



Research Article

COPING IN FAMILY CAREGIVERS OF ONCOLOGY INPATIENTS IN A TERTIARY CARE HOPITAL AT SOUTH INDIA

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ABSTRACT

Background: Coping in family caregivers of cancer patients is relatively less studied AIMS; This cross sectional observational study was doneto understand the coping strategies used by family caregivers of cancer patients

Materials and Method: 50 informal caregivers of various types of cancer inpatients of a medical oncology ward at a south Indian tertiary care hospital were selected by random sampling. Assesment was done using ways of coping (revised) [Folk man and lazarus, 1985], ECOG (eastern cooperative oncology group) performance status.

Results: Both positive (58%) and negative global ways of coping were used. Commonly used strategies weresocial support seeking(commonest positive coping strategy),followed byself controlled (common negative coping strategy),planful problem solving and positive reappraisal .

Conclusion: Family cancer caregivers had unique coping strategies which was associated to the disease status.

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INTRODUCTION

Cancer has become one of the ten leading causes of death in India. It is estimated that there are nearly 2 - 2.5 million cancer cases at any given point of time. Over 7 lakh new cases and 3 lakh deaths occur annually due to cancer.¹Cancer is a chronic disease with uncertainty in course and prognosis, eventually requiring support or care from an informal caregiver, during any phase of cancer trajectory. In Indian scenario, an informal caregiver is mostly a family member .For some, caregiving can extend for several years with significant consequences and burdens.²Their role however often being an overwhelming, demanding and an emotionally draining experience, they use certain coping strategies, that may be unique for their situation. Coping refers to the thoughts and actions we use to deal with stress. A study of caregiver burden within different caregiving populations like Alzheimer’s disease, Amyotrophic Lateral Sclerosis or Cancer reported that burden was a factor of different aspects of the caregiver including coping rather than the disease characteristics and progression.³ A research on family caregivers of terminal cancer patients has showed that keeping busy, thinking positively, and learning more about the problem, and talking the problem over with family and friends were effective coping strategies.⁴ Caregivers who are more optimistic, those who use problem-solving coping strategies or who seek social support are less distressed than those that use avoidant or impulsive strategies.

Negative expectation in coping strategies and cancer caregivers' perceptions of not coping well were most significantly associated with emotional distress and negative psychological outcomes.⁵According to a report given by Stajduhar *et al* in 2008, the three most prominent ways of coping reported by family caregivers in their study were:Planful problem solving , Seeking social support and Self-controlling.⁶In their literature review, Northfield S *et al* (2010) reported that there is an abundance of research on the numerous challenges encountered by families living with cancer, with only little research on the coping strategies used by family caregivers at specific stages along the illness trajectory.⁷Family caregivers have received very little attention in published literature from India .A review of psycho-oncology research literature from India by Seema Malhotra (2008) indicates that most of the studies focused on cancer patients or survivors .Most psycho-oncology studies on cancer caregivers have focused more on caregiver burden in palliative and Hospice care of terminally ill cancer patients.⁸The purpose of our study was to obtain preliminary findings regardingcoping among such family caregivers of cancer patients to understand the gravity of the situation in Indian scenario better.

Aims and Objectives

1. To know the type of coping strategies used by family caregivers of cancer patints.
2. To study the association of their coping strategies with the variables related to caregiver & cancer patient.

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MATERIALS AND METHODS

We did this Cross sectional, observational, Descriptive, Correlational study with family caregivers of cancer patients in the Inpatient wards of the Department of Medical Oncology, Government Rajaji Hospital, Madurai. The study was conducted between September 2018 to December 2018. Caregivers identified as family caregivers of cancer patients, related to the patient by marriage / blood, those of age 18 & above attending to the day to day care of the cancer inpatient were alone included in the study after obtaining an informal consent in their native language explaining about the study. Caregivers of cancer patients with previous H/O significant mental illness & neuropsychiatric problems, Those with history suggestive of a cognitive insufficiency an those caring to terminally ill cancer patients were excluded. A semi structured proforma was used to collect data regarding cancer patients' relevant sociodemographic details, their disease and functional status, their ongoing cancer treatment details, the family caregivers' sociodemographic profile, details regarding their health status, family history of mental illness, time allotted in caregiving, and availability of help and support in caregiving. The functional status of cancer patients was studied using ECOG (Eastern Cooperative Oncology Group) Performance Status (Oken M.M., *et al*, 1982). These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. Grading is from 0 to 5, with 0 meaning the patient is fully active, and higher grades meaning worsening disability, and 5 meaning death.

To study the coping strategies WAYS OF COPING (REVISED) [Folkman and Lazarus, 1985] was used. In the revised Ways of Coping (Folkman & Lazarus, 1985), the subject responds on a 4 point Likert scale (0 = does not apply and/or not used; 3 = used a great deal). We had used the 50 item questionnaire developed by Folkman *et al* in 1986, who used it in a community sample leading to a construct of 8 scales namely confrontation, distancing, self controlling, and escape-avoidance classified under Negative ways of coping and seeking social support, accepting responsibility, planful problem solving and positive reappraisal, classified under Positive ways of coping.

Statistical analysis was done using descriptive statistical methods, parametric and non parametric tests, test for significance, Pearson's correlation coefficient testing. Statistical procedures were performed by the statistical package IBM SPSS statistics 20. The P values less than 0.05 (P<0.05) were treated as significant, and P<0.01 as strongly significant.

RESULTS

In our study the Mean age & Standard deviation of the cancer patients was 55.6±8.8 years. The commonest type of cancer in them was breast (48%), followed by head and neck, genitourinary, occult and GIT. The Mean duration of diagnosis of cancer & S.D was 10.04±11.2 months. Almost 68% of them were in the late stages of cancer, 64% undergoing curative and 36% undergoing palliative treatment. 68% of them were with poor functional status with an ECOG (Eastern Cooperative Oncology Group Performance Status) score of 2 & above, with loss of organ function in almost 72% of the total patients

in sample. The Mean age and S.D of caregivers studied was 45.4±12.54 years. They were predominantly female caregivers (70%), from lower socioeconomic status (68%), and married (92%). 52% of them were unemployed, 88% of them coming from rural areas, with most of them living in a nuclear family type (72%). With regard to their relationship to the patient spouses were the most common, contributing to 46% of study population, children -32 %, and others (parents, siblings, cousins) contributing 22 %. 58% of sample population of caregivers had more positive global type of coping with a mean & S.D of 28.12±12.75 and 42% had more negative global type of coping with a mean & S.D of 24.55± 9.26. There was no significant association between caregiver global way of coping & caregiver's age or duration of diagnosis. There was statistically significant relationship evident between caregiver's global type of coping and patient's performance status only (Table 1). There were statistically significant association between caregiver's global WOC and both positive (Mean-28.12, SD-12.75) and negative (Mean-24.55, SD-9.26) ways. Their global ways of coping showed statistically significant relationship with their individual coping strategies namely self controlled (t=-5.593), social support seeking (t=5.637), planful problem solving (t=2.563), positive reappraisal (t=2.1334). The highest mean value for more positive coping ways was seen for social support seeking (79.88). The highest mean value for more negative coping ways was seen for self controlled coping (63.49). (Table 2)

Correlation between caregivers variables and their ways of coping (Table 3) showed the following:

Statistically significant (p<0.05) positive correlations were seen between Caregiver's age, negative ways of coping, self controlled and accepting responsibility strategy, between Caregivers' positive reappraisal and confrontation, accepting responsibility, planful problem solving strategies, between Caregivers' distancing and escape avoidance strategies*. Strongly significant (p<0.01) positive correlations were seen between Caregivers' confrontation coping and negative ways of coping, between positive global coping along with other positive strategies and social support seeking, between negative global coping and self controlled coping strategy.

Statistically significant negative correlations were seen between Caregivers' positive ways of coping especially social support seeking and negative ways of coping especially self controlled coping, between planful problem solving and distancing.

Table 1 showing relationship between caregiver's global type of coping and patient related variables

Variable	Positive Woc	Negative Woc	Statistics (* p<0.05)	
Age in yrs	<55	16	8	1.423
	>55	13	13	
Sex	M	15	10	0.082
	F	14	11	
Type of Cancer	Ca head & neck	14	10	7.683
	Ca breast	7	1	
	Ca genitourinary	6	9	
	Ca git	0	1	
	Ca cups	2	0	
Durn of diagnosis	< 6 months	16	12	0.446
	7 - 12 months	9	5	
	Above 13 months	4	4	

Disease severity	Early	9	7	0.030
	Late	20	14	
Loof	Yes	21	15	0.006
	No	8	6	
Ecog status	≤ 1	13	3	5.221*
	2 & above	16	18	
Type of rx	Curative	19	13	0.069
	Palliative	10	8	

Table 2 showing relationship between caregiver Global WOC & various coping strategies

Variable	Global woc	Mean	S.d	T value
Confrontation	1 -more +ve	32.56	25.918	1.195
	2 -more -ve	23.28	28.739	
Distancing	1	12.45	14.89	-1.416
	2	19.31	19.37	
Self controlled	1	33.49	18.46	-5.593*
	2	63.49	19.06	
Escape-avoidance	1	5.93	8.90	-1.946
	2	11.11	9.78	
Social support seeking	1	79.88	39.24	5.637*
	2	29.36	13.84	
Accepting responsibility	1	11.49	10.54	1.899
	2	6.54	6.53	
Planfull problem solving	1	49.42	30.44	2.563*
	2	29.89	19.99	
Positive repraissal	1	19.04	18.35	2.134*
	2	9.97	7.51	
Positive ways coping	1	36.20	9.10	7.895*
	2	16.97	7.56	
Negative ways coping	1	21.11	9.46	-3.401*
	2	29.29	6.62	

Table 3 showing correlation between caregiver variables & their coping strategies

r = Pearson's correlation coefficient. *p<0.05, ** p<0.01

Code	Variable	Code	Variable
V1	Age of patient	Ra27	Escape-avoidance
V4	Duration of diagnosis	Ra28	Social support seeking
A1	Age of cg	Ra29	Accepting responsibility
Ra24	Confrontation	Ra30	Planfull problem solving
Ra25	Distancing	Ra31	Positive repraissal
Ra26	Self controlled	X1	Positive ways coping
		X2	Negative ways coping

Variable	R	V1	V4	A1	RA24	RA25	RA26	RA27	RA28	RA29	RA30	RA31	X1	X2
V1	R	1												
V4	R	-0.210	1											
A1	R	-0.053	0.233	1										
RA24	R	-0.142	0.014	-0.117	1									
RA25	R	0.209	-0.021	0.108	-0.203	1								
RA26	R	-0.181	-0.141	0.162	-0.060	-0.247	1							
RA27	R	0.125	0.109	0.062	0.013	0.335*	0.072	1						
RA28	R	-0.022	0.059	-0.194	0.042	-0.080	-0.553**	-0.027	1					
RA29	R	-0.178	0.095	-0.039	0.346*	-0.103	0.095	0.228	0.159	1				
RA30	R	-0.251	-0.118	-0.135	0.608**	-0.296*	-0.005	-0.206	-0.087	0.257	1			
RA31	R	-0.054	0.058	-0.079	0.295*	-0.153	-0.066	-0.146	-0.043	0.346*	0.309*	1		
X1	R	-0.192	0.003	-0.239	0.049	-0.254	-0.423*	-0.102	0.761**	0.471*	0.549*	0.263	1	
X2	R	-0.093	-0.062	0.084	0.606**	0.239	0.503**	0.468*	-0.368*	0.326*	0.254	0.066	-0.084	1

DISCUSSION

As they were caregivers, not patients in agony, their cooperative level was not a hindrance in study. The caregivers were assessed at appropriate time of the day, which was comfortable for the both caregivers and the treating team, without disturbing their routine. More than 50% of the caregivers were under the age of 45 years and were predominantly women(70%) which is similar to findings from both western world, and traditional countires.^{9,10,11}Spouses contributes to a majority of 46%, followed by children (daughters constituting majority). Most of the caregivers were from lower SES, unemployed, with almost 80% of those who

were unemployed reported having quit or unable to go to work u to caregiving. This was a grossly different scenario compared to western literature.¹²(reporting job quitting prevalence of 20-30%),which could be explained by factors such as our study sample population being predominantly daily wage labourers who belonged to both genders.58% of them had more positive global type of coping and 42% had more negative global type of coping. Among the various coping strategies our Caregivers had employed, both positive (seeking social support, accepting responsibility, planful problem solving and positive reappraisal) and negative (confrontation, distancing, self controlling and escape-avoidance), with a majority using social support seeking followed by self –controlled coping strategy. Our study results were almost similar to Stajduhar *et al* (2008) study on most prominent ways of coping in family caregivers. Lack of statistically significant association between caregiver related demographic variables and their Global type of coping strategy was in contrast to study by Gage –Bouchard *et al* (2003) have reported an association between that SES of caregivers and coping. Caregiver's global type of coping differed significantly with respect to patient's performance status which may be due to the associated burden. There were significant association between caregiver's global WOC and both positive and negative ways of coping. More positive WOC was in the form of social support seeking in our study establishing the need for more support groups available for the caregivers. More negative way of coping was predominantly in the form of self control which may have to be discouraged by offering support so that it may not lead to caregiver stress. An interesting finding in our study was Caregivers' confrontation coping showing positive correlations with strategies like namely accepting responsibility, positive reappraisal, planful problem solving strategies.

Limitations of our study were that results cannot be generalized for all other types of informal cancer care across the cancer trajectory, with varying disease severity and treatment phase owing to the small (N).

Also our finding of Social support seeking being the most common positive coping strategy cannot be generalised, as our sample population was amidst a non stigmatizing environment. Caregiver factors like education status, duration of care, availability of support were not focused in our study.

CONCLUSION

Our study was a preliminary attempt in exploring the coping methods in cancer caregivers in the background of dearth of psycho oncological research in Indian literature, not to mention a country where families are considered the backbone of society. Our findings revealed family caregivers using individual coping strategies that are unique for this

situation and patients' disease and functional status having significant association with family caregivers' coping strategies. These findings have some urgency, given that most families experience cancer at some time and that it will probably be a drawn-out, chronic ordeal. Considering these results as a reflection of Indian scenario, raises significant concern regarding the necessity to do further large scale psycho oncology research, focusing on reasons for such negative coping strategies, and other factors that can be associated with caregiver distress. The results of such studies can aid in planning of interventions for such caregivers suitable to our society and culture. Attending to caregivers' mental health issues will have a sure positive impact in the psycho-oncologist's satisfaction in his wholistic care to his patient.

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