correlation with burden at 0.01 level of significance (r= -0.688\*\*). Perceived social support was high in those caregivers who were caring for their sibling relationship, had sufficient help for caring and belongs to local (distance). Burden was high in those caregivers who had not help for caring and belongs to other district (more distance).

**Conclusion:** Study concluded that low perceived social support of caregivers of cancer patient results in high burden. Oncology nurses should regular assess the social support of caregivers of cancer patients as it directly affects the burden. Policy makers can plan and organize support group or other intervention for caregivers so that they can get more social support while caring with their cancer patient.

Key Words: Perceived social support, burden, family caregiver, cancer.

#### **INTRODUCTION**

Cancer is the leading cause of death in developed countries and the second most prevalent cause of death in developing countries. According to GLOBOCAN 2012, there are 32.6 million people (over the age of 15 years) alive who had had a cancer diagnosed in the previous five years. <sup>[1]</sup> The Punjab State of India has seen greater prevalence of cancer with 91 per lakh people suffering from cancer, 215 per lakh deaths from cancer in

last 5 years and 318 per lakh suspected cancer cases as per the survey report of 2013.<sup>[2]</sup>

With cancer rapidly developing into a continuous care problem because of increasing incidence rates, longer survival times, and a trend toward outpatient treatment, providing support and managing care has placed added responsibilities on family caregivers. The caregiver may be a family member or close friend who wishes to help the patient, but lacks the necessary preparation. When the disease is cancer, the situation gets worse as caregivers for persons with cancer encounter additional burdens. Family caregivers are forgotten patients and their symptoms such as mood swing, fatigue, headaches, joint and muscle pains, marital and family conflicts, and financial problems may be a reflection of caregiver stress in looking after a sick relative. <sup>[3]</sup>

Family forms the backbone of support during illness in a country like India with limited availability of tertiary supports. All interpersonal relations which. have a major place in individuals' lives and provide emotional, physical and cognitive assistance to individuals whenever needed, are defined as "Social Support Systems" that support the state of health. It has been emphasized that social support, which is conceptualized as the support given to any person in a troublesome or burdensome situation by family members, relatives as well as resources exerted by social connections, is effective in promoting physical health and feeling oneself good (Ardahan, 2006).<sup>[4]</sup> There are certain studies reporting that caregivers receiving social support feel the less care burden and that there exists a negative- relation between the increase in social support and intensity of care burden (Edwards and Scheetz, 2002; <sup>[5]</sup> Chiou et al., 2009). <sup>[6]</sup> Research has been shown that, lack of social support will lead to detrimental effects on our health particularly stress and burden which lead to negative effect on immune system leading to infection. <sup>[7]</sup> Much research interest has focused on the potential beneficial effect that social support may have for persons who experience stress. Two theoretical hypotheses have been proposed to explain the relations between stress and social support (Cohen & Wills, 1985). <sup>[8]</sup> The direct effect hypothesis states that social support has a beneficial effect on peoples' health and well-being, regardless of how much stress they may be experiencing. The stress-buffer hypothesis

states that social support acts to protect people from the potentially harmful effects of stressful situations or stressful life events.

Surprisingly family caregivers in India have received very little attention in published literature related to psychological effects of caring for a cancer patient. <sup>[9]</sup> So the current study is undertaken with the aim to scrutinize the relation between burden among family caregivers of cancer patients and the level of the perceived social support.

Study will also measure the association of burden and perceived social support with selected socio-demographic variables of family caregivers. Findings of this study will have significance in the field of caregiving as it may help the future nurse practitioner and researcher to develop support interventions for family caregivers and recommendations for further research in field of caregiving will be drawn from the results of this study.

## MATERIALS AND METHODS

А descriptive cross sectional survey was done to assess the relationship of burden and perceived social support with each other and with other sociodemographic variables of family caregivers of cancer patients undergoing chemotherapy and radiation therapy in selected hospital. The present study was conducted in May-December 2014 at cancer OPD of GGS medical Hospital, located in Faridkot districts of Punjab. The population under study family is caregivers of cancer patients undergoing chemotherapy and radiation therapy. Sample consisted of family caregivers of cancer patients undergoing chemotherapy and radiation therapy in GGS medical Hospital, Faridkot (Punjab.), those meeting the inclusion criteria were selected by the researcher for the study. The group included only adult (more than or equal to 18 years) family caregivers who were living with cancer patient, able to understand Punjabi/ English, willing to participate and nominated by cancer patient to provides significant care at home and to accompany patient during most of therapy visits. Family caregivers were not eligible for the participation if their cancer patient has already finished the first cycle of chemotherapy/ first day radiation therapy of current treatment plan and if the family caregiver was unable to cooperate due to physical, psychological or emotional reasons.

A sample of convenience was taken to recruit 225 family caregivers of cancer patients for study. The tools used for the study were Socio demographic Data Sheet, Caregiver Reaction Assessment (CRA), and Multidimensional Scale for Perceived Social Support (MDSPSS).

Tool no. 1- Socio-demographic data sheet: Socio-demographic data sheet is developed by researcher and used for recording of socio-demographic and caregiving information of the family caregiver and their patients. Administration time is approximately 7-8 minutes. This tool had two sections. Section A: It has total nine items related to socio-demographic information of the family caregiver such as age, gender, religion, marital status, education, occupation, income, type of family and residence. Section B: It has total fourteen items related to caregiving information of the family caregiver such as relationship with patient, duration of caregiving in months, average no. of hours spent in caregiving per day, any cut back in usual working hours provision of unpaid help in caregiving, provision of paid help in caregiving, distance from treatment centre, presence of a health professional in family, presence of any co-morbid chronic illness, presence of any health problem in last month, any information/education received support caregiving role, patient's to diagnosis, stage and type of current treatment. Appropriate content validity of the tool was established by twelve experts from oncology, nursing, psychiatry, and

psychology fields and appropriate modifications were made. The reliability was established through test retest method (r = 1).

Tool no. 2-Caregiver Reaction Assessment Instrument (Given 1992): <sup>[10]</sup> Caregiver burden was measured using the Caregiver Reaction Assessment scale (CRA), was usassesses the burden of caregiving and evaluates the caregiving experience. There are 24 items and 5 subscales i.e. 'Impact on Schedule' (5 items), 'Impact on Finances' (3 items), 'Lack of Family Support' (5 items), 'Impact on Health' (4 items), and Caregiver Esteem' (7 items). Respondents are asked to rate the perceived impact of caregiving on a 5-point Likert scale ranging from 1 (Strongly disagree) to 5 (Strongly agree). All the positively worded questions of scale were reverse scored. A higher score represented higher burden. The subscales of the CRA are found valid and reliable (Cronbach's a -coefficients ranged from 0.68–0.90<sup>[11]</sup>) in samples of caregivers of cancer patients. The reliability was established for the present study through test retest method (r = 0.81)

## Tool no. 3- The multidimensional scale of perceived social support (Zimet 1988):<sup>[12]</sup>

Perceived Social Support Assessment scale was used in this study to measure social support of the caregivers of the cancer patient. The scale is an attempt to achieve a one-dimensional measure of perceived social support from family, friends and significant other. It is a standardized, short structured, self report 12 items multi dimensional scale. Items are answered on a 7-point scale from very strongly disagree to very strongly agree. All the items are positive statements. All items were only related to the self acceptance aspect of social support and not with any others. Perceived Social Support Assessment Scale is widely used as an assessment tool for health care researcher in Indian setting. Administration time is approximately 3-5 minutes. Scores range from 12 to 84. The higher the score indicates the high perceived social support. For each assessment, there is an algorithm leading to one of three acuity ranges i.e. high acuity (total score, 69-84), moderate acuity (total score, 49-68) or low acuity (total score, 12-48). The MSPSS has shown high internal reliability (Cronbach's alpha =0.93 for the total score). <sup>[13]</sup> The reliability was established for the present study through test retest method (r =0.89).

The tools were translated into Punjabi language under the guidance of language experts and amendments were made according to suggestions. Back translation in English was done to ensure the content and meaning. Try out of the tool was done to ensure the reliability and understanding of the tool. Pilot study was conducted and the study was found to be feasible.

*Ethical considerations:* Prior to administration to tools, an informed written consent form was signed by the each subject before data collection. All the subjects were ensured that confidentiality and anonymity will be maintained

throughout the study. Permission was obtained from Institutional Ethical Committee to carry out the study. Written permission was also obtained from Medical Superintendent of selected hospital.

Statistical methods: The data was analyzed by Statistical Package for Social Sciences (SPSS) version 21. The p<0.05 level was established as a criterion of statistical significance for all the statistical procedures performed. Appropriate descriptive and inferential statistics were employed to analyze data as per objectives of the study. Frequency and %age distribution of sample characteristics was computed. Mean (SD) of burden and support of perceived social family caregivers was calculated. Correlation between burden and perceived social support was determined by Carl Pearson's method. ANOVA or t-test was used to determine the relationship of selected socio-demographic characteristics with a burden and perceived social support score.

#### **RESULTS**

Socio-demographic cha	f (%)	
Age	Mean (SD)	40.98 (12.2)
Gender	Male	139 (61.8)
	Female	86 (38.2)
Marital status	Married	182 (80.9)
	Unmarried	37 (16.4)
	Widow/widower	6 (2.7)
Religion	Sikh	170(75.6)
	Hindu	54 (24)
	Christian	1 (0.4)
Education	Upto 5 <sup>th</sup>	27 (12)
	Upto 10 <sup>th</sup>	105 (46.7)
	Upto 12 <sup>th</sup>	69 (30.7)
	Graduation and above	24 (10.4)
Occupation	Unemployed	7 (3.1)
	Govt service/ Retired	18 (8)
	Labor	7 (3.1)
	Self employed	73 (32.4)
	Homemaker	43 (19.1)
	Student	24 (10.7)
	Agriculture	53 (23.6)
Family Income/ year	<1 Lakh	56 (24.9)
	1-3 Lakh	96 (42.7)
	> 3-5 Lakh	54 (24)
	>5 Lakh	19 (8.4)
Type of family	Nuclear	71 (31.6)
	Joint	119 (52.9)
	Extended	35 (15.6)
Residence	Rural	155 (68.9)
	Urban	70 (31.1)

 Table 1: Distribution of Subjects as per their Socio-demographic Characteristics (N=225)

Socio-demographic characteristics: As shown in table 1, the mean age of the family caregivers (N=225) was 40.98 (SD=12.2) years. The family caregivers predominantly were male (61.8%), married (80.9%) and belonged to Sikh religion (75.6%). All the participants were literate with maximum (46.7%) educated upto tenth standard followed by (30.7%) educated upto 12th standard. Maximum participants were self employed (32.4%) followed by agriculture profession (23.6%). Yearly family income of maximum subjects (42.7%) was between 1-3 lakhs/year. Majority of the subjects belonged to joint family (52.9) and were residing in rural area (68.9%).

**Care giving related characteristics:** As shown in table 2, maximum (42.2%) caregivers were spouse followed by children (33.3%). Family caregivers were providing care from a mean duration of

4.96 (3.2) months with an amount of caregiving being mean 5.84 (1.78) hrs/day. All 225 (100%) family caregivers had to cut back number of hours they worked due their caregiving usually, to responsibility. Maximum (52.9%) participants reported to get minimum unpaid help followed by (42.2%) getting sufficient unpaid help in caregiving. Paid help in caregiving had to be taken by 45.8% participants. Majority (80.4%) participants belonged to other districts and (19.6%) participants were local. Twenty percent participants were having atleast one health professional in family. Chronic disease was present in eight percent whereas 52% participants had health problem in past one month. None of the participants ever received any formal education or information to support their caregiving role.

 Table 2: Distribution of Subjects as per their care giving related characteristics (N=225)

Care giving related characteristic	J (70)	
Relationship with patient	Child	75 (33.3)
1 I	Spouse	95 (42.2)
	Daughter in law	26 (11.6)
	Parents	6 (2.7)
	Siblings	15 (6.7)
	Others	8 (3.6)
Duration care giving in months	Mean (SD)	4.96 (3.2)
Amount CG (hrs/day)	Mean (SD)	5.84 (1.78)
Cut back hours	Yes	225 (100)
	No	0
Unpaid help	No	11 (4.9)
	Minimum help	119 (52.9)
	Sufficient help	95 (42.2)
Paid help	No	122 (54.2)
-	Yes	103 (45.8)
Distance from hospital	Local	44 (19.6)
-	Other district	181 (80.4)
Health professional in family	No	180 (80)
	Yes	45 (20)
Chronic disease	No	207 (92)
	Yes	18 (8)
Health problems of caregiver	No	108 (48)
	Yes	117 (52)
Resources related to care giving	No	0
	Yes	225 (100)
Diagnosis of patient	Breast	56 (24.9)
	Cervix	40 (17.8)
	Head and neck	58 (25.8)
	GI tract	27 (12)
	Reproductive	22 (9.8)
	Others	22 (9.8)
Stage of patient	Progressive stage	56 (24.9)
	Advance stage	169 (75.1)
Treatment	Chemotherapy	66 (29.3)
	Radiation therapy	54 (24)
	Concurrent chemotherapy	105(46.7)

Among all cancer cases, head and neck cancer was at top (25.8%) followed by cancer of breast (24.9%) and cervix (17.8%). Most of (75.1%) patients were receiving treatment for advance stage (stage III and IV) cancer. Majority (46.7%) of cancer patients were receiving concurrent chemotherapy followed by Chemotherapy (29.3%) and Radiation therapy (24%).

Table 3 states that the mean (SD) of burden was 66.48 (13.3) and it range from 39 to 92. Similarly, mean (SD) of perceived social support was 48.63 (12.3) and it range from 16 to 73. The correlation between burden and perceived social support was calculated with Pearson's product moment correlation and it was found that burden had large negative correlation with perceived social support at 0.01 level of significance (r= -0.688\*\*), indicating that as the perceived social support increased, burden level go down.

As shown in table 4, there was no significant association of burden with socio-demographic characteristics of caregivers. Gender, marital status, religion, education, occupation, family income, type of family and residence had no relationship with burden.

Table 5 shows that there was significant association of burden with unpaid help ( $p = \langle 0.001 \rangle$ ) and distance from hospital (p = 0.02). Hence, it can be concluded that unpaid help and distance from hospital had significant association with burden.

Relationship with cancer patient, provision of paid help in caregiving, health professional in family, presence of chronic disease, present health problem of caregiver in last month, patient's diagnosis, stage and type of current treatment had no relationship with burden.

Fable 3	Mean (SI	)) score of	burden a	nd perc	eived socia	l support	and their	correlation	(N=225)
	· · · ·	/							<u> </u>

	Variable	Range	Mean (SD)	df	r	p value		
	Burden	39-92	66.48 (13.3)					
	Perceived social support	16-73	48.63 (12.3)	224	-0.688**	0.01		
**	** Correlation is significant at the 0.01 level (2 tailed), 0.5-0.7 indicates large correlation.							

Socio-demographic cha	racteristics of caregivers	f	Mean (SD)	t/F	df	p value	
Gender	Male	139	65.53 (13.3)	-1.370	223	0	.172
	Female	86	68.02 (13.2)				
Marital status	Married	182	65.90 (13.3)	1.153	2	0.317	
	Unmarried	37	69.51 (13.4)				
	Widow/widower	6	65.50 (10.2)				
Religion	Sikh	170	66.95 (13.3)	0.530	2	0.589	
	Hindu	54	65.15 (13.3)				
	Christian	1	59.00 (-)				
Education	Upto 5 <sup>th</sup>	27	63.56 (12.5)	0.872	3	0.457	
	Upto 10 <sup>th</sup>	105	66.33 (12.9)				
	Upto 12 <sup>th</sup>	69	66.78 (13.7)				
	Graduation and above	24	69.54 (14.6)				
Occupation	Unemployed	7	67.71 (13.0)	0.741	6	0.617	
	Govt service/ Retired	18	64.22 (14.2)				
	Labor	7	68.71 (13.4)				
	Self employed	73	65.04 (12.0)				
	Homemaker	43	66.37 (13.7)				
	Student	24	71.04 (14.6)				
	Agriculture	53	66.79 (13.9)				
Family Income/ year	<1 Lakh	56	66.89 (12.6)	0.385	3	0.764	
	1-3 Lakh	96	67.27 (13.6)				
	> 3-5 Lakh	54	65.02 (13.1)				
	>5 Lakh	19	65.42 (14.5)				
Type of family	Nuclear	71	68.37 (11.7)	1.947	2	0.145	
	Joint	119	66.39 (14.1)				
	Extended	35	62.97 (12.8)				
Residence	Rural	155	67.05 (13.3)	0.947	223	0.345	
	Urban	70	65.23 (13.2)				

 Table 4: Relationship of selected socio-demographic characteristics with burden score (N=225)

\*\* Significant at the 0.01 level

Care giving related characterist	ics of caregivers	(%)	Mean (SD)	t/F	df	p value
Relationship with patient	Child	75	66.20 (13.5)	2.120	5	0.064
	Daughter in law	26	66.00 (13.9)			
	Others	8	67.38 (5.4)			
	Parents	6	59.50 (11.6)			
	Siblings	15	57.87 (11.7)			
	Spouse	95	68.56 (13.2)			
Unpaid help	No	11	76.45 (16.7)	25.355	2	< 0.001***
	Minimum help	119	70.79 (11.8)			
	Sufficient help	95	59.93 (11.7)			
Paid help	No	122	65.33 (13.8)	-1.416	223	0.158
	Yes	103	67.84 (12.6)			
Distance from hospital	Local	44	62.36 (14.1)	-2.308	223	0.022*
	Other district	181	67.48 (12.9)			
Health professional in family	No	180	67.04 (13.5)	1.261	223	0.209
	Yes	45	64.24 (12.3)			
Chronic disease	No	207	66.87 (13.3)	1.511	223	0.132
	Yes	18	61.94 (11.9)			
Health problems of caregiver	No	108	66.60 (13.8)	0.132	223	0.895
	Yes	117	66.37 (12.8)			
Diagnosis of patient	Breast	57	67.98 (13.5)	0.209	5	0.959
	Cervix	39	66.15 (14.9)			
	GI tract	25	66.28 (15.2)			
	H & N	60	65.73 (12.4)			
	Others	22	65.50 (13.5)			
	Reproductive	22	66.41 (10.3)			
Stage of patient	Progressive stage	56	65.21 (12.9)	-0.820	223	0.413
	Advance stage	169	66.90 (13.4)			
Treatment of patient	Chemotherapy	66	68.12 (13.8)	1.131	2	0.325
	Radiation therapy	54	67.15 (12.3)			
	Concurrent	105	65.10 (13.3)			
	chemotherapy					

Table 5: Relationship of selected caregiving characteristics of caregiver with burden score (N=225)

Significant at the 0.01 level

Table 6: Relationship of selected socio-demographic characteristics with perceived social support score (N=225)

Socio-demographic cha	aracteristics of caregivers	f(%)	Mean (SD)	t/F	df	p value
Gender	Male	139	48.73 (12.5)	0.158	223	0.875
	Female	86	48.47 (12.1)			
Marital status	Married	182	49.10 (12.2)	0.681	2	0.507
	Unmarried	37	46.62 (12.1)			
	Widow/widower	6	46.83 (18.7)			
Religion	Sikh	170	48.48 (12.1)	0.173	2	0.841
	Hindu	54	49.20 (13.3)			
	Christian	1	43.00 (-)			
Education	Upto 5 <sup>th</sup>	27	49.59 (12.6)	1.543	3	0.204
	Upto 10 <sup>th</sup>	105	48.95 (11.8)			
	Upto 12 <sup>th</sup>	69	49.52 (13.2)			
	Graduation and above	24	43.58 (11.3)			
Occupation	Unemployed	7	50.00 (7.9)	1.005	6	0.423
	Govt service/ Retired	18	45.94 (12.5)			
	Labor	7	48.00 (8.9)			
	Self employed	73	50.88 (12.5)			
	Homemaker	43	49.09 (10.8)			
	Student	24	44.79 (12.2)			
	Agriculture	53	47.72 (13.9)			
Family Income/ year	<1 Lakh	56	48.71 (12.2)	0.153	3	0.928
	1-3 Lakh	96	48.83 (12.6)			
	> 3-5 Lakh	54	48.83 (11.7)			
	>5 Lakh	19	46.79 (13.7)			
Type of family	Nuclear	71	47.85 (12.2)	2.067	2	0.129
•••	Joint	119	47.96 (12.7)			
	Extended	35	52.51 (10.7)			
Residence	Rural	155	48.25 (12.1)	-0.684	223	0.494
	Urban	70	49.47 (12.7)			
** Significant at the 0.01 level						

As shown in table 6, there was no significant association of perceived social socio-demographic support with

caregivers. Gender, characteristics of religion, status, education, marital occupation, family income, type of family and residence had no relationship with perceived social support.

As shown in table 7, there was significant association of perceived social support with relationship of caregiver and patient (p=0.02), unpaid help (p=<0.001) and distance from hospital (p=0.01). Hence, it can be concluded that perceived social support was significantly associated with relationship of caregiver and patient, unpaid help and distance from hospital.

Provision of paid help in caregiving, health professional in family, presence of chronic disease, present health problem of caregiver in last month, patient's diagnosis, stage and type of current treatment had no relationship with perceived social support.

Relationship of age, duration of caregiving and amount of caregiving with burden and perceived social support

Care giving related characteristics of caregivers		f (%)	Mean (SD)	t/F	df	p value
Relationship with patient	Child	75	49.91 (12.3)	2.604	5	0.026*
	Daughter in law	26	48.88 (12.7)			
	Others	8	52.13 (8.5)			
	Parents	6	52.50 (12.2)			
	Siblings	15	56.20 (11.0)			
	Spouse	95	45.82 (12.1)			
Unpaid help	No	11	33.55 (17.4)	34.637	2	< 0.001
	Minimum help	119	44.87 (11.1)			
	Sufficient help	95	55.08 (9.3)			
Paid help	No	122	49.51 (12.3)	1.159	223	0.248
	Yes	103	47.59 (12.3)			
Distance from hospital	Local	44	52.86 (11.8)	2.564	223	0.011*
	Other district	181	47.60 (12.2)			
Health professional in family	No	180	48.32 (12.4)	-0.762	223	0.447
	Yes	45	49.89 (12.1)			
Chronic disease	No	207	48.66 (12.3)	0.106	223	0.915
	Yes	18	48.33 (13.0)			
Health problems of caregiver	No	108	49.39 (12.5)	0.883	223	0.378
	Yes	117	47.93 (12.2)			
Diagnosis of patient	Breast	57	49.46 (12.0)	0.655	5	0.658
	Cervix	39	46.44 (12.5)			
	GI tract	25	46.20 (11.9)			
	H & N	60	50.05 (12.2)			
	Others	22	48.64 (14.2)			
	Reproductive	22	49.27 (12.2)			
Stage of patient	Progressive stage	56	49.18 (12.9)	0.382	223	0.703
-	Advance stage	169	48.45 (12.7)			
Treatment of patient	Chemotherapy	66	47.23 (11.9)	0.602	2	0.549
-	Radiation therapy	54	49.30 (12.8)			
	Concurrent chemotherapy	105	49.17 (12.3)	]		

Table 7: Relationship of selected caregiving characteristics of caregiver with perceived social support score (N=225)

\*\* Significant at the 0.01 level

Table 8: Relationship of age, duration of caregiving and amount of caregiving by caregiver with burden and perceived social support (N=225)

Outcome variables	Age of caregiver	Duration of caregiving	Amount of caregiving				
Burden	-0.128	-0.358**	0.182**				
Perceived social support	0.034	0.067	-0.215**				
** Completion is significant at the 0.01 level (2 toiled)							

\*\*. Correlation is significant at the 0.01 level (2-tailed).

As table 8 shows, duration of caregiving had a significant moderate negative correlation with burden (r= $0.358^{**}$ , p=0.01) whereas amount of caregiving had significant, moderately positive correlation with burden (r= $0.182^{**}$ , p=0.01) and negative correlation

with perceived social support (r=-0.215\*\*, p=0.01).

Hence, it can be concluded that as the duration of caregiving increased, burden among caregivers decreased and as the amount of caregiving increased burden also increased. Also caregivers with low perceived social support had high burden and provided more amount of care (hrs/day).

# DISCUSSION

The present study is an attempt to understand the relationship of burden and perceived social support among family caregivers of cancer patients. Results revealed that there is a large negative significant relationship between burden and perceived social support and family caregivers with low perceived social support has high burden. This is consistent with previous research studies reporting that caregivers with little social support have higher levels of caregiver burden. <sup>[14-</sup> <sup>16]</sup> This result is also consistent with. Casado and Sacco (2011) <sup>[17]</sup> who found that good family support, understanding and patient self- management were related to less burden. In one study it was found that informal social support was mentioned as resources for caregivers to alleviate or lessen the burden <sup>[18]</sup> Apart from low burden, the patient outcome was found to be good in caregivers with good informal support. [18]

Current study has reported that as the duration of caregiving increased, burden among caregivers decreased. These finding are consistent with Ferrell et al (1995) <sup>[19]</sup> suggesting that caregiver reactions do not increase with time whereas Milbury et al (2013). <sup>[20]</sup> Inconsistently reported that level of burden increased significantly (P=< 0.001) with the duration of care.

Present study has revealed that there was significant association of burden with unpaid help and distance from hospital whereas relationship of caregiver with cancer patient, provision of paid help in caregiving, health professional in family, presence of chronic disease, present health problem of caregiver in last month, patient's diagnosis, stage and type of current treatment had no relationship with burden. Inconsistent with these findings, previous studies have found that patient characteristics, including diagnosis, treatment and stage of disease, have influence on caregiver burden. <sup>[14,21-23]</sup>

In this study perceived social support was significantly associated with relationship of caregiver and patient, unpaid help and distance from hospital. Whereas age, gender, and other sociodemographic characteristics of family caregivers had no relationship with perceived social support. Similar findings are been reported by Okamoto and Tanka (2004) <sup>[24]</sup> that age and gender has no statistical significant impact on social support. Lueboonthavatchai and [25] Lueboonthavatchai (2006)also reported consistently that family income and education had no impact on social support.

# Implications and Recommendations

The findings of this study highlight how important it is that nurse, physicians and other health-care professionals should provide supportive measures integrated into treatment and care in order to decrease burden among family caregivers of cancer patients. Caregiver assessment, followed by nursing interventions tailored to match caregiver needs can be used to address their burden and social support. Nursing students should be trained in conducting caregiver family assessment and conducting family meeting. Findings of the study will act as a catalyst to carry out more extensive multi-site research with a large sample and will enforce evidence based practice.

Study recommends improving social support networks to help caregivers and caregivers should be taught how to manage the stress caused by their taking care of patients. They should also be encouraged to join caregiver support groups and spare time for themselves. Probable bio-psycho-social problems might thus be minimized; caregivers who get professional support appear to have better physical health, less care burdens and better quality of life. A longitudinal study may be conducted on large sample to assess the effects of various supportive interventions improving outcome of caregiving.

## CONCLUSION

Social support from family was associated with caregiver burden in this study. Strengthening family relationship and supporting their effort should be done via community based formal support Community services. based support intervention for example support group should exist in order to help the caregivers with poor social support and high burden. In a community which has proper linkage of social support for example the availability of temporary care facilities or respite care, carer has good social support thus lower their burden and improve their quality of life. Therefore it would be an important act to provide social support for this group of population.

*Limitations:* The study is limited to single setting and to the family caregivers of cancer patients during the time when patients were undergoing cancer chemotherapy and radiation therapy. These caregivers family may not be representative of the entire family caregiver population. Self report method was used to collect data in current study. Use of objective methods could strengthen researcher the study. Finally, acknowledges the limitation of cross sectional design with respect to temporal relationship and imputation of causality of study findings.

# Financial and material support: Self Conflicts of interest: None

#### REFERENCES

- 1. Jacques Ferlay, et al. Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012 International Journal of Cancer Volume 136, Issue 5, pages E359–E386, 1 March 2015.
- 2. Punjab State Report on Cancer Awareness & Symptom Based Early Detection Campaign. State Health

Systems Resource Centre, Punjab....pbhealth.gov.in/canceraware ness/Outcome.pdf

- 3. Medalie Jack. The caregiver as hidden patient: theory and research on health care triads. J Health Soc Behav. 1994; 35:1-12.
- 4. Ardahan M (2006). Social support and the nursing. J Ataturk University School of Nursing. 9, 68-75.
- Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with Parkinson's disease. J Neuro Sci Nurs. 2002; 34:184-190. PMid:12197259
- Chiou CJ, Chang HY, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. Arch Gerontol Geriatr. 2009; 48: 419-424. PMid:18602706
- Devor, M. &Renvall, M. An Educational Intervention to Support Caregivers of Elders With Dementia. Am Alzheimers Dis Other Demen,2008, 23: 233-241.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98, 310–357.
- 9. Mehrotra Seema. Psycho-Oncology Research in India: Current Status and Future Directions. Journal of the Indian Academy of Applied Psychology, January 2008;34(1), 7-18.
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Research in Nursing and Health, 15, 271–283.
- Nijboer, C., Triemstra, A. H. M., Tempelaar, R., Sanderman, R., & Van den Bos, G. A. M. (1999). Measuring both negative and positive reactions to giving care to cancer patients: Psychometric qualities of the Caregiver Reaction Assessment (CRA). Social Science and Medicine, 48,1259–1269.
- Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived

Social Support. Journal of Personality Assessment, 52, 30-41.

- Lisa M. Edwards. Measuring Perceived Social Support in Mexican American Youth: Psychometric Properties of the Multidimensional Scale of Perceived Social Support. Hispanic Journal of Behavioral Sciences, May 2004; Vol. 26, No. 2: 187-194.
- Ferrell, B.; Mazanec, P. Family Caregivers. In: Hurria, A.; Balducci, L., editors. Geratric Oncology: Treatment, Assessment, and Management. New York: Springer; 2009. p. 135-155.
- Gaugler JE, Hanna N, Linder J, Given CW, Tolbert V, Kataria R, Regine WF. Cancer caregiving and subjective stress: a multi-site, multi-dimensional analysis. Psychooncology. 2005; 14(9): 771–785.
- Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman. The role of social and psychologic resources in caregiving of cancer patients. Cancer. 2001 Mar 1;91(5):1029-39.
- Casado, B., & Sacco, P. Correlates of caregiver burden among family caregivers of older Korean Americans. The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 2011, 1-6.
- Iecovich E. Caregiving Burden, Community Services and Quality of Life of Primary Caregivers of Frail Elderly Persons. Journal of Applied Gerontology, 2008, 27; 309-332.
- 19. Ferrell B, Grant M, Chan J, Ahn C, Ferrell B. The impact of cancer pain education on family caregivers of

elderly patients. Oncology Nursing Forum 1995;22(8):1211–1218.

- 20. Milbury K, Badr H, Fossella F, Katherine M, Pisters, Cindy L, Carmack. Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. Support Care Cancer 2013 September; 21(9): 2371–2379.
- Given BA, Sherwood P, Given CW. Support for Caregivers of Cancer Patients: Transition After Active Treatment. Cancer Epidemiology Biomarkers & Prevention. 2011; 20(10): 2015–2021.
- 22. Hwang SS, Chang VT, Alejandro Y, Osenenko P, Davis C, Cogswell J, Kasimis B. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. Palliat Support Care. 2003; 1(4):319–329.
- 23. Sharpe L, Butow P, Smith C, McConnell D. Clarke S. The available relationship between support, unmet needs and caregiver burden in patients with advanced their cancer and carers. Psychooncology. 2005 Feb: 14(2):102-14.
- 24. Okomoto K, Tanka Y. Gender differencesin the relationship between social support and subjective health among elderly persons in japan. Preview Med2004; 38(3):318-22.
- 25. Lueboonthavatchai P, Lueboonthavatchai O. quality of life and correlated health status and social support of schizophrenic patients' caregivers. J Med Assoc Thai 2006 Sep; 89(3):13-19.

How to cite this article: Maheshwari PS, Kaur MR. Perceived social support and burden among family caregivers of cancer patients. Int J Health Sci Res. 2016; 6(1):304-314.

\*\*\*\*\*\*