

Stress and Coping Strategies among Caregivers of Cancer Patients

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Abstract

Caring for someone with a cancer can affect the dynamics of a family. It takes up most of the carers' time and energy. Currently, for people, there are more than thirty million family caregivers providing assistance to their elderly parents, siblings and/or spouses who suffer from Cancer (Clint, 2000). The objective of the study is to assess the relationship between the level of stress, coping strategies and quality of life of care givers of cancer patients. The psychological well being of care givers and the religious coping strategies employed is focused in this research. To assess the level of stress of the care givers, Kingston Care giver Stress Scale (Hopkins & Kilik, 2004) was used, brief COPE inventory (Carver, 1997) and RCOPE inventory (Pargament, 1997) was used. It is important for the mental health professionals to support the caregivers and provide interventions when most needed since they have a better understanding of the impact of stress and burden that individuals go through in an oncology setting.

Keywords: Stress; Coping, Religious Coping, Caregivers, Cancer Patients

Introduction

A diagnosis of cancer is a major event for the person diagnosed and also to his or her family and caregivers. According to some studies it is reported that a cancer diagnosis actually has a greater impact on family members than patients. Most of the cancer care is community based. Elderly patients being treated for cancer is associated with ageing and growing population. The shifts in health care services and population demographics result in cancer being one of the most common health conditions in receipt of informal care giving. Because of the family responsibility, majority of caregivers report taking on the role of caring because of very little choice and no one else present to provide care. For some, caregiving can extend for several years and be equivalent to a full-time job. The aim of this research is to provide an overview of the issues faced by caregivers of family members diagnosed with cancer, with a particular emphasis on the physical, psychosocial, and economic impact of caring. So, it is important for the mental health professionals to support the caregivers and provide interventions when most needed since they have a better understanding of the impact of stress and burden that individuals go through in an oncology setting.

A review of the literature identified that with the majority of caregivers reporting taking on the role of caring because of family responsibility and there being little choice or no one else to provide the care. Cancer is now one of the most common health conditions in receipt

of informal caregiving in India. For some individuals, caregiving can extend for many years and almost become equivalent to a full-time job, with significant impact on health, psychosocial, and financial conditions (Agarwal, 2002).

In the past 5 years, one in 10 people having provided hands-on care for someone at the end of life (the majority of whom had cancer) and therefore, caregiving is a common task. According to the intensity of care, distinct caregiver groups with differing needs are present. The extent of the care giver's role may have been unaware to themselves and may often experience an insidious onset to the role they are playing; others feel that they have little choice (Lauren, 2010). A study done by Kim and Schulz (2008) reported comparable levels of burden across cancer and dementia caregivers; however, both these groups have provided more hours of care per week, assisted with a greater number of daily activities, and have reported greater levels of physical burden and psychological distress than caregivers of individuals with diabetes or frail elderly.

Caregiving activities done are varied and numerous, including personal care, transportation, mobility, emotional support, communication, housework; coordination and management of medical care, administration of medications and therapies, assisting with the personal care, social services, organizing the appointments, assistance with the help of social activities, managing the money; transferring, ambulating, incontinence care, shopping, housework, meal

preparation, telephone calls and managing finances. (McMillan, 1999)

It is a complicated transition to take on the role of the care givers that involves patients, families, and health professionals to varying degrees and it may not have a definite start point. Furthermore, for type of care as per patient and caregiver preferences are not always congruent and require negotiation. When it comes to care for the patient and who will be involved in the caregiving, health care professionals adopt varying degrees of involvement in the decision about the type but commonly initiate the discussion. Caregivers who are more able to cope and are prepared with their role would involve in an open discussion between the caregivers and patients.

The degree of burden and stress experienced by the care givers has been the focus of a considerable amount of research given the potential impact of caring for a person with cancer. The definition of caregiver burden is defined as the extent to which caregivers feel that their physical and emotional health, social life, and financial status have suffered as a result of caring and due to stress. The care giver's needs are frequently considered secondary to those of the patient or are overlooked despite caregiving having a significant impact on their well-being. According to some studies, it has been reported that there is increased morbidity and mortality associated with caregiving. Frequently, the caregivers themselves are aged (primary care givers age > 65) and have significant health problems that affect and are affected by the caring role.

A recent review by Stenberg *et al* (2010) found that the most prevalent physical problems were reported by caregivers included fatigue, sleep disturbance, loss of appetite, loss of physical strength, pain, and weight loss. In an Australian study of caregivers, more than half reported that caregiving had directly affected their overall physical health, including tiredness and exhaustion (54.5%); back, neck, and shoulder problems (33.8%); stress-related illnesses (6.6%); arthritis (10%); digestion and bowel problems (4.6%); blood pressure and/or heart problems (12.6%); being physically unfit and weight problems (5.5%); and leg and foot problems (4.6%). A study of caregivers of people with advanced cancer found that more than two third individuals reported fatigue (69% at baseline), which increased as time went on and as the patient deteriorated. Fatigue was reported as a result of decreased motivation (58%), decreased ability to perform usual activities (42%), affected relationships (46%), decreased concentrate (in 69% of cancer caregivers), and effects on mood (35%). Grbich *et al* (year) identified that individuals reporting back and leg strain caused by heavy lifting which is a substantial physical impact of the caring role, with, furthermore, due to the increased amount of washing, physical strain was being reported when the patient was incontinent of urine and feces. Due to continual lack of sleep if patients needed care during the night, the impact of the constancy

of care for physical needs was exacerbated. Up to 82% of female cancer caregivers reported sleep disturbances, with sleep disturbances significantly associated with anxiety depression, and anger (Jones, 2005).

Cancer caregiving also has a negative impact on health-related activities such as skipping exercise or yoga. A study by Beesley *et al* (2011) found that slightly more than one third gained weight to a level that exceeded their healthy body mass index range and 42% of caregivers of people diagnosed with ovarian cancer reported decreasing their physical activity since their family member was diagnosed with cancer. Though most caregivers did not report a change in their vegetable and fruit consumption, 12% increased their alcohol intake. Prevalence of depression and anxiety among spouses and caregivers ranges from 10% to 53% and 16% to 56% respectively and, in some studies, exceeds patients' rates. For example, a study of caregivers who had been caring for a patient with cancer for an average of 2 years it was reported that 52.9% were at risk of clinical depression (ie, Center for Epidemiological Studies-Depression scale > 15). Lambert *et al* (2012) found that more than one third of caregivers reported clinical levels of anxiety, and almost 17% reported borderline or clinical depression, with most depressed caregivers also reporting anxiety, at 6 and 12 months after patient diagnosis.

The main concern is that the caregivers of people with cancer who have more restrictions in their daily activities and limited or no social networks are more likely to report caregiver burden. A study by Price *et al* (2006) found that lower social support was a predictor of depression and anxiety for caregivers of women with ovarian cancer.

Caregivers often report giving up and stop trying to participate in social activities as a result of concern for the patient while they are absent. In a study by Payne *et al* (2006), younger caregivers found it difficult to express their own needs, unless asked specifically away from the hearing of the patient and particularly felt that caring impinged on their own life, and they.

It is more and more understood about the significant toll that a cancer diagnosis takes on a relationship. Even high-functioning couples may struggle to manage the challenges and stress of cancer, as well as changes in their relationships brought on by the cancer diagnosis during the course of time. Due to such stress, it may lead to conflict and tension within the couple. A qualitative study by Fergus and Gray (2009) among spouses facing cancer found that patient reactions that impede couple adjustment included exaggerated dependency, being overly controlling self-absorption and being overly independent. Similarly, spouse reactions were found to contribute to discord or tension included not knowing how to support the patient, withdrawing from the situation, not prioritizing the patient and unexpressed anger. Even though it has been suggested that cancer might lead to higher rates of divorce, but a review by Dorval *et al* (2005) among couples facing breast cancer does not support this study.

The risk of abuse in the families of cancer patients receiving palliative care and caregiver abuse has been examined to a small degree. According to an Australian study, it was reported that almost 5% to 13% of elderly people experience physical, psychological or financial abuse occurred mostly by people in a caregiving relationship. According to a US study it was found that 26% of care recipients living in the community were exposed to potentially harmful caregiver behaviour and abuse. As established patterns of family interaction are carried into a caregiving relationship when a family member becomes ill, abuse of patients may be occurring but not be evident as a result of the stigma of reporting abuse and the secluded lives of patients. Risk factors for caregiver abuse include greater levels of patients' needs in activities of daily living, being a spousal caregiver, greater caregiver cognitive impairment, physical symptoms, and depression symptoms. Research suggests that early intervention and support may prevent abuse from occurring or reoccurring. Community palliative care nurses in particular may be well placed to identify where abuse is occurring or likely to occur.

Despite the physical, social, and emotional burden of care, respite services are not well utilized by caregivers. Some patients and caregivers do not access specialist services because of the emotional difficulties in discussing death and dying.

Caregiving creates a lot of financial burden for family members, both in outright expenses and in loss of income and benefits. Few of the studies have documented that the economic burden of informal caregiving in the United States of America. For instance, Hayman *et al* (2001) found out that treatment of cancer was associated with an incremental increase of almost 3.1 hours per week of informal caregiving, which then translates into an additional average yearly cost of just over \$1 billion nationally and \$1,200 per patient.

A person's chance of being employed also appears to reduce, and many caregivers are not able to work, need to take a leave without pay, work from home to manage the caregiver demands are in lower paid jobs or have fewer work hours. Social isolation is contributed due to reduction in paid work. The long-term impacts of caregiving with regard to finance will include loss of savings for retirement.

While many of the caregivers report experiencing surprise, depression, distress, disbelief, anger, shock and fear in response to a cancer diagnosis, they also felt that taking care for a person with cancer is an experience that will be able to produce positive emotions and hope. In one Australian study, 60% of the caregivers were able to identify the positive and worthy aspects of their role. The time together was described very emotively as "precious time" during the time patients' symptoms were minor, which allowed them to explore the emotions and express their love for the patient. The quality of time spent with the patients brought happiness in them, the ability to explore, resolve issues, and feelings of self-worth and

value have all been reported by caregivers. In addition to this, it has been suggested that by caring for the patient, it may help the caregivers to accept the death of the patient and manage to work through their grief.

Although the caregivers face a range of challenges as mentioned above, they are often patients' primary source of support and often receive very little or no preparation. Though supportive care interventions have been shown to improve the quality of life among patients who have been diagnosed with cancer, few studies of them have examined psychosocial interventions to optimize the adjustment outcomes among caregivers. A recent meta-analysis by Northouse *et al* (2007) found out that three types of interventions are typically offered to caregivers: training (coping, problem-solving skills and communication), psycho educational, skills and therapeutic counselling. Even though these interventions were found to have a small to medium effects, it was reported that they significantly reduced the caregiver burden, improved aspects of quality of life and self-efficacy (ie, preparation, perceived, mastery and/or confidence to provide care).

Though these interventions are promising in enhancing caregivers' illness adjustment, limiting their accessibility due to high costs, most are delivered by highly trained health care professionals; transportation costs and accessibility, particularly for people in rural areas; limited availability of qualified and trained professionals, especially in nonmetropolitan areas. Many self-directed interventions have been proposed to overcome these limitations, with evidence of acceptability to partners and patients. Caregivers have many potential advantages because of self-help supportive care interventions, including enabling caregivers to select what, when, and how they want to learn.

Some of the studies have examined the potential of self-directed interventions to enhance the patient adjustment. Beatty *et al* (2007) examined that the efficacy of a self-directed, coping skills workbook for women recently diagnosed with cancer and found support for the efficacy of the workbook in improving cognitive avoidance, PTSD symptoms, and feelings of hopelessness or helplessness. Lambert *et al* (2012) have tested the feasibility of a self-directed intervention for the patients and their partner and found out that many people rather prefer a self-directed format. To support the efficacy of self-directed interventions, evidence is urgently needed in enhancing the caregivers' illness adjustments.

Objectives

The present study aims at:

- To assess the relationship between stress and coping strategies among caregivers of cancer patients.
- To assess the relationship between stress and religious coping strategies among caregivers of cancer patients.

Method

Sample

Data was collected through semi structured interviews. The question was often reframed at the time of the interview to suit the respondent's language, style and educational level. The participants were not interrupted in their narratives and minimum interjections were made. This approach allowed participants to discuss their experience in their own language and in their own way, according to their level of comfort in disclosure. By entering the participants' life world it was possible to access the private meanings of participants. The data was collected at Rajiv Gandhi Cancer Institute & Research Centre, New Delhi. Purposive random sampling method was employed for the data collection. The sample included 31 caregivers aged between 23 and 68 living in India. Caregivers were defined as persons who assisted individuals with at least one activity of daily living or instrumental activity of daily living (NAC/AARP 2004c). The question used to identify caregivers was "In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing.

Tools

Demographical variables

Standard questionnaires were used to collect data on age, gender, education, marital status, annual income, relationship with care-recipients, family type and place. Also patient's information was collected such as age, gender, education, annual income, marital status, illness duration, hospitalized or not, type of cancer.

Caregiver Stress

Caregiver Stress was measured with the help of Kingston Care giver Stress Scale (Hopkins & Kilik, 2004). This is a 5 point scale with 1 being 'Feeling NO Stress', 2 being 'Some Stress', 3 being 'Moderate Stress', 4 being 'A lot of Stress' and 5 being 'Extreme Stress'. The results for the reliability and the validity of the scale were satisfactory and the tool had high reliability of 0.85 and validity of 0.82.

Coping Strategies

To measure the coping strategies, COPE inventory (Carver, 1997) was used. This is a 4 point scale with 1 being 'I haven't been doing this at all', 2 being 'I've been doing this a little bit', 3 being 'I've been doing this a

medium amount' and 4 being 'I've been doing this a lot'. The results for the reliability and the validity were 0.73 and 0.68 respectively.

Religious Coping

To measure the religious coping strategies, RCOPE inventory (Pargament, 1997) was used. This is a 4 point scale with 1 being 'Not at all', 2 being 'Somewhat', 3 being 'Quite a bit' and 4 being 'A great deal'. The results for the reliability and the validity were 0.80 and 0.77 respectively.

Procedure

Data were collected using standardized questionnaires to obtain demographical data on respondents, data on the household and data on both the caregivers and care-recipients. Each participant was given three scales. After establishing good rapport with the subject individually, they were asked to reply confidentially to each item in the questionnaire. Each questionnaire was explained in an easier way to make them understand. Any misconceptions were removed. All data collection and interviews were conducted face to face, mostly in the English and Hindi language. Data were collected from on 3rd October and 10th October 2015.

Data analysis

The analysis of data was done using Statistical Package for the Social Sciences version 16 (SPSS 16.0). A correlation analysis was constructed among all the variables, based on Pearson's correlation coefficients for significance. The impact of predictors on caregiver burden was tested using correlational analysis. The caregiver's socio-demographical variables were entered first, followed by Stress score, Coping score and Religious score. Modifiable variables were included in the last block to suggest possible interventions that might help caregivers. The amount of missing data for all the independent and dependent variables tested was less than 5% to ensure quality of data and generalizability of the research conclusions.

Result and Discussion

Correlational analysis were carried out in order to find out the degree of relationship between all the variables viz. stress and coping. A separate analysis was carried out for stress and religious coping among the caregivers.

Table 1 shows the demographic information about the caregivers. According to the result obtained, there were a total of 31 caregivers in which 52% were males and 48% were females. The average age of the caregivers was obtained as 41 years. 48% caregivers were below the age

of 40, 45.6% were between 40 to 60 years and 6.4% were above the age of 60.

Table 1 Socio demographic characteristics of caregivers (N = 31)

Variable	N	Percentage
Gender		
Male	16	52
Female	15	48
Age		
Less than 40 years old	15	48
40–60 years old	14	45.6
Older than 60 years old	2	6.4
Marital status		
Unmarried	3	9.6
Married	28	90.4
Relationship to patient		
Father	2	6.4
Mother	1	3.2
Spouse	13	41.9
Son	3	9.6
Daughter	3	9.6
Other Relatives	9	29
Annual income		
Low	13	41.9
Middle	19	61.2
High	5	16.1
Family Type		
Joint	12	38.7
Nuclear	19	61.2
Education Qualification		
Uneducated	2	6.4
Middle School	4	12.9
High School	5	16.1
Undergraduate	11	35.4
Postgraduate	9	2.9

In terms of marital status of the caregivers 90.4% were married and 9.6% were unmarried. Regarding the caregivers' relationship to the patients, 6.4% were fathers, 3.2% were mothers, 41.9% were spouses, 9.6% were sons, 9.6% were daughters and 29% were other relatives and friends. 38.7% lived in a joint family. Whereas 61.2% lived in nuclear family. Among the caregivers, 41.9% had low annual income (below 1 lakh per annum), 61.2% had moderate income (1 lakh to 5 lakh) and 16.1% had high income (more than 5 lakh). In terms of education qualification, 6.4% were uneducated, 12.9% were middle school educated, 16.1% were high school educated, 35.4 % were undergraduates and 2.9% were postgraduates.

Table 2 Sociodemographic characteristics of patients (N = 31)

Variable	N	Percentage
Gender		
Male	19	61.2
Female	12	38.7
Age		
Less than 40 years old	10	32.2
40–60 years old	17	54.8
Older than 60 years old	4	12.9
Marital status		
Single	6	19.3
Married	25	80.64
Illness Duration		
Less than 1 year	7	22.6
1 year to 5 years	14	45.2
5 years and above	10	32.3
Education Qualification		
Uneducated	2	6.5
Middle School	5	16.1
High School	5	16.1
Undergraduate	13	41.9
Postgraduate	6	19.4

According to the table no. 1 there were a total of 31 patients in which 61.2% were males and 38.7% were females. The average age of the patients was obtained as 49.8 years. 32.2% patients were below the age of 40, 54.8% were between 40 to 60 years and 12.9% were above the age of 60. In terms of marital status of the patients 80.64% were married and 19.3% were unmarried. In terms of education qualification, 6.5% were uneducated, 16.1% were middle school educated, 16.1% were high school educated, 41.9% were undergraduates and 19.4% were postgraduates. Regarding the illness duration, 22.6% were suffering from the illness less than 1 year, 45.2% between 1 to 5 years and 32.3% for more than 5 years.

Table 3: Correlations between Stress and Cope

	Coping
Stress	.456*

* Correlation is significant at the 0.05 level (2-tailed)

From the above table it is clear that there is significant correlation at 0.05 level between Stress and Coping Strategies among caregivers. Pearson Correlation was used to correlate for 31 samples. For stress and coping, a value of .456 significance was obtained.

Table 4: Correlations between Stress and Religious Cope

	Religious Coping
Stress	.285

From the above table it is clear that there is no significant correlation between Stress and Coping Strategies among caregivers.

Table 5: t-test for Stress between Male and Female

Patient	N	Mean	Sd	T
Male	15	33.3125	5.28796	.451
Female	15	34.9333	6.37480	

From the above table it is clear that there is no significant correlation between Stress and Coping Strategies among caregivers.

Table 6: t-test for Coping between Joint and Nuclear family type

Patient	N	Mean	Sd	
Joint	12	67.1667	5.32291	-.513
Nuclear	19	68.3684	7.71874	

Table 7: t-test for Cope between Married and Unmarried caregivers

Patient	N	Mean	Sd	
Joint	12	67.9643	6.81764	.127
Nuclear	19	67.3333	8.32666	

From the above table it is clear that there is no significant correlation between Stress and Coping Strategies among caregivers.

The above result was obtained with the help of SPSS. There is significant correlation at 0.05 level between Stress and Coping Strategies among caregivers as is evident from table 3. For stress and coping, a value of .456 was obtained which is significant at 0.05 level. But there was no significant correlation between Stress and Religious coping as shown in the table no. 4. For stress and religious cope, a value of a value of .285 was obtained. According to the results obtained, it is seen that there is a positive correlation between stress level and coping strategies among caregivers. When the amount of stress increases, the need for coping also increases. Studies conducted by Heejung Kim (2011) also shows that there is a positive correlation as confirmed by the result obtained. Women and men did not differ in the use of informal and formal support. The results support stress-and-coping theories on gender differences in caregiving. Some authors had argued that activities of daily living and instrumental activities of daily living are significant predictors of caregiver burden (Rinaldi *et al.* 2005, Molyneux *et al.* 2008, Sussman& Regehr 2009), but

others disagreed (Clyburn *et al.* 2000, Campbell *et al.* 2008). Table 5 shows T-test analysis which says that gender plays no role on stress. There was no significance on stress and gender of the caregivers. A standard deviation of 5.28 and 6.37 was obtained for males and females respectively. The t-values obtained when equal variances were assumed and not assumed were .456 and .451 respectively. In an Australian study, the researchers disagreed the fact that there is relationship between stress of caregivers and the religious coping methods employed. (Perry *et al.* 2004). Table 6 shows T-test analysis which says that family type i.e. joint family and nuclear family has no relationship with coping among the caregivers. A standard deviation of 5.32 and 7.71 was obtained for joint and nuclear family respectively. The t-values obtained when equal variances were assumed and not assumed were -.472 and -.513 respectively. Pelletier *et al* (2007) examined that family type has no significance with the coping strategies among the cancer caregivers. Table 7 shows T-test analysis which says that marital status i.e. married or unmarried has no relationship with coping among the caregivers. A standard deviation of 6.81 and 8.32 was obtained for married and unmarried respectively. The t-values obtained when equal variances were assumed and not assumed were .150 and .127 respectively. To support this result is the study conducted by Lazarus (1998) which says that emotional support for coping may not always be related to marital status for cancer caregivers as there are other factors responsible.

Limitations of existing research

The main limitation of the study is the sample size. Nonetheless, the results obtained in the current study are supported by previous studies. Though the caregiving literature is very vast, much of it is based on the cross-sectional analyses of relatively small opportunity samples. Confounding effects such as the caregiver's level of education and health status have often not been controlled for in the study's design or statistical analysis. For instance, differences in illness rates between caregivers and non-caregivers may not be the result of the caregiving experience, but may instead reflect differences that existed prior to assuming the caregiving role. One example of it may be socioeconomic status; individuals of low socioeconomic status are more likely to take on the caregiving role, and lower socioeconomic status is a risk factor for poor health itself. Higher rates of illness in spouse caregivers may be the result of assortative mating (people tend to choose spouses who are similar to themselves) or life circumstances (such as access to medical care) and shared health habits (such as diet and exercise). As a result of these factors, older spouses tend to develop few illnesses and disabilities at about the same time; if one partner may have health problems that require a caregiver, chances are that the other partner also has health problems, although they may be less severe.

Conclusion

This research adds knowledge on the associations between stress and coping strategies of caregivers of cancer patient. A significant correlation was found between stress and coping strategies but no significant relationship was found between stress and religious coping. In addition, socio-demographical factors and caregiving-related factors aggravated burden. The findings point to the importance of examining multifactual components of burden and taking comprehensive approach to help caregivers cope with providing care to a person with cancer.

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