

Stress and Hopelessness among Caregivers of Life Threatening Illnesses

Ansa Talib Dr Khalid Mahmood

Department of Applied Psychology, Government College University, Faisalabad, Pakistan

Abstract

The current study aimed to measure and stress and hopelessness among caregivers of life threatening illnesses. Purposive sampling technique was used and a sample consisted of 180(90 male & 90 female) caregivers of cancer and liver cirrhosis patients aged 17 to 60 years was taken from Liver Center DHQ and Cancer Center Allied Hospital. DASS Stress scale by Lovibond & Lovibond (1995) and Beck Hopelessness Scale by Beck (1993) was used. Pearson's product Moment Correlation and independent T. test were computed for the statistical analysis of the data. Findings indicate high level of stress and hopelessness among caregivers of low socio economic status as compare to high socio economic status caregivers of life threatening illnesses. Further this study find out that female caregivers experience high level of stress and hopelessness as compare to male caregivers of life threatening illnesses.

Keywords: Stress, Hopelessness, Caregivers, Life Threatening Illnesses, Pearson Product Moment Coefficient Correlation, Independent sample t-test.

Introduction

The present study was conducted to explore the level of stress and hopelessness among caregivers of life threatening illnesses. There is a paucity of studies that has examined the psychological impact of cancer on caregivers. This study will focus on psychological problems and assumed that high level of stress and hopelessness among caregivers of life threatening illnesses.

When an event or moment breaks one's sprits or one's ability function then a feeling associated with hopelessness, loss and sadness appears in one's life process and disturbed daily functioning. And these impairments have a clinical significance. (Elper, 2007).

Hopelessness means there is no hope, the feeling that has been destroyed or diminished and facing a dilemma that cannot be solved. It is subjective emotion which has a negative view point for the future and due to hopelessness one of losing control, confidence, courage and the energy to reach one's goal. Hopelessness can threaten a caregiver's physical as well as psychological health and it also affect the patient's process of recovery and rehabilitation. (Pan & Chiou, 2004).

Stress can be viewed as a response to a stimulus or as the stimulus itself but neither view is without problems. Different people experience different degrees of stress in relation to the same stimuli. These differences relate to ways in which people perceive or appraise events and to peoples coping styles, some of which are beneficial for health whereas others are not. People with structural social support have better health. (Davison, 2008).

The clinical manifestation of cancer are usually due to pressure effects of local tumor growth, infiltration or metastatic deposition of tumor cells in variety of organs in the body, or certain systemic symptoms. General problems observed in many patients with advanced or widespread metastatic cancer include anorexia, malaise and weight loss and sometimes fever. These characteristics must be considered when evaluating a patient with an undiagnosed illness. Except in the case of functioning tumors such as those of the endocrine glands systemic symptoms of cancer usually are not specific often consisting of weakness, anorexia and weight loss. (Albert, 2007).

A caregiver is typically a family member or friend who willingly sacrifices time, energy and, in some cases, their entire being to tend to the needs of a loved one. A caregiver as one who is prepared to be with the patient day and night, through thick and thin, providing anything and everything their care recipient needs. For most, that means "around the clock care". Many caregivers exist on little sleep and likely experiences physical, emotional and mental exhaustion over a prolonged period of time. They receive absolutely no compensation and little, if any, positive reinforcement from others. An illness that will cause premature death is called life threatening illness. The experience Cancer is a physical disease that threaten life and also a circumstance that has major psychological effects. Patients with cancer experience many stressors related to diagnosis, illness and treatment. Cancer affects the lives of the patients and also their families in different ways. The diagnosis and treatment of cancer changes patient's and caregivers personal life, and their daily activities, work, relationships, and family roles, and it also related to the high level of psychological stress in the patients and caregivers. The result of this stress is high level of hopelessness. (Karabulutlu, 2010).

Cirrhosis is the twelfth leading cause of death in the United States, is the end result of hepatocellular injury that leads to both fibrosis and nodular regeneration throughout the liver. Causes include chronic viral

hepatitis, alcohol, drug toxicity, autoimmune, metabolic liver diseases and miscellaneous disorders. Many patients have more than one risk factor (e.g., chronic hepatitis and alcohol use). The clinical features of cirrhosis result from hepatocyte dysfunction, porto systemic shunting and portal hypertension. Patients may have no symptoms for long periods. The onset of symptoms may be insidious or, less often, abrupt, weakness, fatigability, disturbed sleep, muscle cramps and weight loss are common. In advanced cirrhosis, anorexia is usually present and may be extreme, with associated nausea and occasional vomiting. Abdominal pain may be present and is related either to hepatic enlargement and stretching of Glisson Capsule or to the presence of ascites. (Arvaniti, 2010).

Only a century ago death was common at every age and dying usually quickly followed on the set of disease or injury. Now public health measure and health care prevent or cure many previously fatal illnesses or injuries, allowing most people to live into old age medications and treatment now often allow prolonged survival with serious chronic conditions. An important group of chronic condition consists of those that typically worsen and eventually cause death (e.g. cancer, chronic heart disease, lungs, liver etc). (Baravelli, 2009).

Literature Review

Petrie, (2001) conducted a study on gender differences on stress and hopelessness in caregiver spouses of people with cancer in Pakistan revealed that female caregiver spouses manifested more stress and hopelessness than males. It was found that caring for patients worsened health, impaired social and family life and increased stress and hopelessness among caregivers. The reasons behind these results might be, female spent more time with their loved ones than male in every society. Female also play a vital role in patient's illness phase. Besides it female's sex (woman)also has a great impact on these results because female's tend to be more emotional and sensitive towards their relationship with their parents, friends, children and siblings in global researches than male.

Bart (2006) conducted a study on caregivers stress and hopelessness. Results showed that female caregivers took an added responsibilities for assisting with activities of daily living, such as bathing and feeding, and instrumental activities of daily living, such as shopping, managing the household finances after hospitalization. Female caregivers also performed nursing duties, such as changing dressing and administering medications. In other studies performed by Lillius (2006), the female caregivers were detected to undergo changes in the family processes, they had to make changes in the individual programs and they had some difficulties for those reasons. All these responsibilities create stress and hopelessness among female caregivers.

Wheaton, (1993), conducted a study on gender differences on level of stress and hopelessness among caregivers. Results showed that women are most distress by stressors that involve social and family relationships, whereas men feel distressed mostly because of work and financial events. Caregiving for a loved one can be very rewarding, but it also involves many stressors. Changings in the family dynamics, household disruption, financial pressure and the added work load.

Pinquart, (2005),conducted a study on caregivers financial hardships. Results showed that caregiver's financial hardship was significantly associated with BHS scores. Limited financial resources placed low socio economic status caregivers at risk for strain or hopelessness. This result made them think that the caregiver with low economic levels has problems in accessing the treatment and social opportunities affected the treatment process in a negative way.

Pinquart, (2001) conducted a research to measure of psychological wellbeing such as hopelessness and stress, have been the most frequently studied consequences of caregiving. This research has consistently shown relatively large effects which are moderated by age, gender, socioeconomic status and those with limited support networks report poorer psychological and physical health than caregivers who have more economical and interpersonal resources.

Objectives

- To find out the difference of stress and hopelessness among male and female caregivers of cancer and liver cirrhosis patients.
- To find out the difference of stress and hopelessness among low socio economic status caregivers and high socio economic status caregivers of cancer and liver cirrhosis patients.

Hypotheses

1. There would be a significant difference on stress score between male and female caregivers of life threatening illnesses.
2. There would be a significant difference on hopelessness score between male and female caregivers of life threatening illnesses.
3. High socio economic status caregivers would have low level of hopelessness as compare to low socio economic status caregivers of life threatening illnesses.

4. High socioeconomic status caregivers would have low level of stress as compare to low socio economic status caregivers of life threatening illnesses.

Method

Participants

A sample consisted of (N=180) caregivers of life threatening illnesses was taken for the current study from DHQ and Allied hospital Faisalabad. The sample was further divided into (n=90)male and (n=90) female. The age range of participants taken was from 17 to 60 years. The minimum education of participants was matric.

Research Design and Sampling Strategy

Correlational and comparative group design were used for the current study. Purposive sampling technique was used to select the sample.

Inclusion and Exclusion Criteria

180 caregivers of cancer and liver cirrhosis patients were included in the sample. Married and unmarried both caregivers were included in the sample. Caregivers who were caring for other diseases were not included in the sample. Caregivers who were below age of 17 or above 60 were also not included in the sample.

Instruments

The following instruments were used to assess the level of stress and hopelessness among caregivers of life threatening illnesses.

Depression Stress Anxiety Scale (DASS)

The Depression Stress Anxiety Scale (DASS) by Lovibond & Lovibond (1995) was used to assess the level of stress among caregivers of life threatening illnesses. It has 42 items, and three sub scales of depression, anxiety and stress. Each scale consist of 14 items, each reflecting a negative emotional symptom. Each of these rated on a four-point Likert scale of severity of the participant's experience over the previous week with the intention of emphasizing states over traits.

All the items of DASS are designed to measure the symptoms of depression, anxiety and stress among participants. All DASS items took five to ten minutes for completion. This scale is made up for adult population. This scale allowed to measure the severity of a participant's symptoms of depression, anxiety and stress. The DASS stress scale assessed different symptoms of stress, i.e. worthlessness feeling, upset, etc, and it assessed the difficulty in relaxing, nervous arousal, agitation, upsetting, impatient and over reaction. Stress scale of DASS has 14 items, So the minimum score could be 0 and maximum score could be 34+

In the present research, translated Urdu version of depression, anxiety and stress (DASS)by Maria Habib was used to assess the stress level of the caregivers of life threatening illnesses. The coefficient alpha value of the instrument was $\alpha=.93$.

Beck Hopelessness Scale (BHS)

Beck Hopelessness Scale (BHS) was developed by Dr. Aaron T. Beck in 1978. The questionnaire BHS consists of 20 items. The Beck hopelessness scale measures negative attitude about future. The beck hopelessness scale takes approximately 5-10 minutes to administer. It is appropriate for person aged 17 years & adults. The beck hopelessness scale can be administered individually or in a group. The coefficient correlation of the instrument was .57 and internal consistency was satisfactory (Cronback's $\alpha=.88$).

BHS is appropriate in clinical, medical and research settings. In psycho-diagnostics, it can assess client's feelings of hopelessness about future, pessimistic attitude about the world and depressed feelings. It can be applied to map out the areas that need future exploration in the assessment process as well as to help determine the overall need for therapy.

Procedure

Sample was selected through purposive sampling technique from Liver center DHQ and Cancer center Allied Hospital Faisalabad. Informed consent was obtained from the administration and the respondents. The ethical standards of research were considered as the participants were given a brief description about the research and were insured that information will be kept confidential. The demographic information about the variables such as age, gender, education and socio economic status was gathered. Depression, Anxiety, stress Scale and Beck Hopelessness Scale were used to measure the variables of stress and hopelessness in the study.

Statistical Analysis

Pearson product moment correlation and Comparative group design T-test was used for the statistical analysis of the data all the way through Statistical Package for Social Sciences (SPSS).

Results

Table 1

Gender difference in stress score among caregivers. (N=180)

Difference between male (n = 90) and female (n = 90) caregivers of life threatening illnesses for their score of stress on stress sub scale of DASS.

Variables	Gender	M	S.D	t	p-value
Stress	Male	38.84	11.77	- 6.004*	0.000
	Female	36.61	3.46		

$df = 178, *P < 0.05$

Result shows significant difference in the mean score of stress between male and female caregivers of life threatening illnesses $t (-6.004^*)$, $P < 0.05$ that is significant. The hypothesis is accepted. Table 2

Gender difference in hopelessness score among caregivers. (N=180)

Difference between male (n = 90) and female (n = 90) caregivers of life threatening illnesses for their score of hopelessness on BHS.

Variables	Gender	M	S.D	t	p-value
Hopelessness	Male	12.60	3.99	-3.30***	0.036
	Female	14.40	3.28		

$df = 178, ***P < 0.05$

Result significant difference in the mean score of hopelessness between male and female caregivers of life threatening illnesses $t (-3.30)$, $P < 0.05$ that is significant. The hypothesis is accepted.

Table 3

Difference in stress score among upper class and lower class caregivers. (N=180)

Difference between upper class (n = 90) and lower class (n = 90) caregivers of life threatening illnesses for their score of hopelessness on BHS.

Variable	SES	M	S.D	t	p-value
Hopelessness	U.C	15.95	4.94	-2.522	0.000
	L.C	14.10	3.98		

$df = 178, **P < 0.01$

Result shows significant difference in the mean score of hopelessness between upper class and lower class caregivers of life threatening illnesses $t (-2.522)$, $P < 0.01$ that is significant. The hypothesis is accepted.

Table 4 Difference in hopelessness score among upper class and lower class caregivers. (N=180)

Difference between upper class (n = 90) and lower class (n = 90) caregivers of life threatening illnesses for their score of stress on stress sub scale of DASS.

Variable	SES	M	S.D	t	p-value
Stress	U.C	23.54	9.46	2.37*	0.001
	L.C	30.89	8.07		

$df = 178, *P < 0.01$

Result shows significant difference in the mean score of hopelessness between upper class and lower class caregivers of life threatening illnesses $t (2.37)$, $P < 0.01$ that is significant. The hypothesis is accepted

Discussion

Hypotheses 1; The findings show that there is a significant difference among male and female caregivers in stress scores. Results show that female caregivers have high level of stress than male caregivers of life

threatening illnesses. Furthermore it has been observed that male caregivers were optimistic and physically and psychologically less fatigued as compared to female caregivers. Men are considered more dominant in Pakistani society that's why they show themselves stronger and emotionally stable as compared to women. The reason might be that they have responsibilities to earn and to run whole family. It has also been observed that male have more social support and have less expressive in their emotions but, they are sensitive about their relationships. This hypotheses is supported by a study by Canning (1996) that women react to caregiving with a greater tendency to become depressed, distressed and to feel burden by caregiving. This has been attributed to women experiencing more caregiving stressors, such as higher social expectations and lower social support for women than men. These all facts support the results of current study that female caregivers have high level of stress than male caregivers.

Hypotheses 2; The findings support the hypothesis and significant difference was found on hopelessness score among male and female caregivers. It has been observed that in Pakistani society female have to suffer a lot of problems than male. There are little opportunities of emotional expression for female in a society like Pakistan as compare to male. Moreover life threatening illnesses treatment is costly and prolonged. Prolong treatment but low rate of recovery develops feelings of hopelessness among female caregivers. Pakistan is an underdeveloped country, in this respect, no proper programmes for psychological and mental health of caregivers are provided to educate and make them aware about the treatment, recovery and even financial aid. All these factors created high level of hopelessness among caregivers.

Hypothesis 3; The findings support the hypothesis as there is a significant difference on the hopelessness score among high socio economic status caregivers and low socio economic status caregivers. These findings indicate that low socio economic status caregivers experience more psychological distress and hopelessness as compare to high socio economic status caregivers. This hypothesis is supported by a study by Nijboer (1998), found that individuals of lower socio economic status may experience the increased burden of financial strain due to the expenses involved in cancer care. This may cause them to experience more psychological distress and hopelessness from cancer caregiving than other caregivers. It has been observed that family members confronting serious illness have been found to experience more distress as compare to any other disease. This distress arises from the caregiving role itself as well as witnessing the patient's suffering. Moreover the financial impact and hidden cost of cancer and liver cirrhosis may affect caregiver's burden. All these factors caused increased stress and other psychological problems among low socio economic status caregivers of life threatening illnesses.

Hypothesis 4; The findings support the hypothesis as there is significant difference on the stress score among high socio economic status caregivers and low socio economic status caregivers. These findings indicate that low socio economic status caregivers experience high level of stress as compare to high socio economic status caregivers. This hypothesis is supported by a study by Memmott,(1999) conducted a research to measure stress level of caregivers and emotional status. He stated that low socio economic status has affected most families, including those who are caregiving. Caregivers of cancer and liver patients reported a moderate to high degree of financial hardships as a result of caregiving. Increased burden of chemotherapies increased stress among caregivers of low socio economic status. Furthermore Pakistan is a developing country where mostly people are living with financial hardships. Due to inflation everything is very costly including treatment of chronic illness. Good health facilities are not available for all citizens. Diagnosis of cancer or liver disease is an event for stress and hopelessness. Stress can be observed clearly among low socio economic status caregivers from an imbalance between care demands and the availability of resources to meet these demands.

Conclusion

The present study concludes with the evidence that a significant gender difference was found on stress and hopelessness score among caregivers of life threatening illnesses. Female caregivers feel high level of stress and hopelessness as compare to male caregivers. Furthermore, it has been found that low socio economic status caregivers showed more stress and hopelessness than highly socio economic status.

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