



EFFECTIVENESS OF THERAPEUTIC INTERVENTION FOR PSYCHOLOGICAL WELL BEING AMONG CARETAKERS OF CANCER PATIENTS

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Abstract:

Coping with a loved one's terminal illness may be one of the hardest challenges that one can face in life. Cancer makes a person unable to perform his/her own chores and his/her work usually falls on the shoulders of immediate family member. For this family member will have to work extra and taking on the responsibility of caring may become overwhelming leading to feeling of frustration and resentment. Caregivers feel intense amount of emotions like anxiety, depression, nervousness, sadness, fear, restlessness etc. Cognitive Behavior Therapy has proved to be effective in treating depressive patients, whether can be used for caretakers of persons with Cancer has been one of the fundamental questions in this research. Aim: To experiment the efficacy of Cognitive Behavior Therapy in improving the Psychological Quality of Life among caretakers of persons with Cancer. Methods: One hundred and twenty caretakers of newly diagnosed Cancer persons were recruited for study. These were randomized into controls (n=60) and experimental (n=60) groups. Cases and controls were screened to know the level of Quality of Life in Psychological domain administering the WHOQOL - BREF (WHO 1991). Experimental group received a structured Cognitive Behavior Therapy intervention which focused on two components- Cognitive restructuring and problem solving. Intervention was on individual basis which lasted for four months on the basis of one session for 15 days. Control group did not receive therapeutic intervention but on ethical ground they were provided with informational support. Post intervention test was done administering the WHOQOL- BREF to measure the effectiveness of the interventions and the results were compared between controls and cases. Results: Results sample 't' test showed that after going through Cognitive Behavior Therapy experimental group had positive results as their psychological domain of Quality of Life improved significantly. Findings suggest that individual sessions of Cognitive Behavior Therapy for caretakers can be successfully delivered to improve the Psychological well-being.

Index Terms: Cancer, Caretaker, Cognitive Behavior Therapy & Quality of Life

1. Introduction

In Indian traditional families, each member is responsible for specific tasks or chores. Likewise caring for a terminally ill is also generally a family responsibility. Coping with a loved one's terminal illness may be one of the hardest challenges that one can face in life. A diagnosis of Cancer changes the family forever. Cancer makes a person unable to perform his/her own chores and his/her work usually falls on the shoulders of immediate family member. For this family member will have to work extra and taking on the responsibility of caring may become overwhelming and leads to feeling of frustration and resentment. Day to day responsibility becomes more demanding and life can be more traumatic. Care taking is an exhausting task and caretakers are reported to experience a significant amount of strain. They supervise the medication intake, and provide emotional, social and financial support for the affected member. In addition to it watching the declining health of the loved one makes dealing with terminal illness

difficult and adds to the emotional devastation. Therefore, Cancer is often identified as a family disease because of its impact on the family functioning and relationship (Smith Nick 1990).

Cancer diagnosis has proven to be disrupting physical, psychological, social and spiritual wellbeing of both patients and caretakers. Health professionals so far have been giving more preference to psychological well being of patients but primary and informal caretakers' well-being was seldom spoken or considered in Cancer care. Off late it is realized that this population suffers equal to patients of Cancer. Therefore recently Quality of Life is considered as an issue of psychological importance. In general Quality of Life means both positive and negative aspects of life or well being of a person. World Health Organization defines Quality of Life as individual's perception of their position in life in the context of culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It's a broad ranging concept affected in complex way by the persons physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Hileman, Lackey and Hassanien (1992) identified six needs of caretakers of Cancer patients; Psychological, informational, patient care, personal, spiritual and household. Among these greatest needs were informational and psychological. The diagnosis revealed to the patient and family members results in overwhelming number of intense emotions. Caregivers feel intense amount of emotions like anxiety, depression, nervousness, sadness, fear, restlessness etc. Few studies have demonstrated the psychological burden encountered by the caregivers. Haley, W.E., et al., (2001) found more depression in Cancer caregivers than in general population.

The psychological domain of Quality of Life is measured by a six facets. Caretakers countless number of hours are spent in meeting the needs and looking after a loved family member. This exhausting task can change the appearances of the caretaker in the form of weight loss, dark circles around the eyes, poor grooming and so on. Hence the caretakers view on ones own body image; whether they are able to accept the changes or not is assessed. Negative feelings like guilt, stress, helplessness, irritability, fear, anger, nervousness is generally the outcome of being a caretaker and seeing a loved one suffering. Therefore secondly the impact of such negative feeling on caretakers day to day life is assessed. Thirdly the extent of positive feeling experienced by care taker's are measured. Some caretakers are genuinely motivated to look after a person, because they do it with greater sense of meaning and duty. Lower scores in this facet indicate the poor psychological wellbeing. Fourth one examines the self esteem from caretakers perception. That is his/her worthiness, satisfaction with self. This is followed by assessing individuals spirituality and personal beliefs. Spirituality provides a sense of meaning, purpose of what one is doing. Suffering, pains are given a meaning. So does ones personal beliefs on God and religion. But on the other hand care takers of terminally ill after going through tough time come in conflict with their God and beliefs too. Questions on whether religion and personal belief ensure or hinder the Quality of Life are covered. Lastly caretakers ability to concentrate, take a decision to think rationally are examined. Because cognitive beliefs are key areas in evaluating ones psychological health.

Though there are enough evidences to prove the psychological distress in caretakers of persons suffering from Cancer, there is lacunae in interventions (Randy S. Hebert, Robert M. Arnold, Richard Schulz 2008). These empirical evidences reveal the

need for therapeutic intervention and also need for research- tested interventions to help caretakers in overcoming their psychological burden.

Cognitive Behavior Therapy (CBT) has proved to be effective in treating depressive patients, whether can be used for caretakers has been one of the fundamental questions in this research. Family caretakers have received very little attention in published literature as far as use of CBT is concerned. But use of CBT for depressive symptoms in other patients is well documented. Paykel et al (1999) and Scott et al (2000) tried using CBT to prevent relapse in residual depression. Controlled trial which did not receive CBT along with antidepressant medication had a relapse rate of 47% where as experimental group had only 29% of relapse rate. Robin et al (2006) Meta analysis indicated that CBT is effective for short term management of anxiety depression. Meta analysis of Gloaguen V (1998) and Wampold BE (2002) showed that CBT is equally effective like interpersonal, psychodynamic and pharmacotherapy in treating depression. Researcher initiated Randomized Control Trial of CBT focusing on monitoring and altering the thoughts and also problem solving for treating the depressive symptoms of care takers.

2. Materials and Methods:

'Caretaker' in this study would mean a family member closely associated or living or being with the person with Cancer for more than ten hours in a day meeting the physical and psychological needs of the patient. Caretakers above the age of 18 years, looking after a person who is newly diagnosed for Cancer (during the period of data collection), knowing English and other local languages of District were eligible for the study. Study was conducted in a clinical setting. After obtaining the consent, 120 caretakers were recruited for study and they were randomized into control (n=60) and experimental groups (n=60). Cases and controls were screened to know the level of QOL in Psychological domain administering the WHOQOL – BREF (WHO 1991). This baseline interview also elicited the socio demographic data of both patients and caretakers. Therapist met the caretakers of experimental group for therapeutic intervention on an individual basis. Sessions were held for four months on a basis of one session for 15 days out of which two sessions were through telephone. If at any stage of therapy there was deterioration in physical health, they were treated by a physician of their choice. The CBT intervention focused on two components – Cognitive restructuring and problem solving. Though the CBT manual was structured, it was used according to the caretakers need and pace of adaptability to the intervention.

The therapist helped each care taker to identify the negative thoughts, events, beliefs that disturbs their psychological well being. They were also assisted to evaluate those negative thoughts and substitute those thoughts with self enhancing thoughts. Behavioral consequences of those thoughts and beliefs were analyzed thereby to restructure their cognitions. Problem solving strategies were taught to the caretakers and homework was given to them to apply those techniques to the problems caused due to caring their terminally ill family member. Each session started by evaluating the homework given in the previous session. Control group did not receive therapeutic intervention but on ethical ground, they were provided with informational support. Post intervention test was done administering the WHOQOL- BREF to measure the effectiveness of the interventions and the results were compared between controls and cases.

3. Results and Discussion:

The respondents include 44 (73.3%) female and 16 (26.7%) male in control group and 43 (71.7%) female against 17 (28.3%) male. Mean age of controls is 44 years

and case's is 41 years. Majority of caretakers in the study are married. Control group has 70% married subjects and experimental group contains 76.7% married respondents. Number of widows/ widowers in control and experimental group are 10% and 8.3% respectively. Remaining are unmarried. Relationship of care taker with person living with Cancer is important. Control group has 36.7% children as primary caretakers for their parents with Cancer, followed by 30% spouses. A good number of parents constituting 20% are caretakers for their children suffering from Cancer. However, experimental group contains spouses as majority group i.e., 36.7% followed by children (26.7%) as caretakers for their parents with Cancer. Fifteen per cent in experimental group are siblings of persons with Cancer. In total, spouses, Children and also parents are found to be the primary caretakers.

4. Psychological Quality of Life in Before Intervention:

Domain	Groups	N	Mean	Std. Deviation	t test
Psychological	Control	60	11.256	1.606	1.721
	Cases	60	10.722	1.784	p=0.088 ns

Table 1: Showing Psychological Domain of Quality of Life among Caretakers before the Intervention

The scores an individual can avail in this domain of QOL ranges from 4-20 (mean of 12). Higher the scores better is the QOL. In the psychological domain cases and controls have the mean scores of 11.256 and 10.722 respectively. Scores are less than the mean of 12, which indicates lower QOL. It can be interpreted that being a care taker for terminally ill will disturb the individual and his/her psychological well being gets affected. Research by Waldron E.A., Janke E.A., et al., (2013), Morris J.N., Sherwood S (1987) on caretakers of Cancer patients, reported a decreased psychological status of caretakers. The findings of these studies on caretakers psychological morbidity are in par with the current research findings. In general caring to the family member with Cancer launches a range of emotional problems and hence reduces the Quality of Life and there is need for therapeutic intervention. The above shown results were also considered as baseline data to give intervention to the cases. Independent 't' test did not show significant differences in caregivers psychological domain between the cases and controls indicating that the level of psychological well being was almost similar in both groups.

Psychological Quality of Life after the Intervention:

Domains	Group s	N	Mean (Pre Intervention)	Mean (Post Intervention)	Mean difference	Std deviation	t test
Psychological	Control	60	11.256	10.478	.778	2.59615	10.841 p<0.001 vhs
	Cases	60	10.722	13.289	-2.567	1.40306	

Table 2: Showing the Mean Difference of Pre – Post Intervention Mean Scores – Cases Vs Control in Psychological Domain of Quality of Life of Caretakers of Persons with Cancer

After the exposure to Therapeutic Intervention the scores in psychological domain of cases improved by – 2.567 units. It can also observed that controls mean scores at post phase has reduced (Mean difference of .778) revealing the decrease in

psychological health over a period. The 'f' value of 10.481 which is very highly significant at .001 level indicates that cases and controls have very significant differences in their psychological well being.

Caring the Cancer patient involves complex physical and medical tasks resulting in fatigue, burnout, anxiety and physical exhaustion. In such a condition continuing to look after a patient without any supportive intervention reduces the psychological well being. Hence strengthening the Social Work Intervention improves the Quality of Life and decreases the caretaker's burden. This in turn improves the quality of care.

The intervention in terms of cognitive restructuring and problem solving has helped cases to perceive that they have better life with increased ability to concentrate, satisfaction in life and having less negative feelings compared to controls. When the caretakers are torn by emotions they often vacillate between two extremes of psychological status. Stanley and Selwyn (2007) suggested intervention for such ambivalent emotions. They said intervention geared them towards resolving ambivalence can be done through open communication.

5. Conclusion:

In summary, it can be said that the therapeutic interventions have helped the caregivers of Cancer patients to lessen the emotional burden and improved the QOL. The findings reveal the role of the professional health care team in assisting the caregivers. Although the intervention has shown to improve the QOL in psychological condition of caregivers of Cancer patients, effects are not seen in ensuring maximum improvement in QOL. Possible explanation for this could be based on few factors like, duration of intervention; as in many caregivers, the positive effects will be delayed and long term studies would be more preferred. Stage of patients illness or poor prognosis; in the course of time when a patient is deteriorating physically it can make the caregivers less receptive to the intervention. Caregiver distress increases after six months of Cancer diagnosis (Longacre et al 2012). Therefore ongoing interventions at the complete phase of caring will be beneficial to the caretaker.

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