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GRIEF AMONG CANCER PATIENTS: PREDICTOR OF BURDEN OF CARE AND MENTAL HEALTH AMONG THEIR CAREGIVERS

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ABSTRACT

This study was aimed to investigate grief among cancer patients as the predictor of burden of care and mental health among their care givers. It was hypothesized that the grief among the cancer patients will positively predict the caregiver's burden and poor mental health among caregivers of these cancer patients. It was further hypothesized that there would be significant gender differences and significant correlations among the caregiver burden and mental health among caregivers and grief among cancer patients. Data was collected from primary caregivers of the cancer patients from different hospitals (n= 250). The Caregiver Strain Index (CSI), General Health Questionnaire (GHQ-28) and Grief Scale were used as psychometric tools. Correlational research design was implied. Non-probability convenient sampling technique was used. Data analysis was done by using SPSS 21. Pearson product moment correlation was applied to measure the nature of relationship among study variables. Significant positive correlations among caregiver burden, mental health of caregivers and grief among the cancer patients indicated that grief among cancer patients leads to poor mental health and excessive burden of care among the care givers. Independent sample t-test revealed that although there is no significant gender difference on caregiving strain index but female caregivers had comparatively higher mental health problems than male caregivers. Regression analysis revealed grief in cancer patients and poor mental health of caregivers as predictors of burden of care. The importance of this study lies in the fact that the findings will be highly valuable in

gaining insight into the psychological problems experienced by the family caregivers in Pakistan to device better strategies to eradicate their effects on their mental health.

INTRODUCTION

One of the leading causes of death worldwide is cancer and that also with an increasing ratio of patients (National Institute of Health, 2015). Although the use of latest technology has stood in the favor of better prognosis but still improvement is needed. It does not only make the patient to suffer but the family members of the patients and health care providers also suffer. Present study has tried to unfold this phenomenon where grief among cancer patients serve as a predictor of the burden of care and poor mental health among their caregivers.

In relation to the psychosocial responses to an end stage disease different interchangeable term of distress, grief, bereavement, and mourning are mostly used. Depression and anxiety (psychological distress) and pain and nausea (physical stress) have been definite signs used to show the difference of type of distress (Cameron, Franche, Cheung, & Stewart, 2002). As per definition of distress by The National Institute of Health (2015) "a multifactor unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment". Multidimensional response to the deceased and all kind of losses, including emotional (affective), psychological (cognitive and behavioral) and bodily responses is termed as grief (Stroebe, Hansson, Stroebe, & Schut, 2001).

According to the literature, the number of cancer survivors with diagnosis of less than 5 years is almost 28.8 million (Louis, Adams & Brown, 2017). Throughout the phase of disease, several formal and informal family members like their partners, parents, siblings, children or friends provide support to the cancer patients. The help of these members is not only limited to the practical help but also provide huge psychological support to face the uncertainty and fear during diagnosis and first stage of illness (Bevans & Sternberg, 2012). With every advancing stage caregiving also intensifies that includes assistance in self-care and emotional support (Siefert, Williams, Dowd, Chappel-Aiken, McCorkle, 2008).

Regardless of ethnic, racial and cultural variations burden of caregiving is experienced by the caregivers (Stenberg, Ruland, & Miaskowski, 2010) but caregivers in various countries may experience their role in different ways depending upon their cultural values, beliefs and family systems. For example, the regions with combined family system and closely living families offer more help. In other areas, however, the nuclear family may be the only source for caregiving (Sklenarova, et al., 2015). Even in European countries the difference of end life care, diagnosis revelation, different approaches to end of life, euthanasia, family role and hospital accessibility are also recorded proving that even in “western” countries there is no specific practice to provide care to cancer patient (Gysels, Evans, Menaca, et al, 2012).

The socio-demographic values of the families of the cancer patients also affect the mental health of the caregivers. Psychological distress is found to be higher among female caregivers in general and younger, working caregivers, particularly those with lower socioeconomic status (Kim & Given, 2008). A little bit of attention in different studies has also been given to the important aspects of cancer patients' life including their psychological issues (anxiety, depression and fear of death), a wide range of physical difficulties (e.g., sleep disturbance, fatigue, weight loss and loss of appetite), sexual problems, discrepancy in their social ties, and professional instability (Stenberg, Ruland, Miaskowski, 2010). There are some researches that show that such physical problems are also experienced by the caregivers throughout the course of disease (Grov & Valeberg, 2015). Insomnia, headaches and tiredness have also been reported by the caregivers of recently diagnosed cancer patients (Rivera, 2009) that may lead to more healthcare burden (Sjovall, Attner, Lithman, et al, 2009). On the other hand, the family and partners have been reporting better physical condition (e.g., better mobility and health care use, lack of pain or discomfort) during disease free period of the patients (Clay, Roth, Wadley, & Haley, 2008).

The intensity of caregiving, type of the caregiving task and perception of burden of care cause variations in experience of the caregiving. For caregivers' physical health there are no known subjective or objective burden evaluating researches, what is evident in literature is that family members somehow adapt the burden of care due to which the emotional distress becomes low (McCann, Bamberg, & McCann, 2015). Researchers with the caregivers of cancer patients using self-reporting measures and diagnostic interviews have reported 20-30% prevalence of psychological morbidity usually symptoms of anxiety or depression (Fuchs & Flügge, 2003). Comparison studies between caregivers and groups of healthy people have also been the focus of attention for the researchers aiming to explore the effects of caregiving on their mental health (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). In a comparative research having sample of 257 caregivers of cancer survivors in UK and Europe found quite similar findings about rate of anxiety and depression i.e., 9% and 3%, respectively (Turner, Adams, Boulton, et al, 2013) but the rate of these psychological issues exceeds in the case when the condition of the patient is severe (Ostlund, Wennman-Larsen, Persson, Gustavsson, & Wengstrom, 2010).

Both the diseased and the caregivers experience loss by terminal condition. The loss during the period of caregiving has got less attention until now than the grief after the death of the patient. Physical loss that is loss of something related to the bodily components like loss of functioning or dependence and psychological loss due to social contact like assistance to carryout daily activities is related to the advance illness (Rando, 2014). The initiation of loss starts with start of disease such as decreased functioning and increased tired ness that intensifies with the advancement of disease and dominates during the evident dying course (Loscalzo & Brintzenhofeszoc, 1998).

As the ratio of cancer victims is increasing in Pakistan due to which they along with the caregivers have to face psychological, physical, social and economic strains therefore the researchers designed this study to shed light upon this sensitive and neglected area in our country to investigate how grief among cancer patients predict burden of care and poor mental health among the caregivers. This study will not only highlight the problems faced by cancer patients but also the sufferings of the least noticed people the caregivers. It will eventually guide the hospital and healthcare policy makers to improve the facilities for reducing the sufferings of the both patients and caregivers.

The hypotheses of the study were

- There would be a significant positive relationship between burden of care among caregivers and grief among cancer patients.
- Significant positive relationship would exist between poor mental health among caregivers and grief among the cancer patients.
- Burden of care and mental health of the caregivers of cancer patients would have a significant negative correlation.
- Female caregivers would experience significantly higher burden of care and poor mental health as compared to male care givers.
- The grief in cancer patients would be a significant predictor of poor mental health of the caregivers.

METHOD

Sample

The present study comprised of the 250 cancer patients and their primary caregivers (Men= 132, Women= 118) from different cancer hospitals in Lahore. Data was collected by using convenient sampling technique. Age range of the caregivers was 13-57 years (*M* = 34.38, *SD* = 10.40).

Instruments

Demographic information sheet.

In order to collect the demographic characteristics of the participants the demographic information sheet was prepared by the researcher that included information about age, gender, education, marital status, economic status, no of siblings and profession.

General Health Questionnaire (GHQ-28);

The General Health Questionnaire (GHQ) is a 28 item, most widely used mental well-being assessment tool designed to examine an individual's current mental health by asking whether or not a specific behavior or symptom has recently been experienced. Each item has a four-point rating (better than usual=0 to much worse than usual= 3) (Goldberg & Hillier, 1979). GHQ evaluates the most common mental health problems on four subscales including Somatic Symptoms, Anxiety/Insomnia, Social Dysfunction and Severe Depression. Scale’s reliability ranges between 0.78 and 0.95. It is easy to administer and to score the general health questionnaire.

Caregiver Strain Index (CSI) (Robinson, 1983);

The Caregiver Strain Index is a 13-item screening instrument which can be used to identify strain of carers, assess their ability to go on caring and to identify areas where support may be needed. The questions are provided, with answers being Yes or No. The instrument can be either answered by the carer or with staff asking questions in an interview situation. In the current study the instrument was used with the caregivers of the cancer patients directly and the scale was highly reliable (α=.89) for the present sample. A score of 7 or greater indicated a high level of stress. Time frame for administration was approximately 5 minutes.

Grief Scale (Arshad & Muazzam, 2016);

Tackling chronic diseases and life-threatening conditions requires a sense of grief. To evaluate the grief among the cancer patients the indigenous grief scale (Arshad & Muazzam, 2016) was used. It was a 30 items scale with four subscales, i.e., Physical Grief, Emotional Grief, Cognitive Grief and Social Grief. Scale was highly reliable (α=.93) for the present sample.

Procedure:

After getting formal permission from three hospitals of Lahore, a sample of 250 cancer patients and their primary caregivers was selected. Participants were provided with a brief summary of the research project together with terms of confidentiality and data use. Then each participant was asked to complete the consent form, demographic sheet and questionnaires. Caregivers Strain Index (CSI) to evaluate burden of care and General Health Questionnaire (GHQ-28) were administered on caregivers while Grief Scale was applied on cancer patients. In the end, participants were thanked by the researcher for their cooperation. Collected data was entered and run in SPSS 21 to evaluate the hypotheses.

RESULTS

Percentages, means, and standard deviations of demographics of the study sample were calculated. Among 250 caregivers 132 (52.8%) were male while 118 (47.8%) were females. 84 (33.6%) participants were uneducated whereas among educated ones 62 (24.8%) reported to complete their education till matriculation and only 4 (1.6%) were post graduates. 147 (58.8%) caregivers were employed and doing different jobs while unemployed participants were 103 (41.2%). Parents 141(52%), spouses 45(18%), siblings 47(18.8%) and relatives in other capacity 27(10.8%) were different categories of the caregivers of the cancer patients. Cancer patients in the study had various durations of their illness, among them 65 (26%) were diagnosed 6 months before, 67 (26.8%) had been fighting the illness since last one year and 40 (16%) were suffering from last 2 years.

Further Pearson Product Moment Correlation, Regression analysis and Independent Sample *t*-test were applied as statistical analysis to test study hypotheses.

Table 1 Summary of Inter correlation for Scores on Major Study Variables (N = 250)

Correlations											
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Physical Grief	-	.39**	.44**	.46**	.77**	.26**	.10	.14*	.17**	.15*	.20**
2. Emotional Grief		-	.46**	.48**	.78**	.26**	.05	.13*	.03	.20**	.15*
3. Cognitive Grief			-	.59**	.78**	.26**	.18**	.12	.17**	.12*	.21**
4. Social Grief				-	.76**	.14*	-.03	.06	.08	.11	.08
5. Grief Scale total					-	.32**	.11	.15*	.14*	.19**	.21**
6. Care Giver Scale						-	.09	.02	.24**	.04	.14*
7. Somatic symptoms							-	.35**	.35**	.23**	.65**
8. Anxiety Insomnia								-	.43**	.27**	.71**
9. Social Dysfunction									-	.44**	.77**
10. Severe Depression										-	.70**
11. GHQ Scale Total											-

Note: Note. p≤ .05*, p≤ .01**

Table shows the correlations among various types of grief in cancer patients, caregiver burden and mental health of the caregivers. Physical grief among cancer patients in addition to sharing significant positive correlations with all other types of grief is also found to share positive relationship with burden of care (r =.26**, p<.01), and three subscales of mental health including anxiety insomnia (r =.14*, p<.05), social dysfunction (r =.17**, p<.01), and severe depression (r =.15*, p<.05). Emotional grief on the other hand similarly shared significant positive correlations with all types of grief, caregivers' strain (r =.26**, p<.01), and two subscales of mental health including anxiety insomnia (r =.13*, p<.05) and severe depression (r =.20**, p<.01). Cognitive grief shows highly significant positive correlation with social grief (r =.59**, p<.01), burden of care (r =.26**, p<.01), and three subscales of mental health including somatic symptoms (r =.18**, p<.01), social dysfunction (r =.17**, p<.01), and severe depression (r =.12*, p<.05). Social grief has been found to share significant correlation with caregiver burden only (r =.14*, p<.05). Further all the subscales of mental health were found to share positive correlations among them.

Table 2 Independent Sample t-test indicating Mean differences between men and women on Caregiving Strain Index, General Health Questionnaire and Grief Scale (N=250)

Variables		**(N=250)**					**CI (95%)**		
	Men (n=132)		**Women (n=118)**						
	M	**SD**	**M**	**SD**	**T**	**P**	**LL**	**UL**	
Caregiver Strain Index	8.64	2.28	118	8.72	-.26	.78	-.77	-.08	
GHQ	29.67	9.13	32.25	9.47	-2.18*	.03	-4.90	-.24	
Physical Grief	28.26	5.20	28.58	5.54	-.46	.64	-1.6	1.02	
Emotional Grief	24.93	5.60	25.84	5.01	.183	.18	-2.25	.43	
Cognitive Grief	15.82	4.15	16.81	4.18	-1.86	.06	-2.02	.05	
Social Grief	14.06	3.42	14.86	2.99	-1.96*	.05	-1.60	.00	

Note. *p<.05, ** p≤.01

High scores on caregiver strain index show higher strain due to caregiving. Independent sample t-test indicated significant gender differences on caregiving strain index, women got high score on caregiving strain index (M= 118, SD=8.72) than men (M= 8.64, SD=2.28) at t = -.26, p<.05 indicating that women have higher caregiving strain compared to men but not significant.

Higher score on GHQ indicates poor mental health. Significant gender differences in mental health were indicated by independent sample t- test, with women having a high scoring GHQ (M=32.25, SD=9.47) in t=-2.18* and p<.05

as compared to men (M= 29.67, SD=9.13). Hence mental health of female caregivers is poor as compared to male caregivers.

Slight gender differences were observed on different forms of grief among male and female cancer patients. Overall men got slight low score on physical grief (M=28.26, SD=5.20) as compared to women (M=28.58, SD=5.54) at t =-.46, p<.05 that is not significant, slight low scores on emotional grief (M= 24.93, SD= 5.60) than women (M= 25.84, SD=5.01) at t = .18, p<.05, slight low scores on cognitive grief (M=15.82, SD= 4.15) than women (M= 16.81, SD=4.18) at t = -1.86, p≤.01, and slightly low on social grief (M= 14.06, SD= 3.42) than women (M= 14.86, SD=2.99) at t = -1.96*, p<.05. Overall women were found to report all types of grief experienced by them more than men during their disease period.

Table 3 Summary of Simple Linear Regression Analysis for Mental Health and Grief Predicting Caregiving Strain among the caregivers of the cancer patient (N = 250)

Variables	**Model 1**		
	B	SE	B
(Constant)	3.95	.879	
Physical Grief	.076	.029	.181***
Emotional Grief	.093	.030	.222**
Cognitive Grief	.072	.042	.135**
Social Grief	.090	.056	-.130
Somatic Symptoms	-.005	.050	-.007
Anxiety Insomnia	-.096	.047	-.140*
Social Dysfunction	.235	.052	.334***
Severe Depression	-.081	.042	-.130*
R	.448		
R^2	.173		
ΔR^2	.201		
F	7.30		

Note: p≤.05*, p≤.01, ** p≤.001***

Simple linear regression analysis was run to study type of grief and mental health as predictor of burden of care. Physical grief (β=.181, $p \leq .001$), emotional grief (β=.22, $p \leq .01$) and cognitive grief (β=.13, $p \leq .01$) in cancer patients and social dysfunction in caregivers (β=.33, $p \leq .001$) predict burden of care significantly positive. While anxiety insomnia (β=-.14, $p \leq .05$) and severe depression in caregivers (β=-.13, $p \leq .05$) are negative predictors. Social grief in cancer patients and somatic symptoms in caregivers are non-significant predictors of caregiver burden.

DISCUSSION

This research is significant both globally and with respect to Pakistani culture because the ratio of patients suffering from numerous kinds of cancer is increasing day by day. According to literature, grief among cancer patients predicts the burden of care and poor mental health among caregivers of the cancer patients, therefore the researchers aimed to explore this phenomenon by conducting this cross-sectional study. For this purpose, cancer patients in various hospitals of Lahore and their caregivers (spouses, parents, siblings, others) were studied as target population and the findings revealed that care giving to the patients with cancer can be quite tough, profoundly impacting the psychological health of the caregivers. Findings of the current study will be helpful in adding valuable information in already existing literature and future researchers can explore this area more so that caregivers can be psycho-educated about strategies to reduce, prevent and even treat their mental health issues due to excessive burden experienced during caregiving.

The study revealed expected yet interesting results that there is significant positive relationship between burden of care and mental health of the caregivers of cancer patients. The burden of care and mental health of the female caregivers was significantly higher as compared to the male care givers. The type of grief of cancer patients is significantly related to the mental health and burden of the care of caregivers of cancer patients. There was positive relationship between burden of care and grief. There was significantly negative relationship between poor mental health among caregivers and grief among the cancer patients. Type of grief in cancer patients and caregivers' mental health are significant predictor of caregiver burden among caregivers of cancer patients.

It was hypothesized that there is significant relationship between burden of care and mental health of the caregivers of cancer patients that was found significantly positive in this study. In a similar study by Anjum, Rasheed, Haroon and Irfan (2010) on the caring burden in caregivers, 55% of the caregivers reported higher ratings in the general health questionnaire showing poor mental health and psychological well-being. Managing multiple caregiving tasks during the challenging time and ensuring the availability of excessive resources for treatment of cancer are most likely expected to lead to adverse physical and mental health effects on the caregivers. It might include a broad range, from mild irritation to drastic dysfunction, which can cause serious health concerns. Burn-out, physical exhaustion and mental and physical health deterioration may also include. Limitation of social life is mostly mentioned by the caregivers of moderately and severely impaired cancer patients.

The current study hypothesized that different types of grief in cancer patients are related to poor mental health and increased burden of care among the caregivers, the result indicated that there is significant positive relationship between types of grief (physical, emotional and cognitive), burden of care and poor mental health among the caregivers of cancer patients. It means that grief of undergoing the terminal illness among cancer patients resultantly worsens the caregiving burden and mental health of the caretakers. Relatives of cancer patients experience variety of emotions, from fear of loss and grief to guilt and wrath. They also have the feeling of being isolated and stigmatized like the patient (Lefley, 1987; Sobocki, et al., 2007). Caregivers are often bound to such family obligations which are far beyond those that normally relate to a family role at a given time, to the assumption of certain duties and responsibilities. When the care is prolonged (and it can last until one of the pair dies in many health conditions), problems can be exacerbated. Another challenge is that caregivers do not have an option (Kuipers, Paul, & Bebbington, 1998).

Research also found that the burden of care and mental health problem of the female caregivers was higher as compared to the male care givers but it was not significant. Previous researches support this finding as women, especially younger ones are more likely to perceive care as negative and burdensome than older men and report higher levels of psychological disorders, although care is provided or health levels are controlled (Blood et al. 1994; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). In comparison with other informal caregivers, the most vulnerable group of caregivers are women and partners.

Another aim of the present study was to identify the predictors among cancer patients' caregivers. Grief among cancer patients was assumed to be an important predictor of the burden of care and mental illness among the caregivers and the results supported the hypothesis. The burden of caregiving is basically the distress experienced by the caregivers which differs from depression, anxiety and other emotional responses (Ferrell & Mazanec, 2009). Patient’s characteristics as well as the caregiving environment including diagnostic and treatment procedures and care giving tasks influence the intensity of burden on the caregiver (Grassi, 2007). Older caregivers have distressed relationships with patients with anxiety and depression (Bakas, Lewis, & Parsons, 2001).

CONCLUSION

This study was conducted to assess grief among cancer patients as predictor of burden of care and mental health among their caregivers in different roles in Pakistan. The results showed that grief among cancer patients has negative effects on the caregivers’ mental, physical, and emotional health, hence adversely impacting their quality of life and psychological well-being. The mental health of female caregivers has been found to be more affected by the burden of care than men. Both the male and female groups revealed substantial gender differences in mental health problems. The intensity of care or caregiving hours, gender differences among the caregivers, types of caregiving tasks performed during the care process, relationship of both caregivers and patients, support and assistance from other family members, personal characteristics of caregivers, as well as the needs and obligations of caregivers in particular cultures can be the factors affecting caregiving and future researchers can do exploratory studies in this regard.

LIMITATIONS AND SUGGESTIONS

This study of 250 cancer patients and their caregivers was performed on a relatively small sample, researchers aim to conduct a future study on a larger sample, preferably covering more cities in Pakistan. There can also be a cross-cultural, comparable study to see differences in the care and mental health burden of patients with cancer in families. Further, the effectiveness of assistance and mental health interventions on caregiver adaptation and quality of life should also be analyzed in relation to present study variables in order to better meet the mental health needs of caregivers.

IMPLICATIONS

The study provides an insight into how the grief among the caregivers in Pakistani society impacts the mental health of the caregiver. These findings can help professionals in mental health to determine certain support and self-help strategies as intervention tools that can help caregivers to better manage their health and well- being. Furthermore, psychiatric assessment of both the patients and the caregivers is emphasized by understanding emotional problems, subjective complaints, and functional impairment which can help in developing effective therapeutic interventions. Current findings further motivate social support networks and encourage caregiver to use the helpful facilities for coping with patient care problems, adapting their roles, and alleviating isolation (by interacting with friends / neighbors, discussing issues / feelings that can help relieve the stress of caring for a person). Study findings are very important because they will contribute to the development of sufficient information in psychological education programs for elderly families to provide practical support. Last but not least, providing caregivers with social assistance will reduce the costs of using caregivers' homes.

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