



Perceived Burden Among Caregivers of Patients Receiving Chemotherapy

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Abstract

Background: Cancer is a major cause of morbidity and mortality in the present time across the world including India. Caregivers are essential for the patients' recovery in day-care, inpatient, or in critically ill setup because they communicate well with the patient and treating them, understand the patients' feelings, and motivate the patients in their struggle to survive critical illness.

Objectives: To assess the perceived burden among the caregiver, To assess the perceived social support among the caregivers. 3. To find out the association between the perceived burden and perceived social support among caregivers.

Material and Methods: The study was conducted to assess the perceived burden and perceived social support among caregivers of patients receiving chemotherapy at selected hospitals in Punjab. A quantitative approach and non-experimental design was used to assess the burden and social support among caregivers of patients receiving chemotherapy by using the Zarit burden scale and Multidimensional scale of perceived social support.

Results: The burden of care as experienced by the caregivers was reported as majority of the subjects 91(91%) had mild burden and 09(09%) subjects reported no burden. Most subjects 87(87%) received moderate social support and 13(13%) subjects received higher support. The result signifies that there is association between perceived burden and perceived social support among caregivers ($p < 0.05$).

Conclusion: The study concluded that caregivers of the patients had varying degree of burden while caring for their patient where as the social support observed was from moderate to high degree.

Keywords: Perceived Caregiver Burden; Perceived Social Support; Chemotherapy

Introduction

Cancer is the uncontrolled growth and spread of cells. It can affect almost any part of the body. The growth often invades surrounding tissue and can metastasize to distant sites. Many cancers can be prevented by avoiding exposure to common risk factors, such as tobacco smoking [1]. Caregivers are individuals, usually family members or relatives (e.g., partner, parents, siblings, close friends, children), who have a significant relationship with the patient suffering from a life-threatening illness and provide assistance to them for day to day care [2]. Literature reports that

cancer affects the emotional, social, physical, and spiritual well-being of patients and their family members [3].

Caregiver is the key person who supports the patient and usually provides the biggest care. A cancer patient in family forces the caregivers to face new circumstances into which they must adapt. The longevity of this sickness state which impacts the whole family, life threatening effects of the ailment, inability of the patient to engage in work and social activities are a few of the reasons further climbing the responsibilities of the caregiver and transforming the roles within family [4].

The lack of social support leads to detrimental effects on the health of the patient particularly stress and burden which lead to negative effects on immune system leading to infection [5]. All interpersonal relations which, have a major place in individuals' lives and provide emotional, physical and cognitive assistance to individuals whenever needed, are defined "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 [6].

Objectives

- To assess the perceived burden among the caregivers.
- To assess the perceived social support among the caregivers.
- To find out the association between the perceived burden and perceived social support among caregivers.

Material and Methods

A quantitative approach a descriptive study design was used, The study was conducted at a multispecialty hospital of Mohali Punjab, having a specialised unit for oncology management, The patients and their care givers were interviewed by the investigator in the OPD as well as IPD of the hospital, all the caregivers who accompanied their patients for the treatment and were willing to participate after an informal consent were included in the study. Total 100 subjects (caregivers) were interviewed to assess the perceived burden and perceived social support. The investigator developed a socio demographic record data sheet, its content validity was established, The Standardized Zarit burden scale and Multidimensional scale of perceived social support was used each interview was completed in 30-35 minutes by the investigator the responses were noted on the proforma which were analysed later.

Results

Table 1 depicts the frequency and percentage distribution of patient as per their sociodemographic variables. nearly half of the subject 47(47%) were in the age group of 48-64 years, 34(34%) subjects were in the age group of 15-47 years, 18(18%) subjects were in the age group of >64 years and only one subject was in the age group of 0-14 years. Half of the subjects 50(50%) were male and half of the subjects 50(50%) were female, 35(35%) subjects were

illiterate, 35(35%) subjects had studied up to matric, 20(20%) subjects had their education up to higher secondary, 09(09%) subjects were graduate, and only one subjects were postgraduate.

Majority of the subjects 89(89%) were married, 07(07%) subjects were widow/widower and 04(04%) subjects were unmarried. Majority of the subjects 75(75%) were residing in rural areas, whereas 25(25%) subjects were residing in urban areas, 38(38%) were unemployed, 33(33%) subjects were self-employed, 26(26%) subjects were private employee and 03(03%) subjects were government employee. Majority of the subjects 69(69%) were living in the joint family and 31(31%) subjects were living in nuclear family. 65(65%) subjects had their monthly income between (10,001-20,000), 18(18%) subjects had between (20,001-30,000), 15(15%) subjects had income less than 10,000 and 02(02%) subjects had income more than 30,000.

Table 2 depicts the frequency and percentage distribution of patient as per their clinical profile. According to organ infected with cancer, 58(58%) had other cancers of Caecum, femur, stomach, ovary, Urinary bladder, lymphoma, nasopharyngeal malignancy, throat, cervical lymph node, gall bladder, tongue, rectum, multiple myeloma, buccal mucosa, soft tissue carcinoma, colon, pancreas, oropharynx, Hodgkin lymphoma, uterus, neck etc, 14(14%) subjects had breast cancer, 13(13%) had lung cancer, 09(09%) had esophagus cancer and 06(06%) subjects had cervix cancer. 29(29%) subjects were in stage 3, and 26(26%) subjects were in stage 1, 22(22%) subjects were in stage 2, of cancer 12(12%) subjects were in stage 4 and 11(11%) subjects were stage 0. According to frequency of chemotherapy, half of the subjects 50(50%) were receiving chemotherapy once a week, followed by 46(46%) subjects who were receiving chemotherapy twice a week and 04(04%) subjects were receiving chemotherapy thrice a week.

Among 59(59%) of the subjects chemotherapy was started since less than one year, 33(33%) subjects were undergoing chemotherapy since last 1-2year, 07(07%) subjects were receiving chemotherapy since last 3-5 year and only 01(01%) subject was getting chemotherapy for more than five years. According to cycle of chemotherapy, 31(31%) subjects had second cycle, 24(24%) subjects had thirdrapy, 15(15%) subjects had fifth cycle and 11(11%) subjects had first cycle of chemotherapy, 09(09%) subjects had fourth cycle 04(04%) subjects had seventh cycle of

chemotherapy, 03(03%) had eighth, 02(02%) had sixth 01(01%) subjects had ninth cycle of chemotherapy. According to alternate therapy, majority of the subjects 73(73%) had not taken any alternate therapy to treat cancer whereas 27(27%) subjects had taken any type of alternate therapies for the treatment of cancer.

Majority of the subjects 74(74%) experienced side effects, however 26(26%) subjects had not experienced side effects during the course of chemotherapy. As per their subject's relation with caregiver, 68(68%) were spouse, 17(17%) subjects were parents, 10(10%) subjects had other relation, 03(03%) subjects were daughter and only 02(02%) subjects were son.

Table 3 depicts the item analysis of perceived caregiver burden among the caregivers. It shows that 45% subjects rarely felt that they don't have enough time for themselves, 45% subjects rarely felt stressed between caring for relative and trying to meet other responsibilities, all subjects reported that they never felt anger while being around their patients, 98% subjects never felt that their relative will affect their relationship with family member or friends in a negative way, 59% subjects rarely felt strained while providing the care, all the subjects said that they never felt that their own health was affected because of their involvement with patient, 70% subjects rarely felt that they don't have as much privacy because of a sick relative, 50% subjects sometimes felt that their social life had suffered because caring for relative, 99% subjects felt that they had never lost control of their life because of their relative, 66% subjects nearly always felt uncertain about what to do about their relative, All the subjects always felt that they should be doing more for their relative, 73% subjects nearly always felt that they could do a better job in caring for relative, 87% subjects never felt that their relative asks for more help than he/she needed, subjects never felt embarrassed over their relative's behaviour, and all of them were always afraid of the future of the patient, 37% subjects rarely felt that their relative is dependent upon them, subjects never felt uncomfortable about having friends over because of their relative, 46% subjects sometimes thought that their patients were depending on them for care, 65% subjects never felt that they don't have enough money for their relative, in addition to the rest of expenses, 96% subjects rarely felt that they will be unable to take care of their relative for a longer period. The caregivers reported that they never felt burdened while being with their patient. Table 4 depicts the frequency and percentage

distribution of perceived burden among caregivers. The findings revealed that most of the subjects 91(91%) reported having mild burden whereas 09(09%) subjects had no burden of caring their relatives who were getting treatment of cancer.

Table 5 depicts the item wise frequency and percentage distribution of perceived social support among caregivers. Majority of subjects 83% disagreed very strongly that there is a special person who is around when in need, 83% subjects disagreed very strongly that there is a special person with whom they can share their joys and sorrows, 59% subjects very strongly agreed that their own families really try to help them, 59% subjects very strongly agreed that they get the emotional help and receive support from their own family when needed, 83% subjects very strongly disagreed that there was no special person who is the real source of comfort to them, 56% subjects strongly agreed and reported that their own friends tried to provide help, 55% subjects strongly agreed that they can count on their own friends when things go wrong, 60% subjects very strongly agreed that they can talk about problems with their own family, 53% subjects strongly agreed that they have friends with whom they can share joys and sorrows, 83% subjects very strongly disagreed that there is no special person in their life who cares about their feelings, 57% subjects very strongly agreed that their own family will help them to make decisions and 55% subjects strongly agreed that they can talk about their problems with their own friends.

Table 6 depicts the frequency and percentage distribution of perceived social support among caregivers. The findings revealed that majority of the subjects 87(87%) had moderate social support whereas 13(13%) subjects had high social support.

Table 7 depicts the association between the perceived burden and perceived social support among caregivers. The findings revealed that the association between perceived burden and perceived social support among caregivers was found to be significant, ($p < 0.05$). Hence it was observed that subject (caregiver) who had moderate social support they were having mild burden of caring their relative (patient with cancer).

Discussion

Caregiver burden is considered a "multi-dimensional biophysical reaction resulting from an imbalance of care demands

Sr. No.	Sample characteristics	Frequency (f)	Percentage (%)
1.	Age		
	0-14 years	01	01%
	15-47 years	34	34%
	48-64 years	47	47%
	>64 years	18	18%
2.	Gender		
	Male	50	50%
	Female	50	50%
3.	Educational Status		
	Illiterate	35	35%
	Matric	35	35%
	Higher secondary	20	20%
	Graduate	09	09%
4.	Marital Status		
	Married	89	89%
	Unmarried	04	04%
	Widow/Widower	07	07%
5.	Residence		
	Rural	75	75%
	Urban	25	25%
6.	Occupation		
	Govt. employee	03	03%
	Private employee	26	26%
	Unemployed	38	38%
7.	Types of family		
	Nuclear	31	31%
	Joint	69	69%
8.	Total family income		
	<10,000	15	15%
	10,001-20,000	65	65%
	20,001-30,000	18	18%
	>30,000	02	02%

Table 1: Frequency and Percentage Distribution of Patient as per their Sociodemographic Variables N = 100.

Sr. No	Sample characteristics	Frequency (f)	Percentage (%)
1.	Cancer of which organ		
	Ca Breast	14	14%
	Ca Cervix	06	06%
	Ca Esophagus	09	09%
	Ca Lung	13	13%
	Others	58	58%

2.	Stage of cancer		
	Stage 0	11	11%
	Stage 1	26	26%
	Stage 2	22	22%
	Stage 3	29	29%
3.	Frequency of chemotherapy		
	Once a week	50	50%
	Twice a week	46	46%
4.	Time duration since chemotherapy started		
	<1 year	59	59%
	1-2 year	33	33%
	3-5 year	07	07%
	>5 year	01	01%
5.	Cycle of chemotherapy		
	C1	11	11%
	C2	31	31%
	C3	24	24%
	C4	09	09%
	C5	15	15%
	C6	02	02%
	C7	04	04%
	C8	03	03%
C9	01	01%	
6.	Had you taken any alternate therapy		
	No	73	73%
7.	Have you experienced any side effect		
	No	27	27%
	Yes	74	74%
8.	Relationship with caregiver		
	Spouse	68	68%
	Daughter	03	03%
	Son	02	02%
	Parents	17	17%
	Others	10	10%

Table 2: Frequency and Percentage Distribution of Patient as per their Clinical Profile N = 100.

	“Never” (0) f (%)	“Rarely” (1) f (%)	“Sometimes” (2) f (%)	“Quite Frequently” (3) f (%)	“Nearly Always” (4) f (%)
Do you feel.....					
That because of the time you spend with your relative that you don't have enough time for yourself?	40(40)	45(45)	15(15)	00	00
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	21(21)	45(45)	34(34)	00	00
Angry when you are around your relative?	100(100)	00	00	00	00
That your relative currently affects your relationship with family members or friends in a negative way?	98(98)	02(02%)	00	00	00
Strained when you are around your relative?	27(27)	59(59)	14(14)	00	00
That your health has suffered because of your involvement with your relative?	100(100)	00	00	00	00
That you don't have as much privacy as you would like because of your relative?	22(22)	70(70)	08(08)	00	00
That your social life has suffered because you are caring for your relative?	14(14)	34(34)	50(50)	02(02)	00
That you have lost control of your life since your relative's illness?	99(99)	00	01(01)	00	00
Uncertain about that what to do about your relative?	00	02(02)	08(08)	24(24)	66(66)
You should be doing more for your relative?	00	00	00	00	100(100)
You could do a better job in caring for your relative?	00	00	00	27(27)	73(73)
That your relative asks for more help than he/she needs?	87(87)	10(10)	02(02)	01(01)	00
Embarrassed over your relative's behaviour?	100(100)	00	00	00	00
Are you afraid what the future holds for your relative?	00	00	00	00	100(100)
Your relative is dependent upon you?	32(32)	37(37)	26(26)	05(05)	00
Uncomfortable about having friends over, because of your relative?	100(100)	00	00	00	00
That your relative thinks you are only expert to take care of his/her, he/she could depend on?	01(01)	03(03)	46(46)	42(42)	08(08)
That you don't have enough money to care for your relative, in addition to the rest of expenses?	65(65)	29(29)	01(01)	05(05)	00
That you will be unable to take care of your relative much longer?	04(04)	96(96)	00	00	00
Do you wish you could just leave the care of your relative to someone else?	100(100)	00	00	00	00
Overall, how burdened do you feel in caring for your relative?	100(100)	00	00	00	00

Table 3: Item Wise Frequency and Percentage Distribution of Perceived Burden Among Caregivers N = 100.

Sr.no.	Categories of Burden	Score	f (%)
1.	No burden	0-20	09 (09)
2.	Mild burden	21-40	91(91)
3.	Moderate burden	41-60	00(00)
4.	Severe burden	61-88	00(00)

Table 4: Frequency and Percentage Distribution of Perceived Burden Among Caregivers N = 100.

Sr. no.	Items	Very Strongly Disagree (1) f (%)	Strongly Disagree (2) f (%)	Mildly Disagree (3) f (%)	Neutral (4) f (%)	Mildly Agree (5) f (%)	Strongly Agree (6) f (%)	Very Strongly Agree (7) f (%)
1	There is a special person who is around when I am in need.	83(83)	03(03)	00	14(14)	00	00	00
2	There is a special person with whom I can share my joys and sorrows.	83(83)	03(03)	00	14(14)	00	00	00
3	My family really tries to help me.	00	00	00	01(01)	03(03)	37(37)	59(59)
4	I get the emotional help and support I need from my family.	00	00	00	01(01)	03(03)	37(37)	59(59)
5	I have a special person who is a real source of comfort to me.	83(83)	03(03)	00	14(14)	00	00	00
6	My friends really try to help me.	00	00	00	04(04)	15(15)	56(56)	25(25)
7	I can count on my friends when things go wrong.	00	00	00	04(04)	19(19)	55(55)	22(22)
8	I can talk about my problems with my family.	01(01)	00	00	01(01)	03(03)	35(35)	60(60)
9	I have friends with whom I can share my joys and sorrows.	00	00	00	04(04)	17(17)	53(53)	26(26)
10	There is a special person in my life who cares about my feelings.	83(83)	03(03)	00	14(14)	00	00	00

11	My family is willing to help me make decisions.	00	00	00	01(01)	03(03)	39(39)	57(57)
12	I can talk about my problems with my friends.	00	00	00	04(04)	14(14)	55(55)	27(27)

Table 5: Item Analysis of Perceived Social Support Among Caregivers N = 100.

Sr.no.	Categories of social support	Score	f (%)
1.	Low support	1-2.9	00(00)
2.	Moderate support	3-5	87(87)
3.	High support	5.1-7	13(13)

Table 6: Frequency and Percentage Distribution of Perceived Social Support Among Caregivers N = 100.

Perceived caregiver burden	Social Support			Calculated chi Square value	df	P value	Significant/Non-Significant
	Low support	Moderate support	High support				
No burden	-	03	06	25.185	1	.000	Significant
Mild burden	-	84	07				
Moderate burden	-	-	-				
Severe burden	-	-	-				

Table 7: Association Between the Perceived Burden and Perceived Social Support Among Caregivers N = 100.

relative to caregiver’s personal time, social roles, physical and emotional states, financial resources and formal care resources given the other roles they fulfil” [7]. Finding of the study concluded about the perceived caregiver burden that maximum of 91(91%) subjects had mild burden whereas 09(09%) subjects had no burden. Finding regarding perceived social support revealed that most of the subjects 87(87%) had moderate support whereas 13(13%) subjects had high support. The association between perceived burden and perceived social support among caregivers was found to be significant ($p < 0.05$). In a similar study conducted among family caregivers by S Likhmana, SK Bhasin, P Chhabra, *et al.* (2015). 113 (56.5%) caregivers reported no or minimal burden while 75(37.5%) caregivers reported mild to moderate burden. Using logistic regression marital status, education, and type of family of caregivers, occupation of cancer patients and type of treatment facility were found to be the predictors of burden on caregiver [8]. The study population consisted of 90(45%)

males and 110(55%) female caregivers aged 18-65 years. Hence these findings are similar. In the present study 53(53%) subjects were male whereas 47(47%) subjects were female. According to educational status, 33(33%) subjects were matric, as per marital status, 93(93%) subjects were married, as per residence, 61(61%) subjects from rural and 39(39%) subjects from urban, as per the occupation, 41(41%) subjects were self- employed, 63(63%) subjects from joint family, as per family income, 59(59%) subjects had Rs 10,001-20,000, as per the relation with patient, 68(68%) subjects were spouse, they were caring for their patient since last one year In another study conducted by (9) study on the burden among family caregivers of elderly cancer patients in the National Institute of Oncology in Moroccan population. The majority were females (59.3%), living in urban areas (66.7%). Offspring (sons or daughters) represented 56.7, 54% lived with their relatives in the same house. Most of the participants were married and had familial responsibilities. In relatives, anxiety was found in 79.3%, it was

related to fear of losing the patient in 57% and resulted in the use of anxiolytics among 10%. Guilt feeling towards patients regarding neglecting their early symptoms was reported in 38%. Depression and anxiety were more frequent among female relatives and among those of urban origin [9]. The similar descriptive cross-sectional study was conducted by (10) on Burden of Care as Perceived by Informal Caregivers of the Patients Receiving Chemotherapy (N = 200) Findings of the study identified the employment status ($P \leq 0.020$) and the religion of the informal caregivers ($P \leq 0.027$) as significant, demographic variables. The functional level of care receivers was also found to be significant ($P \leq 0.002$). The study also recognized four forms of burdens, with significant mean values, including financial (2.85), psychological (2.50), social (2.58), and physical (2.44). Most of the participants reported experiencing a moderate magnitude of burden, ranging from 40 - 60, on the scale of 0 -80 [10].

The findings of the present study revealed that 87(87%) caregivers had moderate support and 13(13%) caregivers had high support. The similar study was conducted by Maheshwari PS, Mahal RK (2015) that is an exploratory study on perceived social support and burden among family caregivers of cancer patients. They selected 225 family caregivers. The findings showed that the perceived social support has 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) [11].

The similar study was conducted by (12) on the predictive factors for perceived social support among cancer patients and caregivers' burden of their family caregivers in Turkish population. Perceived social support was lower in depressed patients ($p < .001$). Among patients only the depression was negatively correlated with PSS ($p < .001$, $r = -2.97$). presence of depression ($p < .001$, $r = -0.381$) was positively correlated and family caregiver role was negatively correlated ($p < .001$, $r = -0.208$) with caregiver burden. Presence of depression was the independent predictors for both, lower PSS for patients and higher burden for caregivers [12].

The present study findings shows that as per χ^2 test, association between perceived burden and perceived social support among caregivers found significant at level of $p < 0.05$. Hence there is

association between perceived burden and perceived social support among caregivers. The findings of the present study have been in consistent with various research studies conducted on similar topic and have been reported in literature. The study concluded that the care givers of the patients having cancer definitely experience burden of care however the caregivers were willing to look after their relative in need of hour in spite of experiencing various types of self problems.

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