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Relationship of Preparedness and Burden among Family Caregivers of Cancer Patients in India

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Abstract

Introduction: Caregiving is a demanding physical and emotional journey, but most family caregivers assume the role with limited caregiving skills and few resources that may lead to increased levels of stress and feelings of inadequacy causing caregiver to view their role as burdensome. In an effort to understand the negative consequences of caregiving, the present study is aimed at finding the relationship of preparedness for caregiving and burden among family caregivers of cancer patients. **Methods:** An exploratory, co-relational, cross sectional survey assessed 225 eligible family caregivers of cancer patients undergoing chemotherapy and radiation therapy in selected hospital of Punjab. Measures involved Socio demographic Data Sheet, Caregiver Reaction Assessment (CRA), and Preparedness for Caregiving Scale. Data were analyzed using descriptive statistics and Independent t-test, ANOVA and Pearson's correlation. **Results:** Preparedness for Caregiving had moderate negative correlation with burden at 0.01 level of significance (r= -0.531**). Female caregivers and those having sufficient unpaid help in caregiving responsibility had high level of perceived preparedness for caregiving. Burden was high in those caregivers who had no help in caregiving responsibility and belonged to other district (more distance from treatment center). **Conclusion:** Study concluded that low perceived Preparedness for Caregiving results in high burden. Oncology nurses should take the measures to increase the preparedness for caregiving among family caregiver of cancer patients. Study findings also warrant early assessments of caregiver preparedness so that supportive interventions may be targeted to the caregivers who are at risk of poor outcome.

Keywords: Preparedness for Caregiving, burden, family caregiver, cancer.

INTRODUCTION

There are advances in medicine to treat cancer, but the numbers of cancer patients increase every year. Nearly seven lakh Indians died of cancer, while over 10 lakh were newly diagnosed with cancer in India in 2012.[1] The food bowl (Punjab State) of the India, has become the hub of cancer with 91 per lakh people suffering from cancer.[2]

The diagnosis of cancer in a family member entails countless changes in the family structure. Moreover, there are the ongoing changes in the health care system resulting in a shift of cancer care from hospital to home settings (Girgis & Lambert, 2009).[3]This shift indicates increased involvement of family in caring for persons with cancer and increasing impact of cancer on family members (Given, Given & Kozachik, 2001).[4] Caregiving is a demanding physical and emotional journey. Caregivers provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding and results in the neglect of their own needs.[5]

Family caregivers provide care at home that requires high level of knowledge and skills (such as monitoring their family member's acute or chronic conditions, recognizing early signs of impending problems such as medication side effects, knowing how and when to respond, and procedures such as dressing changes), but most family caregivers assume the role without considering that they may lack the skills or resources to handle caregiving tasks. Too often, caregivers are expected to perform these complex tasks alone, without any formal assessment of their level of efficacy related to caregiving or formal support (B. Ferrell & Mazanec, 2009)[6]. Limited caregiving skills and few resources may lead to increased levels of stress and feelings of inadequacy for the caregiver which may cause the caregiver to view his or her role in a negative manner unless some form of intervention is offered to ease the stress or burden.

Family caregiver spends far more time with the care recipient than the formal caregivers and is the least equipped to do so. Unlike healthcare professionals, informal cancer caregivers are not routinely given any formal training to become a caregiver. Preparedness refers to how ready family caregivers perceive they are for the tasks and demands in the caregiving role, such as providing physical care, providing emotional support and dealing with the stress of caregiving.[7]Inadequate preparation for the cancer caregiving role often leads to a heightened stress level for the caregiver.[8] However, cancer caregivers who report a high level of preparedness for caregiving, have been found to experience lower levels of caregiver strain.[7,9,10] If caregivers can understand the value of the care they provide, this can also reduce the burden of caregiving. Finally, preparedness has been shown to predict caregiving rewards and better mental health.[11]

Though preparedness has been confirmed to improve caregiver well-being [7,9] and it can be influenced by interventions within a reasonably short time frame,[12,13] it has not received much attention in research among family caregivers of cancer patients in India. So considering the complexity and importance of caregiving role, present study is undertaken to explore the relationship of preparedness for caregiving and burden among family caregivers of cancer patients.

Current literature supports the significant burden of caregiving and need to develop supportive care interventions for family caregivers of cancer patients. Thus current study, by understanding the relationship of caregiver burden and preparedness, is a first step in designing scientifically-sound, evidence-based nursing interventions to support the family caregivers of cancer patients. Study will also measure the association of preparedness and burden with selected socio-demographic variables of family caregivers and recommendations for further research in field of caregiving will be drawn from the results of this study.

MATERIAL AND METHODS

A descriptive cross sectional survey was done to assess the relationship of preparedness for caregiving and burden with each other and with other socio- demographic 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 is family 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 (Pb.), 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 used to recruit 225 family caregivers of cancer patients for study. The tools used for the study were Socio demographic Data Sheet, Preparedness for Caregiving Scale and Caregiver Reaction Assessment (CRA).

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, marital status, religion, education, occupation, income, type of family and residence. **Section B:** It has total fourteen items related to caregiving characteristics 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 to support caregiving role, patient's 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: The Preparedness for Caregiving Scale (Archbold et al 1990)[7]

Preparedness for caregiving was assessed using Archbold and colleague's Preparedness for Caregiving Scale. The measure is a standardized, short, structured, self administered 8 items rating scale. (Archbold, Stewart, Greenlick, & Harvath,1990). In addition to the eight-item responses, caregivers can specify in writing areas in which they feel unprepared to provide care. Administration time is approximately 3-5 minutes. Items address caregiver's comfort with various physical and emotional patient needs and are scored from 0 (not at all prepared) to 4 (very well prepared). A total score ranging from 0 to 32 is calculated by summing the responses for all items, with higher the score the more prepared the caregiver feels for caregiving. Internal consistency has been reported as moderate to high (Cronbach's alpha 0.88 to 0.93, Carter et al., 1998; Hudson & Hayman-White, 2006) in caregivers of patients in palliative care. Construct and content validity have been demonstrated between caregiver worry and lack of resources (Archbold et al., 1990)[7]. The reliability was established for the present study through test retest method (r =0.90)

Tool no. 3- Caregiver Reaction Assessment Instrument (Given 1992)[14]

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) [15] in samples of caregivers of cancer patients. The reliability was established for the present study through test retest method (r =0.81)

All 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 perceived social support of family caregivers was calculated. Correlation between preparedness for caregiving and burden was determined by Carl Pearson's method. ANOVA or t-test was used to determine the relationship of selected socio-demographic characteristics with preparedness for caregiving and burden.

RESULTS

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 were predominantly 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%).

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

Socio-demographic characteristics of caregivers		***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 5th	27 (12)
	Upto 10th	105 (46.7)
	Upto 12th	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)

Caregiving 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 usually, due to their caregiving 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.

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

Care giving related characteristics of caregivers		***f* (%)**
Relationship with patient	Child	75 (33.3)
	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)

Table 3: Mean (SD) score of preparedness and burden and their correlation (N=225)

Variable	**Range**	**Mean (SD)**	**df**	**r**	**p value**
Preparedness for care giving	9-22	13.56 (2.8)	224	-0.531^{**}	0.01
Burden	39-92	66.48 (13.3)			

** Correlation is significant at the 0.01 level (2 tailed), 0.3-0.5 indicates moderate correlation.

Table 3 states that the mean (SD) of preparedness for caregiving was 13.56 (2.8) and it range from 9 to 22. Similarly, mean (SD) of burden was 66.48 (13.3) and it range from 39 to 92. The correlation between preparedness for caregiving and burden was calculated with Pearson's product moment correlation and it was found that burden had large negative correlation with preparedness at 0.01 level of significance (r= -0.531**), indicating that as the preparedness increased, burden level go down.

Table 4: Association of selected socio-demographic characteristics of caregiver with baseline preparedness score (N=225)

Socio-demographic characteristics of caregivers		***f* (%)**	Mean (SD)	**t/F**	**df**	**p value**
Gender	Male	139	13.94 (2.8)	2.606	223	0.010*
	Female	86	12.93 (2.7)			
Marital status	Married	182	13.58 (2.9)	0.124	2	0.884
	Unmarried	37	13.51 (2.5)			
	Widow/widower	6	13.00 (3.2)			
Religion	Sikh	170	13.51 (2.8)	0.774	2	0.463
	Hindu	54	13.65 (3.0)			
	Christian	1	17.00 (-)			
Education	Upto 5th	27	12.85 (3.1)	1.682	3	0.172
	Upto 10th	105	13.35 (2.7)			
	Upto 12th	69	13.84 (2.8)			
	Graduation and above	24	14.42 (2.9)			
Occupation	Unemployed	7	14.43 (3.4)	1.136	6	0.343
	Govt service/ Retired	18	14.56 (3.1)			
	Labor	7	12.71 (1.8)			
	Self employed	73	13.64 (3.0)			
	Homemaker	43	12.79 (2.9)			
	Student	24	13.50 (2.5)			
	Agriculture	53	13.74 (2.6)			
Family Income/ year	<1 Lakh	56	13.25 (2.7)	1.094	3	0.353
	1-3 Lakh	96	13.46 (2.8)			
	> 3-5 Lakh	54	13.69 (3.1)			
	>5 Lakh	19	14.58 (2.8)			
Type of family	Nuclear	71	13.15 (2.6)	1.034	2	0.357
	Joint	119	13.71 (3.0)			
	Extended	35	13.83 (2.6)			
Residence	Rural	155	13.46 (2.8)	-0.758	223	0.449
	Urban	70	13.77 (2.9)			

As shown in table 4, gender was significantly (p=0.010*) associated with preparedness for caregiving and there was no significant association of marital status, religion, education, occupation, family income, type of family and residence with preparedness for caregiving. Hence, it can be concluded that preparedness for caregiving was significantly associated with gender of caregiver.

Table 5: Association of selected care giving related characteristics of caregiver with baseline preparedness score (N=225)

Care giving related characteristics of caregivers		*f* (%)	Mean (SD)	t/F	df	p value
Relationship with patient	Child	75	13.57 (2.5)	0.695	5	0.628
	Daughter in law	26	12.88 (2.5)			
	Others	8	13.75 (1.8)			
	Parents	6	14.17 (4.0)			
	Siblings	15	14.53 (3.2)			
	Spouse	95	13.52 (3.1)			
Unpaid help	No	11	13.36 (3.8)	4.335	2	0.014*
	Minimum help	119	13.06 (2.5)			
	Sufficient help	95	14.20 (3.0)			
Paid help	No	122	13.64 (3.1)	0.476	223	0.634
	Yes	103	13.46 (2.5)			
Distance from hospital	Local	44	14.41 (3.4)	1.910	56.340	0.061
	Other district	181	13.35 (2.6)			
Health professional in family	No	180	13.66 (2.9)	1.047	223	0.296
	Yes	45	13.16 (2.3)			
Chronic disease	No	207	13.53 (2.9)	-0.428	223	0.669
	Yes	18	13.83 (2.1)			
Health problems of caregiver	No	108	13.69 (2.8)	0.651	223	0.516
	Yes	117	13.44 (2.9)			
Diagnosis of patient	Breast	57	13.40 (2.5)	1.283	5	0.272
	Cervix	39	14.10 (2.8)			
	GI tract	25	14.16 (3.4)			
	H & N	60	12.90 (2.7)			
	Others	22	14.00 (3.0)			
	Reproductive	22	13.64 (3.2)			
Stage of patient	Progressive stage	56	13.36 (2.6)	-0.597	223	0.551
	Advance stage	169	13.62 (2.9)			
Treatment of patient	Chemotherapy	66	13.94 (3.0)	1.783	2	0.171
	Radiation therapy	54	12.96 (2.4)			
	Concurrent chemotherapy	105	13.62 (2.9)			

As shown in table 5, there was significant (p=0.014*) association of preparedness for caregiving with unpaid help. Whereas relationship of caregiver and patient, 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.

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

Socio-demographic characteristics 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 5th	27	63.56 (12.5)	0.872	3	0.457
	Upto 10th	105	66.33 (12.9)			
	Upto 12th	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)			

** significant at the 0.01 level

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

Care giving related characteristics 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 chemotherapy	105	65.10 (13.3)			

** significant at the 0.01 level

Table 5 shows that there was significant association of burden with unpaid help (p= <0.001) 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.

Relationship of age, duration of caregiving and amount of caregiving with preparedness for caregiving and burden

As table 8 shows, duration of caregiving had a significant large positive correlation with preparedness for caregiving (r= 0.567**, p=0.01) and a significant moderate negative correlation with burden (r=-0.358**, p=0.01) whereas amount of caregiving had significant, week positive correlation with burden (r= 0.182**, p=0.01).

Hence, it can be concluded that as the duration of caregiving increased, preparedness for caregiving increased whereas burden among caregivers decreased and as the amount of caregiving increased burden also increased.

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**
Preparedness	0.064	0.567**	-0.090
Burden	-0.128	-0.358**	0.182**

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

DISCUSSION

The present study is an attempt to understanding the relationship of preparedness for caregiving and burden among family caregivers of cancer patients. Results revealed that family caregivers of cancer patients had low level of preparedness and there is a significant moderate negative correlation of preparedness for caregiving and burden. Family caregivers with high perceived preparedness for caregiving have low burden. Finding of low perceived preparedness in current study are consistent with a previous research in which 81% caregivers felt inadequately trained for the skills that they perform, and having never received any formal education in caregiving[16] In another study, more than 50 percent of caregivers of persons with cancer provided care for patients with metastatic disease or severe comorbidities who were undergoing treatment, yet these caregivers received little formal training, information, or support[17] and 77 percent of caregivers reported needing more information about support services.[18]

Findings of current study regarding correlation of preparedness for caregiving and burden are consistent with the studies of **Scherbring and colleagues** reporting that higher caregiver burden and lower caregiver QOL was associated with perceived preparedness for the caregiving role.[9,19] **Schumaker and colleagues**[9] also found consistent results that negative reactions to the family caregiver experience can be buffered when caregivers are better prepared for their role. **Archbold et al.** reported that caregivers who feel unprepared for the caregiving role are at greater risk of caregiving burden, whereas caregivers who feel well prepared in terms of support, skills and knowledge have been found to have decreased levels of depression.[7]

In this study preparedness for caregiving was significantly associated with caregiver's gender and unpaid help whereas other socio-demographic and caregiving characteristics of family caregivers had no relationship with preparedness for caregiving**.** In current study female gender was associated with low level of preparedness compared to male caregivers whereas in the study by Henriksson A.[20] women felt more prepared than men. Results of current study showed that family caregivers who perceived to get sufficient unpaid help also perceived higher preparedness for caregiving. It may explained as in Indian culture, in most of cases person gets the unpaid help from the resources perceived as support system in social network. So this association of preparedness with unpaid help may be a reflection of relationship between preparedness and social support, since both social support and preparedness are known to be important protectors against the harmful effects of caregiving.[21-23]

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.[6,24-26]

In this study, family caregivers reporting higher burden also reported to have no unpaid help for caregiving. This may also be understand in same context as the person not getting unpaid help may lack social support and in literature low perceived social support is reported to have relationship with increased burden.

In current study preparedness for caregiving is found to increase with increased duration of caregiving. It reflects that caregivers learn the skills to manage the care by exposure and adapt to the routines care by the time. It may also be due their routine visit to the hospital and thus having opportunity to ask question and get the information from health professionals as family caregivers who were accompanying patient during most of therapy visits were included in the study. **Henriksson A.**[20] reported inconsistent finding in his study that time since diagnosis was also not associated with preparedness. It may be due to that family caregivers in that study were providing end of life care that may require continuous preparation to meet new challenges of caregiving to the palliative care patients.

Current study has reported that as the duration of caregiving increased, burden among caregivers decreased. It may be explained by stress and adaptation theory. Family caregivers might have adapted with time to the stress imposed upon them by caregiving responsibilities in present study. These finding are consistent with **Ferrell** et al suggesting that caregiver reactions do not increase with time[27] whereas **Milbury et al.** inconsistently reported that level of burden increased significantly (P=< 0.001) with the duration of care.[28]

IMPLICATIONS AND RECOMMENDATIONS

Supportive care intervention could be designed aiming to increase family caregiver's preparedness to care such as practical care, communication and emotional support. An assessment of preparedness could help to identify those at higher risk of negative caregiving outcomes, and specific attention and support for caregivers with low preparedness should be emphasised. Short validated scales needs to be developed and used to facilitate efficient assessment. Caregiver responses may be used to guide tailored interventions, to enhance preparedness of the family caregivers' thus decreasing burden among caregivers. Most importantly, healthcare professionals, including oncology nurses, need to ensure that caregivers receive the appropriate resources, support and are well prepared to care for their loved ones. Expanding the understanding about impact of caregiving and related factors enable nurses to develop innovative interventions to decrease negative outcomes and improve positive outcomes of caregiving for cancer patients. There is need for research to fully elucidate the cancer caregiver's experience throughout the illness and treatment trajectory, and identify the means to effecting positive outcomes for the person with cancer, their family caregiver, and the health care system. The ability of the family caregiver to provide quality care is a vital health care resource. Family members are partners in care and have much to contribute to the care for the individual with cancer. Health care providers must be supportive of family caregivers if they are to maximize patient care.

CONCLUSION

In conclusion, the results from this study have revealed that preparedness for caregiving is associated with caregiver burden. These findings suggest that improving the self- confidence of family caregivers by increasing preparedness for caregiving is vital to reduce the burden, so measures should be taken to increase the preparedness for caregiving among family caregiver of cancer patients. Study findings also warrant early assessments of caregiver preparedness so that supportive interventions may be targeted to the caregivers who are at risk of poor outcome.

LIMITATIONS

The study is limited to single setting and to the experiences of family caregivers during treatment trajectory only (when cancer patients were undergoing chemotherapy and radiation therapy). These family caregivers 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 the study. Finally, researcher acknowledges the limitation of cross sectional design with respect to temporal relationship and imputation of causality of study findings.

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