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Assessment of Physical, Emotional and Life Style Burden among Caregiver of Cardiac Patients at Tertiary Care Hospital, Ranchi, India: A Cross Sectional Study

Cardiology

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ABSTRACT

Background:
This manuscript highlights the physical, emotional social and life style burdens among caregivers of cardiac patients.

Methods:
A cross-sectional, descriptive and hospital based study was carried out. A total of 36 caregivers of cardiac patients were recruited during the period of November 2015 to January 2016 from cardiology department, Rajendra Institute Medical Sciences, Ranchi, India. They were interviewed by Burden Questionnaire for heart failure to assess the burden of caregivers during care giving of the cardiac patients.

Results:
Majority of caregivers are female (69.40%) and most of them are of productive age (25-49 years) group and most of them are married. 41.7% caregivers reported physical tiredness and 27.8 % had found the deterioration of their health during the act of care giving. Moreover, at the same time 38.9% of caregivers reported care giving being physically hard work and 36.1% had lack of sleep and 36.7% reported body ache during the act of care giving. It was also observed that about 50 % of caregivers felt frustrated, whereas average people were stressed, sad, and had inability to concentrate and focus during their act of care giving. Most importantly, 38.9% of caregivers were worried during care giving and 33.3% were mentally tired and also 44.4 % were emotionally drained. Average caregivers (33.3 %) were overwhelmed during care giving and 33.3% had feeling of loneliness while several people (44.4%) were also found who liked their care giving. It was also noted that 50% had good support from others while, rest lacked that support during care giving. About 44 % Caregivers responded for average impact on relationship with patient and 33.30% had moderate Impact on their relationship with partner, family or friends. We also enquired about their lifestyle and found that about 33.3% felt that they had no time for themselves and even 38.9% of caregivers had avoided making plans. 44.4% of caregivers were unable to go on to vacations during care giving.

Conclusion:
Care giving has both positive and negative effects on family caregivers of Cardiac patients.

KEYWORDS

Physical, Emotional and life style, Caregiver, Cardiac patients

INTRODUCTION:

With its increasing prevalence, Cardiac diseases affect more than 50 million patients in the India and are the cause of 31% of all deaths worldwide. Consequently, the number of patients' family members who provide care at home to these patients is increasing. Moreover, greater emphasis on self-management for patients with Cardiac disease requires more time and energy from the patients' family caregivers to ensure adherence to complex therapeutic regimens. The Quality of life in cardiac patients is significantly impaired, predominantly as a result of the physical limitations imposed by the disease which can also lead to social limitations and emotional problems. In adjusting to the impact of the symptoms associated with the disease, cardiac patients can become increasingly dependent on caregivers. Although, family caregivers are pivotal in the care of any patient with heart failure, Care giving; unfortunately, can have adverse effects, including physical, emotional, social, and financial problems that often result in stress, health problems, and depression.

Caregiver assessment refers to a systematic process of gathering information about a care giving situation to identify needs, strengths, and resources for the family caregiver. It can be performed by the caregiver's physician, if time permits, or by other health care team members, including a social worker or case manager.7 In 2005, the National Consensus Development Conference for Caregiver Assessment developed a set of guiding principles and practice guidelines, which have been promoted by numerous national organizations and incorporated into the Guided Care model as key components for chronic care delivery.1, 5, 7, 13

According to these guidelines, caregiver assessment is a multidimensional process that should embrace a family-cantered perspective and focus on ways to keep the caregiver on the job while promoting health and safety.5 It includes understanding the context in which the caregiver provides care and exploring the caregiver's perception of the care recipient's functional status, as well as the caregiver's values and preferences. Evaluation of caregivers should also include perception of their own well-being, perceived challenges and benefits of care giving, confidence in their abilities, and the need for additional support systems. The findings from these assessments are used to develop a care plan and to identify appropriate support services.1

A complete assessment can be offered to any person who self-identifies as a caregiver. Because many do not self-identify, it may help to identify assessment candidates by describing caregivers as the care recipient's friends and family who provide assistance.13 Initial assessment may be performed as soon as a caregiver is identified, whereas repeat assessments can be offered as the care recipient's or caregiver's condition changes.1

Physicians may only have time to identify caregivers during an office visit and may refer these persons for full assessments. Referrals for assessment may be triggered by a diagnosis of a medical condition associated with high burden for care giving (e.g., dementia, heart failure, stroke, and cancer), change in functional status of a caregiver or care recipient, or care transitions.

A Caregiver has been defined as an adult, other than the person's general fractioned, specialist physician or other health care professional, who has significant responsibility for managing the wellbeing of a person diagnosed with chronic or debilitating medical condition[1].Caregivers include – “unpaid person” specifically family members – mother, father, wife, brother, sisters or friends, etc. In simple words, Caregiver's Burden is the resistance to providing care caused by addition or expansion of care-activities.

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Eighty percent of adults requiring long-term care currently live at home or in the community, and unpaid family caregivers provide 90 % of their care[1,2]. These caregivers fill an important role for their families and provide an estimated $375 billion in cost savings nationwide[3]. In addition to the growing demand for caregivers, family care giving has been affected in several important ways over the past five years: caregivers and care recipients are older and have higher levels of disability than in years past; the duration, intensity, and burden of care has increased; the financial cost associated with informal care giving has risen; and the use of paid formal care has declined significantly.

Family caregivers serve as a critical extension of the formal Health Care system and supporting family caregivers has recently emerged as a National Public Health priority[2,4].

AIMS AND OBJECTIVES:

Taking care of a loved one can be demanding, but it can also provide rewards and satisfaction. Although many caregivers have described the positive effects on their lives of providing care to patients, the negative aspects, often referred to as caregiver stress or burden, have been a focus of most previous studies. The purpose of our study was to identify factors associated with the impact of care giving—both positive and negative— among family caregivers of patients with heart failure.

The Specific objectives are:

1. To describe the levels of perceived physical and mental health status during the care giving of the cardiac patients.
2. To Identify factors associated with the impact of care giving of the cardiac patients.
3. To determine moderating effects of social support on the impact of care giving of cardiac patients.

METHODOLOGY:

Study design

This study was cross-sectional, descriptive in nature. A total 40 identified primary caregivers of admitted cardiac patients were recruited during data collection period of November 2015 to January 2016 from Cardiology department, Rajendra Institute of Medical Sciences(RIMS), Ranchi, India. Four caregivers were denied to participate in this study. Therefore 36 primary caregivers were willing and available to participate in this study.

Method of data collection:

Informed consent was taken from 36 primary caregivers who were willing to participate. To identify a primary caregiver, patients were asked to name the person who helped them most at the home.

The Caregiver Burden Questionnaire for heart failure:

It is used in this study to assess the impact of care giving of cardiac patients. The CBQ-HF, designed as a paper and pen questionnaire, initially contained 41 items each beginning with a common stem ('how much has care giving…') Items were rated on a 5-point Likert scale anchored at 'not at all' and 'a lot'.

LIKERT SCALE:

- LS 1 = VERY MUCH
- LS 2 = MODERATE
- LS 3 = AVERAGE
- LS 4 = MILD
- LS 5 = NOT AT ALL

The CBQ-HF assessed four burden domains:
1) Physical burdens; 2) Psychological or Emotional burdens;
3) Social burdens; and 4) Lifestyle burdens.

Items for version 1.0 of the CBQ-HF were generated based on the conceptual model and previous qualitative research with caregivers. Following item generation, the next step was to assess the face and content validity of the CBQ-HF. Face validity was based on the caregivers' understanding and interpretation of the items; content validity was based on the relevance of the items to heart patient's caregivers.

Process of face and content validity testing of CBQ-HF Set 1 Cognitive interviews of v1.0 of CBQ-HF with 9 US caregivers (41 items tested)

- 90 minute qualitative interview, including short 'warm up' discussion about care giving followed by the cognitive debriefing interview.

Interim analysis featuring item reduction including deletion of 8 items and rewording leading to Version 2.0 of CBQ-HF (33 items) Set 2 Cognitive interviews of v2.0 of the CBQ-HF with 9 new US caregivers (33 items tested) Full analysis including deletion of a further 7 items and rewording leading to Version 3.0 of CBQ-HF (26 items).

- In the final item the two separate items were merged to reduce the number of items overall (25 items).

Statistical analysis:

Template was generated in MS excel Data was entered under the supervision of our guide. 10% data was randomly cheeked to assess the quality of data. Univariate and bivariate analysis was done through SPSS [IBM SPSS statistics 20].

RESULTS AND DISCUSSIONS:

Table1: Socio demographic Profile of caregivers (N=36)

Sr. no.	Variables	Category	Percentage(%)	
1	Gender	Male		30.6
		Female	69.4	
2	Age	<25 yrs.		13.9
		25-49 yrs.	66.7	
		>50 yrs.		19.4
3	Ethnicity	Tribal		27.8
		Non -Tribal	72.2	
4	Religion	Hindu		69.4
		Muslim	8.3	
		Christian		22.2
5	Marital Status	Unmarried	27.8	
		Married	61.1	
		Divorced		5.6
		Separated		5.6
6	Educational Status	Illiterate	8.3	
		Literate but no formal education		16.7
		Literate with formal education		75
7	Occupation	Service	13.9	
		Business		11.1
		Daily wager	19.4	
		Student		13.9

		Housewife	33.3	
		Others		8.3
8	Type of family	Nuclear	55.6	
		Joint		44.4
9	Type of house	Kuccha	36.1	
		Pukka		47.2
		Semi pukka	16.7	
10	Socioeconomic Status (PRASAD'S Classification)	Class 1		66.7
		Class2	33.3	
		Class3,4 & 5		0

In our study, Majority (69.40%) of caregivers were female (mostly wives and daughters) in which only 33.30 % females were housewives, which is consistent with the result obtained during similar study done upon caregivers of heart patients in America where results came about 71% female caregivers[1]. In this present study, it is found that most of the caregivers (66.70%) are between 25- 49 years of age, literate (91.70%), and married (61.10%). Majority of caregivers (66.70%) belong to upper class [according to PRASAD'S Classification of Socioeconomic conditions, 2013] and mostly (47.20%) live in pukka house. About 55.60% caregivers belonged to Nuclear family structure; this may explain why many caregivers were facing less family and social support (Refer to table 1)

Upon interviewing the caregivers based on CBQ-HF questionnaire, caregivers (41.7%) responded average physical tiredness and 27.8 % had found the deterioration of their health during the act of care giving. Moreover, at the same time 38.9% of caregivers responded care giving been physically hard work and 36.1% had average lack of sleep and also 36.7% reported of Body ache during the act of care giving. Moreover, majority (44.40%) felt they need to do more for the person they care for and also 41.7 % had felt guilty for the time they spent care giving limited what they can do for others, and also for the person they care for. It was also observed that about 50 % of caregivers responded that care giving made them feel frustrated, whereas average people were stressed, sad, and had inability to concentrate and focus during their act of care giving. Most importantly, 38.9% of caregivers were worried during care giving and 33.3% were very much mentally tired and also 44.4 % were emotionally drained. Average caregivers (33.3 %) were overwhelmed during care giving and 33.3% had feeling of loneliness while several people (44.4%) were also found who liked their care giving. It was also noted that 50% had good support from others while, rest lacked that support during care giving. Majority of caregivers (44.40%) responded for average impact on relationship with patient and 33.30% had moderate Impact on their relationship with partner, family or friends. We also enquired about their lifestyle and found that most of the caregivers (33.3%) felt that they had no time for themselves and even 38.9% of caregivers had avoided making plans. Thus, a lot of caregivers (44.4%) were unable to go on to vacations during care giving. (Refer to Table 2,3 and 4)

The negative impact of care giving was most prominent for the caregivers' daily schedules. Many caregivers of patients with heart failure felt the need to be available 24 hours a day and therefore gave up social activities.

Since most of caregivers were housewives, so in our study we found that majority (36.1%) responded with no difficulty in doing paid works, but, at the same time daily wage persons had got a lot of problems in doing paid works. Some of them lost their job during care giving and thus they become weakened financially which affected their family and so the care giving of patients.

Many caregivers have felt rewarded by being able to provide care for a family member. Compared with other caregivers, caregivers of patients with severe heart failure, non-spousal Caregivers , and caregivers with low socioeconomic status and no assistance from others in care giving are more likely to feel burdened in the care giving role. Therefore, Interventions for family caregivers should be aimed at increasing the caregivers' sense of control and social support. Moreover, providing social support may increase positive feelings among family caregivers about providing care

Table 2: Physical burden of Caregivers(N=36)

LIKERT SCALE	Tiredness		Health Deterioration		Physical Effort		Lack Of Sleep		Body Ache	
	f	%	f	%	f	%	f	%	f	%
1.VERY MUCH	0	0%	0	0%	4	11.1%	3	8.3%	0	0%
2.MODERATE	8	22.2%	8	22.2%	14	38.9%	7	19.4%	8	22.2%
3.AVERAGE	15	41.7%	10	27.8%	11	30.6%	10	27.8%	10	27.8%
4.MILD	11	30.6%	9	25%	6	16.7%	13	36.1%	11	30.6%
5.NOT AT ALL	2	5.6%	9	25%	1	2.8%	3	8.3%	7	19.4%

Table 3 : Emotional Burden of caregivers (N=36)

LIKERT SCALE		Very Much	Moderate	Average	Mild	Not at all
Overly Depended upon	N	5	16	11	4	0
	%	13.9%	44.4%	30.6%	11.1%	0%
Guilty for Others	N	1	8	15	11	1
	%	2.8%	22.2%	41.7%	30.6%	2.8%
Guilty for Patient	N	0	5	15	12	4
	%	0%	13.9%	41.7%	33.3%	11.1%
Frustrated	N	1	8	9	10	8
	%	2.8%	22.2%	25%	27.8%	22.2%
Stressed	N	2	8	12	10	4
	%	5.6%	22.25	33.3%	27.8%	11.1%
Sad	N	3	6	12	9	6
	%	8.3%	16.7%	33.3%	25%	16.7%
Unable to Concentrate	N	6	14	13	3	0
	%	16.7%	38.9%	36.1%	8.3%	0%
Worry	N	11	14	9	2	0
	%	30.6%	38.9%	25%	5.6%	0%

Mentally Tired	N	17	12	5	1	1
	%	47.2%	33.3%	13.9%	2.8%	2.8%
Emotionally Drained	N	9	16	8	2	1
	%	25%	44.4%	22.2%	5.6%	2.8%
Overwhelmed	N	1	12	10	10	3
	%	2.8%	33.3%	27.8%	27.8%	8.3%
Loneliness	N	6	9	7	12	2
	%	16.7%	25%	19.4%	33.3%	5.6%
Support from Others	N	9	9	7	6	5
	%	25%	25%	19.4%	16.7%	13.9%
Liking Care giving	N	8	16	12	0	0
	%	22.2%	44.4%	33.3%	0%	0%

Table 4: Social Burden of caregivers (N=36)

LIKERT SCALE		Very Much	Moderate	Average	Mild	Not at All
Relationship with Patient	N	2	5	16	6	7
	%	5.6%	13.9%	44.4%	16.7%	19.4%
Relationship with friends, family, others.	N	7	12	10	5	2
	%	19.4%	33.3%	27.8%	13.9%	5.6%

Table 5: lifestyle Burden of caregivers (N=36)

LIKERT SCALE		Very Much	Moderate	Average	Mild	Not at All
Lack of time for self	N	3	12	8	10	3
	%	8.3%	33.3%	22.2%	27.8%	8.3%
Avoiding Plans	N	7	14	3	6	6
No Vacations	N	16	9	6	2	3
	%	44.4%	25%	16.7%	5.6%	8.3%
Reduced Working hours	N	9	4	4	6	13
	%	25%	11.1%	11.1%	16.7%	36.1%

In the act of care giving, family caregivers can face such problems as insufficiency of time, problems in giving the required care, anxiety and anger, ability to get into the way of such responsibility of care giving to their other important roles (job, spouse, friendship), excessive burden, fear of worsening or dying of the patient, feelings of anger, guilt or incompetence, conflicts concerning the familial relationships, a new role in the family, inability to make long-term plans and changes in the quality of the relationship with the patient.

As it is seen from the results of the studies mentioned in our findings, if the caregivers do not have support during the care giving, or if the support they have is limited, the significant changes in their way of life can increase the risk of stress, anxiety, loneliness, social isolation and depression. This situation negatively affects the quality of life and capability of coping with problems, as well as their roles of care giving.

Discussion:

This study showed that productive age group is affected more which will become an obstacle in the development of India. Hence, it is recommended that India government should look into this issue and strengthen its health care system to not only include patient's care but also unpaid caregivers and the family members wherever needed. Accommodations in the workplace, including flexible scheduling and telecommuting, are important ways that employers can respond to caregivers' needs. New strategies of financial reimbursement for providing caregiver support in the office also need to be implemented and may be a part of health care reform via the patient-centred medical home. Obtaining additional funding for care giving resources is an urgent national public health issue.

The findings suggest the need for interventions to increase caregivers' sense of control and social support. Family caregivers may need additional support immediately after patient hospitalizations to minimize the negative impact of care giving. Our findings reinforce the importance of assessing the needs of family members who provide care for patients with heart failure. The assessment should be initiated during the patient's hospitalization to minimize the negative impact of care giving on caregivers 'health. In addition, clinicians should provide extra support for family caregivers during the period immediately after hospitalization.

Evidence suggests that when patients and caregivers are treated as a dyad, outcomes for both are improved. These interventions come in a variety of formats, from universal, community-based interventions to illness-specific, individualized interventions.5 Caregiver interventions targeting caregivers of older adults, psycho educational and psychotherapeutic interventions had the most consistent effects on all outcome measures. A 2010 meta-analysis that included 29 randomized controlled trials (RCTs) of interventions designed to support caregivers of patients with cancer found that psycho educational, skills-training, and therapeutic counselling interventions reduced caregiver burden and increased caregiver self-efficacy, quality of life, and coping skills with small to moderate effect sizes[16].

Caregiver care is improved by offering innovations in self-management, decision support, information systems, and delivery redesign. One important advance in care giving is the increased use of high-tech home health care, Web-based technology, and assistive technology. Nearly one-half of caregivers use some form of technology to improve the quality of the care they provide.5Examples of new tools include Internet-based solutions such as the Comprehensive Health Enhancement Support System and Link2Care, which have resulted in increased delivery of information to family caregivers, decreased depression, and increased sense of social support. Other tools include home telemedicine, telehealth, and disease-state monitoring systems, which can transmit data on health status to base stations. Devices such as automatic medication dispensers, vibrating alarm watches, scooters, and lifting systems can also relieve caregiver burden and improve the safety of the care recipient at home.

Attending to the experiences of caregivers is important because the patient's psychological adaptation to major cardiac illness has been linked with family function caregivers needs: written document on how to care for the patients at home after discharge; guidance on wound care, discharge program containing information on home-care to be delivered before discharge; written instructions for home care, cardiac rehabilitation and social support programs as well as spiritual support needs.

Lower perceived control was associated with a greater negative impact of care giving. This finding suggests that improving perceived control may reduce the negative impact of care giving. Therefore, interventions for family caregivers of patients with heart failure need to include strategies such as education and counselling to enhance the caregivers' level of perceived control.

Education may assist family caregivers in expanding their coping options when stressful experience is encountered by providing them with more knowledge concerning their situation. Education service starts in the hospital before the discharge, and continues during the care giving at home. Therefore, such services must be given by the critical care nurse, the clinic nurse within the hospital and by the public health nurse at home after discharge.

Conclusion:

Care giving has both positive and negative effects on family caregivers of Cardiac patients.

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