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Psychological well-being and psychological distress of patients suffering from chronic illnesses

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Abstract

When demands placed by patient's chronic health condition exceed caregiver's capability, it leads to emotional distress in caregiver. The caregiver's psychological wellbeing is negatively affected. The attitude and behavior of caregiver can lead to emotional distress in the patient. This in turn may have negative impact on patient's psychological well-being. The present study seeks to understand the level of relation between psychological well-being of patients and their caregivers. It also attempts to identify the factors that lead to increase in emotional stress and reduction in psychological well-being of patient and caregiver dyad. Also, the study endeavors to find ways to reduce stress and enhance wellbeing of patient and caregiver. Finally, the study discusses suggestions about measures that can be adopted by caregivers and patients collaboratively to reduce stress and depression.

Keywords: Psychological well-being, chronic illness, psychological distress, emotional stress

Introduction

Distress is often described in terms of suffering, hopelessness, loss of faith in God, loss of sense of meaning, inability to connect with others, and reduction in quality of life. Overall, it is estimated that 20 per cent of people with long-term physical conditions are likely to suffer from depression, with depression and anxiety being two to three times more common than in the general population. Caregivers are expected to provide complex care to these patients. This subjects them to stress which may have negative impact on their psychological wellbeing. The caregivers may experience anxiety, depression, helplessness, loss of control and consider their care giving role as a huge burden. When caregivers undergo high distress, their immunity system may get disturbed, the glucose levels in the body go out of control, and cardiovascular risks may also increase. When caregivers are distressed and fail to provide optimal care, the patient also may undergo stress.

Psychological distress in patients with chronic illness, especially in advanced stage tends to be under-diagnosed and under-treated. It affects patient's psychological well-being, social functioning and emotional wellbeing. The importance of proper recognition and treatment of psychological distress of these patients cannot be overstated.

Concept of Psychological Well-Being

According to the World Health Organization, health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" and mental health is "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community."

According to Diener and Emmons (1984) [8] in the field of psychology, much attention had been given to human unhappiness and suffering than to the causes and consequences of positive functioning. According to Huppert (2009) [9] -"Psychological well-being is about lives going well. It is the combination of feeling good and functioning effectively." People with high PWB report feeling happy, capable, well-supported, satisfied with life, and so on. According to Deci & Ryan (2008) [10], psychological well-being is defined as combination of positive affective states such as happiness (the hedonic perspective) and functioning with optimal effectiveness in individual and social life (the eudaimonic perspective). The hedonic approach focuses on happiness and defines well-being in terms of pleasure attainment and pain avoidance. According to Eudaimonic view, well-being consists of more than just happiness. It lies instead in the actualization of human potentials.

Chronic Illnesses

A chronic condition is a health condition where an individual suffers from illness for a long period of time, usually more than 6 months. Chronic illnesses include asthma, Alzheimer's disease, parkinson's disease, arthiritis, renal failure, cardiovascular diseases, cerebrovascular diseases, Diabetes, Cancer, HIV, etc. The risk factors include social factors like education, life style, socio-economic status, etc. Lack of access and delay in receiving care can result in worse outcomes for patients suffering from chronic illnesses. There are many people who are living with two or more chronic conditions. The most common chronic conditions that are observed in the elderly are high blood pressure, arthritis, diabetes, coronary heart disease and cancer.

Sources of Distress

Distress is a condition where an individual may experience feelings like sadness, hopelessness, powerlessness, fear, guilt, anxiety, depression and uncertainty. Distress is common in people suffering from chronic illness and in their family members. In pre-diagnosis phase, when patient and his/her beloved ones are waiting for test results, they undergo serious distress. After the test when the disease is diagnosed, patient and family members go into depression thinking why this should happen to us? When treatment starts, the frequent visits to doctor and the side effects of the treatment disturb the daily routine of patient and family members making them feel miserable and depressed. A certain level of distress is normal but when the level reaches too high, it should be considered serious. Some symptoms of abnormal level of distress is unusual irritation, poor concentration, sudden memory problems, thinking about disease and death all the time, loss of appetite, inability to sleep, feeling worthless and useless. If these symptoms are seen in either patient or caregiver, there is need for other family members to immediately seek professional help to reduce their distress.

While in pre-diagnosis phase, awareness about family history of cancer, unfavorable results from genetic testing, worry about future risk can be major source of distress. In diagnosis phase, unmet psychosocial, medical, financial and informational needs, uncertainty about the ways to address patient's emotional concerns, multiple role demands of household work and care giving, feeling of being helpless become sources of distress. In treatment phase, worry about effectiveness of treatment, difficulty in managing side effects of treatment, no support from other family members, social isolation, etc., can be sources of distress. In survivorship phase, fear of recurrence, physical and mental drain out, weakness and family conflicts are the most observed issues causing distress in patient and caregiver. In recurrence phase, increased uncertainty and hopelessness, perceived life threat, decreasing energy levels and lack of support from others act as a source of distress. In advanced stage, high symptom distress in patient, feeling of abandonment, financial burden, lack of family and community support and poor self-care often lead to high distress in patient and caregiver.

Literature Review

Hodges *et al* conducted a meta-analysis of previous studies on Psychological Well-being with a combined sample of 1098 patient-caretaker pairs to determine the relationship between the distress experienced by patient and caregivers. The researchers found a moderate, significant relationship between their distress scores where correlation (r) was 0.35 and $p < 0.0001$. This indicates that patient and caregivers have moderate influence on each other. That is when caregiver is distressed, the patient is also distressed and when patient is distressed, the caregiver is also distressed. Hagedoorn *et al* conducted meta-analysis of 46 studies that investigated the distress in 2,468 couples coping with spouse's cancer condition. The researchers found that there was significant correlation between level of distress of patient and his/her caregiving spouse. It was observed that both patient and caregiver experienced same levels of distress in various phases of disease including diagnosis, treatment, recurrence and advancement of disease. It was observed that caregiver experienced more distress during treatment phase when physical and emotional demands of patient receiving treatment are high. The level of distress reported by patient-caregiver couple facing cancer was high compared to couples facing other illnesses. Female patients and Female caregivers experienced more distress than their male counterparts.

Nakanishi *et al* investigated factors that influence psychological distress of caregivers and family members of cancer patients. He found that the psychological distress of family members increases when the patient is not informed about the cancer diagnosis, when the cancer is recurrent or advanced, and when the family member has a history of a psychiatric disorder. Matthews *et al*. found in their research that the important factors that lead to caregivers' distress include deprivation of feeling of togetherness, greater number of patient care needs and pessimistic expectations. A high degree of dependency of the patient as a consequence of the disease also increases the relatives' distress. The need for performing specific tasks like feeding the patient and helping with personal hygiene regularly have a higher impact on the caregiver's distress. The disturbances in lifestyle, education and career of caregivers also lead to emotional distress.

Alacacıoğlu *et al*. (2010) conducted a study where they measured the depression and anxiety levels and examined the correlation with quality of life. They concluded that depressed cancer patients experienced more physical problems than cancer patients who were not depressed. Isikhan *et al*. (2001) studied the relationship between quality of life in patients with cancer and treatment, early diagnosis, disease acceptance, pain, psychological distress, loss of organ, duration of disease, and caregivers. They found that cancer patients who were diagnosed with a later stage cancer experienced a worsened quality of life, than cancer patients who were diagnosed with early stage cancer.

Objectives

- To study the concept of Psychological well-being and to present the sources of emotional stress
- To find the level of emotional stress experienced by patients and his/her caregiver suffering from chronic illness in sample hospitals.
- To suggest measures to reduce emotional stress

Research Methodology

A sample of 400 patients suffering with various chronic illnesses from three hospitals and their caregivers in Hyderabad were administered questionnaire. 390 patient and caregiver pairs responded to the questionnaire and finally 373 questionnaires were found fit for final analysis. Hence 373 response sheets were taken for analysis. Telephone interviews were taken from patients who could not write the answers to questions. Standard questionnaire for Psychological distress and well-being were used for collecting information. Kessler psychological distress scale (k10) was used to assess the distress level of patients and caregivers. Similarly, the Ryff scales were used to measure the psychological well-being of patients and caregivers. Internal reliability was tested using Cronbach's alpha. Pearson correlation was used to determine the direction and strength of the linear association between the scales. The mean scores for each demographic characteristic were calculated. Significant differences were assessed using T-tests and one-way ANOVA was used to test for significant differences between groups. All post hoc comparisons were conducted using the Scheffe test.

Data Analysis

The data was analyzed using statistical techniques like t-test, ANOVA and correlation coefficient Statistical analysis was done using IBMSPSS18 version.

Table 1: Descriptive Statistics

Sociodemographic variables							
		N	%			N	%
Gender	Female Male	252 121	67.5 32.5	**Marital staus**	Married Unmarried	225 148	60.32 39.68
Age	0-30	35	9.5	**Monthly income**	0-10000	48	12.8
	31-40	47	12.9		10000-30000	142	38.0
	41-50	104	27.2		30000-50000	82	22.0
	51-60	105	27.8		50000-100000	56	15.0
	61-70	82	22.6		>100000	45	12.0
Education	Primary	22	5.90	**Occupation**	Employed	215	57.64
	Secondary	175	46.9		Unemployed	158	42.36
	Graduate	134	35.9				
	PG	42	11.26				

Out of the total sample of 373 patients, 67.5% are females and 32.5% are males. 9.5% of patients are in 0-30 age group, 12.9% are in 31-40 age group, 27.2% are in 41-50 age group, 27.8% are in 51-60 age group, 22.6% are in 61-70 age group. 5.9% of patients had only primary education. 46.9% had completed secondary education. 35.9% had graduation. 11.26% had PG qualification. 60.32% were married, 39.68% were unmarried. 12.8% of patients earned below Rs.10000. 38% earned upto Rs.30000. 22% earned upto Rs50000. 15% earned upto Rs.100000. 12% earned more than 100000. 57.64% were employed and 42.36 were not employed. (Refer Table 1)

Table 2: Independent samples test for PWB of female and male care takers

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Psychological Well-being	Equal variances assumed	.272	.602	.027	1475	.978	.00299	.11067	-.21410	.22008
	Equal variances not assumed			.029	69.844	.977	.00299	.10302	-.20249	.20848

When equal variances are assumed, t value is 0.027. The significance value is 0.602. A P-value of 0.6 would mean that there is a 0.6 (or 60%) chance that the two sets of values come from the same group. In other words, there is a 60% chance that the psychological well-being of male and female nurses is the same. Therefore, there is no significant difference in psychological wellbeing of male and female care takers in hospitals.

When equal variances are assumed, t value is -22.8. When equal variances are not assumed, t value is -17.7. The significance value p is <0.05. Therefore, there is significant difference in psychological wellbeing of single and married caretakers.

Therefore, there is no statistically significant evidence to support the hypothesis which states that there is no significant difference in psychological wellbeing of caretakers with respect to their marital status. And it is observed that psychological well-being of married caretakers is higher than that of caretakers who were single. Hence, there is significant difference in psychological wellbeing of caretakers with respect to their marital status (Refer Table 3).

Table 3: Independent samples test for PWB of married and unmarried care takers

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Psychological Well-being	Equal variances assumed	263.216	.000	-22.806	1475	.000	-1.04642	.04588	-1.13642	-.95642
	Equal variances not assumed			-17.699	420.560	.000	-1.04642	.05912	-1.16264	-.93020

Correlation between Psychological wellbeing of patients and caretakers

There is high correlation between (0.896) psychological well-being of patients and caretakers. If patients are feeling happy and satisfied with their life, behave normally with others then the caretakers feel less burdened. They do not need to make efforts to uplift the spirit of patients. Therefore, the psychological wellbeing of caretakers is also high (Refer Table 4).

Correlation between Psychological distress of patients and caretakers

There is high correlation (0.87) between psychological distress of patients and caretakers, i.e, if patients are highly distressed with their disease symptoms, the impact will be experienced by their caretakers as well. This may in turn effect the quality of service offered by caretakers to patients (Refer Table 5).

Table 4: Correlations

				PWB caretkr	PWB patient
PWB caretkr	Pearson Correlation			1	.896**
	Sig. (2-tailed)				.000
	N			373	373
	Bootstrap[b]	Bias		0	.001
		Std. Error		0	.007
		95% Confidence Interval	Lower	1	.882
			Upper	1	.909
PWB patient	Pearson Correlation			.896**	1
	Sig. (2-tailed)			.000	
	N			373	373
	Bootstrap[b]	Bias		.001	0
		Std. Error		.007	0
		95% Confidence Interval	Lower	.882	1
			Upper	.909	1

**. Correlation is significant at the 0.01 level (2-tailed).

b. Unless otherwise noted, bootstrap results are based on 373 bootstrap samples

Table 5: Correlations

				PD pat	PD caret
PD pat	Pearson Correlation			1	.872**
	Sig. (2-tailed)				.000
	N			373	373
	Bootstrap[b]	Bias		0	-.001
		Std. Error		0	.012
		95% Confidence Interval	Lower	1	.844
			Upper	1	.892
PD caret	Pearson Correlation			.872**	1
	Sig. (2-tailed)			.000	
	N			373	373
	Bootstrap[b]	Bias		-.001	0
		Std. Error		.012	0
		95% Confidence Interval	Lower	.844	1
			Upper	.892	1

**. Correlation is significant at the 0.01 level (2-tailed).

ib. Unless otherwise noted, bootstrap results are based on 373 bootstrap samples

Findings

The following are the findings from analysis of data collected from patients and caretakers:

Psychological distress of patients and caretakers

Patients with chronic illness and nearing death often experience distress that may not be easily measured using regular scales and instruments. Even mild distress can play an important role in shaping the emotional experience of patients in the last weeks of life. The sources of distress in terminally-ill patients included feeling of sense of dependency (38%), meaninglessness in present life (36%), hopelessness (35%), feeling a burden to others (34%), loss of social role functioning (28%), and feeling emotionally irrelevant (26%). Similarly, 51% of patients struggled with issues related to overcoming fears, finding hope (42%), and meaning in life (40%). Thus, finding ways of tracking and measuring distress of patients with chronic illness, especially, in end of life stage is vital to improve their quality of life.

There was significant difference in mean score between genders for the Psychological distress scales. Female patients and female care givers experienced more distress than male patients and male caregivers. There was no significant difference in mean scores for psychological distress of women patients and caregivers living in a household with one or more children and that of women patients having no children (t = -0.367, p >0.0001).

There was no significant difference in psychological distress experienced by people in different age groups (p= 0.17). There was a significant difference in the mean scores (F = 5.51, p = 0.004) for psychological distress of patients and caretakers who were the only adults in the household and those who were not the only adults. In patients and caretakers who were the only adults in the household, the psychological distress was high.

There was no significant difference in patients and caretakers residing in different areas of residence (p=0.07). There was significant difference in the mean scores for patients and caretakers who were married and who were unmarried (F=5.92), p < 0.001). Post hoc comparisons found that married respondents showed lower distress compared to unmarried respondents. Work status demonstrated a significant effect on respondent's mean score for distress. There was significant difference in mean scores for respondents who were employed but were unable to attend work compared to those respondents who were retired/homemakers (F = 20.53, p < 0.001). Respondent's who were employed but unable to attend duties exhibited higher distress compared to respondents who were retired/homemakers.

Individuals scoring higher on the spiritual measure were less depressed. The relationship between spiritual well-being, depression, and end-of-life despair was assessed. The study demonstrated significant negative correlation between spiritual well-being and desire for early death ($r = -0.51$, $p<0.0001$), hopelessness ($r = -0.68$, $p<0.0001$), and suicidal thoughts ($r = -0.41$, $p<0.0001$). Thus, it indicates that spiritual wellbeing helps patients and caregivers overcome emotional distress.

There was a significant difference in the mean scores for distress of patients and caretakers with different income levels ($F = 10.89$, $p < 0.001$). The respondents with higher income reported lesser distress than respondents with lower income.

It was observed that patients who attended psychological intervention training session experienced less anxiety and depression compared to patients who did not attend the training session.

Psychological well-being of patients and caretakers

There is significant difference in the psychological well-being of female and male patients and caretakers ($p>0.001$). The mean scores for psychological well-being of female patients and caretakers are higher than the mean scores for male patients and caretakers. There is significant difference in the psychological well-being of old and young patients and caretakers ($p>0.001$). Patients and caretakers aged 18 to 25 years had a significantly higher mean score compared to those aged 50 and above. There is significant difference in the psychological well-being of patients and caretakers who were the only adults and those who had other adults in the household ($p>0.001$). The mean scores for psychological well-being of patients and caretakers who had other adults in the household were higher than the patients and caretakers who were the only adults in the household.

There was significant difference in psychological well-being of patients and caretakers who lived in different areas ($p>0.001$). The mean scores for patients and caretakers who lived in metropolitan areas were higher than patients and caretakers who lived in rural areas. There was significant difference in the psychological well-being of patients and caretakers who had children in household and that of patients and caretakers who had no children in the household. The mean scores for psychological well-being of patients and caretakers who had children in household was more than that of patients and caretakers who had no children in the household.

There is significant difference in the psychological well-being of patients and caretakers who were married and that of patients and caretakers who were not married. Post hoc comparisons found that the psychological well-being of patients and caretakers who were married and staying together was more than that of patients and care takers who were separated/ divorced. Level of education also had a significant effect on psychological well-being of patients and caretakers ($p < 0.001$.) Respondents with a bachelor degree or higher qualification scored significantly higher in psychological well-being than those who were having lesser qualification. Work status also demonstrated a significant effect on psychological wellbeing score of respondents ($p < 0.001$). Respondents who were unable to work due to disability/incapacity had a significantly lower score for psychological well-being than respondents who were employed full time, part time, undertook home duties, were a student or retired. There was a significant difference in the mean psychological well-being score depending on level of income ($p < 0.001$). Post hoc comparisons demonstrated that respondents reporting an income of up to Rs 15,000 had a significantly lower mean score than respondents earning Rs 40,000 and above.

Relation between psychological well-being and psychological distress of patients and caretakers

Using Pearson's correlation coefficient, a significant negative correlation was found between psychological well-being scores and psychological distress scores of patients and care takers. Respondents who demonstrated higher levels of psychological wellbeing scored less on psychological distress scale and respondents who demonstrated higher levels of psychological distress scored less on psychological wellbeing scale.

Relation between psychological distress of patients and that of caretakers

There is significant relationship between the psychological distress scores of patients with chronic illness and their caretakers where correlation (r) was 0.87 and $p < 0.0001$. This indicates that if patient undergoes high psychological distress that will lead to increase in psychological distress level of caregiver. Hence, it indicates that patient's psychological distress level should be monitored closely and regulated to avoid the influence on caregiver.

Suggestions

The application of basic communication techniques enhances detection of patients' emotional concerns. Training oncologists and nurses in patient-centered consulting techniques can go a long way in improving the psychological well-being of patients with chronic illness. Physicians, specialist doctors, dieticians, psychologists and nurses should form a team to educate patient about the disease, treatment being given, its impact on body and the ways to cope with the effect of treatment on body. This may be referred to as Level 1 intervention where patient is given coaching in self-management. Levels 2 interventions include training patient in cognitive behavioral stress management, cognitive behavioural therapy (CBT), antidepressant therapy, blood glucose awareness training. Level 3 interventions include group psychotherapy, group CBT, integrated inpatient therapy involving behavioural training and family therapy, biostatistics awareness training and psycho-education with attention to disease specific concerns.

Nurses, especially who are in continuous contact with patients and caretakers throughout the period of treatment should listen to the problems expressed by patient and caretaker dyad. Nurses can help them understand the similar problems being faced by other patients and caretakers and the techniques being adopted by them to overcome those problems. Nurses should be empathetic listeners to the problems of patient and caretaker dyad and patiently explain the need for attending psychological interventions and the way they can practice the interventions at home to overcome their psychological distress.

Conclusion

Psychological distress of patients with chronic illness should not be ignored. Patients may express verbally or non-verbally about their emotional state. However, many patients do not reveal their emotional concerns as they believe that doctor's role is only to treat the disease and not to offer counseling services. Moreover, some patients are able to overcome their feelings over a period of time. Anxiety and depression of patients may be concealed behind physical symptoms of disease like weakness, fatigue, loss of appetite and go unnoticed by caregivers and family members. Caregivers have to give careful attention to patient's behavior, statements, ask open questions and console them and inspire confidence in themselves. By administering screening tools for detecting psychological distress of patients prior to the consultation, doctor and nurse team can help caretakers manage their distress level.

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