

Burden, anger and physical health among men and women caregivers of dementia

Abstract

The study aimed to evaluate the efficacy of cognitive behavior therapy (CBT) across gender in alleviating burden, anger and enhancing the physical health of the caregivers of patients diagnosed with dementia in the sociocultural context of Pakistan. Independent groups design was employed and a sample of ten participants was screened through purposive sampling from neurological and psychiatric clinics in Lahore, Pakistan. Ten therapeutic sessions were conducted twice weekly over a period of five weeks. The main techniques included verbal reattribution, triple column, pie chart, advantage-disadvantage analysis, progressive muscle relaxation, sleep hygiene and time management grid. The participants were assessed on General Health Questionnaire-28 (GHQ-28), Burden Assessment Scale (BAS) and State-Trait Anger Expression Inventory-2 (STAXI-2) at pre and post treatment levels. Statistical analyses comprised descriptive statistics along with independent samples t-test. The results showed that the caregiver burden ($t = 3.41, df = 8, p = 0.01$) was significantly different as women tend to have low scores on burden level as compared to men. The findings indicate the need to devise gender sensitive therapeutic intervention.

Keywords: caregivers, dementia, independent groups design, therapeutic intervention

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Abbreviations: CBT, cognitive behavior therapy; BAS, burden assessment scale; STAXI-2, state-trait anger expression inventory-2; GHQ-28, general health questionnaire-28; SPSS-17.0, statistical package for social sciences; TCA's, tricyclic antidepressants

Introduction

In the developing world, the family institution tends to be strong and people with longstanding illnesses such as dementia are provided care at home by immediate family members. This tends to decrease institutionalization of such patients.¹ The family members provide care in terms of emotional, personal and practical help.² The responsibility of caregiving puts great burden over the caregivers and ultimately has a negative impact on their personal relationships, quality of life as well as physical and mental health. It is also evident from the literature that one-third to one-half of caregivers have high rate of psychological distress and poor mental health.³

In a hospital based study conducted in Pakistan, one out of five patients is over 65 years that may not be compatible with other countries. Dealing with an older population with medico-social vulnerability might pose a challenge in our setting on account of scarce resources.⁴ The caregiving of the people with dementia is associated with profound burden globally as they are prone to psychological problems, psychiatric morbidity and poor quality of life. It is evident from literature that emotional ventilation and support, behavioral detachment and self-blaming among caregivers differ in terms of caregivers' relation with the care recipient and duration of caregiving.

Empirical evidence suggests that there are gender differences in performing caregiving tasks as women caregivers provide more intensive assistance and spend significantly more hours in caregiving tasks as compared to men. According to Campbell et al.,⁵ the responsibility of caregiving usually falls on the available member.⁵ Majority of the care is provided by the spouse while a daughter is twice as likely as a son to serve as a primary caregiver. Furthermore, Youn G et al.,⁶ found that sons tend to provide assistance in daily

living activities and daughters-in-law provide caregiving in personal care and household tasks as caregivers among Asian groups.⁶ According to Walker R et al.,⁷ on an average three hours per week are usually spent by men in caregiving tasks while five hours per week by the women caregivers. These differences may be due to obligation and affection as feminist theorists argue that women are culturally conditioned to an ethics of care and sense of obligation.⁸ As the phenomenon of caregiving tends to be predominated by women, it is viewed as being gendered. Heller T⁹ found that 70% of informal caregivers are wives, daughters and daughters' in-law, while 30% are employed and may further be burdened for providing care to their families simultaneously.⁹

The above mentioned findings are applicable in the Pakistani culture as majority of women are providing unpaid and unacknowledged assistance to the chronically and physically disabled older persons due to social factors while men are rarely engaged in caregiving activities. Provision of care is imposed on women for an extended period of time besides other role duties at the cost of their own well-being. Consequently, they tend to be more vulnerable to physical and psychiatric illnesses.

The caregiving of an elderly with disability is taxing and leads to robust detrimental physical morbidity and psychiatric health.¹⁰ The caregivers who are supposed to provide extensive care experience chronic stress, medical issues or psychiatric illness. It has also been found that caregivers scarcely indulged in some preventive health measures that ultimately led to decrease in their immunity resulting in experiencing cardiovascular reactivity and slow wound healing.¹¹ Depression is twice as common among the caregivers. It was reported that family caregiving has negative impact on psychological, emotional, social and physical functioning on the caregivers. Moreover, they also tend to experience burden and financial issues. The caregivers' burden is associated with impairment in cognition and general functioning level of the care-recipients.¹² According to Brodaty & Donkin,¹³ in developed countries the rate of depression varies from 23% to 85% and the rate of anxiety varies from 16% to

45%.¹³ The rate of psychiatric morbidity was found to be in the range between 40% to 75% in the developing countries. According to Teri L et al.,¹⁴ if the patient had comorbid dementia and mood disorder, the caregivers experienced high burden level due to provision of care and assistance in daily living activities.¹⁴ The caregivers reported an inability to have their personal time, social activities, and found difficulty in performing work related tasks.

It has been cited in the literature that few studies provided evidence that women patients obtain more benefits rather than men and in other studies the therapy was effective in case of both the genders when the therapist was a woman.¹⁵⁻¹⁷

Evidence from the literature also supported the fact that there is no significant gender difference. As in a study conducted by Watson & Nathan,¹⁸ 56 men and 105 women diagnosed with depression received group cognitive behavior therapy (CBT) while 35 men and 55 women with depressive disorder underwent individual CBT at an outpatient mental health clinic. The results indicated equivalent severity of illness on depression, anxiety and quality of life between the two groups before and after the completion of CBT treatment.

The current study was designed to examine the efficacy of CBT with regard to gender differences of the caregivers of patients with dementia as there is a dearth of literature on this topic in Pakistani cultural context. The caregiving is an integral phenomenon in Pakistani culture that needs to be thoroughly explored. Furthermore, there is scarcity of studies on individual therapy as well as its efficacy pertaining to gender discrimination due to poor infrastructure and support provided to the clinical psychologists at Government level and due to lack of insight among the population. The prime aim of the study was to assess gender differences of therapeutic intervention on burden, anger and physical health of the caregivers.

Material and methods

Research design

In this study, Independent Groups Design was employed¹⁹. The participants were screened through purposive sampling.

Participants/sampling

The sample size was determined through G-power analysis. A small sample of ten participants ($n = 10$) was determined. Referrals from private psychiatric and neurological clinics were screened according to inclusion criteria; informal men or women caregivers 18 years and older, who had provided care for at least a period of six months. The caregivers with psychiatric illness were excluded.

Tracing the participants who could fulfill the criteria was a tedious task. Each participant underwent 10 structured therapeutic sessions, held twice a week. The time duration of each session was 45 minutes. The structured sessions conducted with all the participants i.e. 80 sessions comprised of 3600 hours of therapy.

Instruments

In order to get the demographic information, a questionnaire was developed to get the bio data such as name, age, gender, religion, education, occupation, monthly income, marital status, number of family members, duration of treatment and caregiving, as well as medical condition/health status of the caregivers.

The caregiver burden was assessed through the Burden Assessment Scale developed by Reinhard SC et al.,²⁰ constitute 19 items. The

objective burden experienced was assessed by 10 items while the subjective burden was assessed through the rest of the nine items.²⁰ The Cronbach's alpha found to be 0.91 for the two different studies for reliability analysis, and 0.90 of the Urdu version.

The General Health Questionnaire-28 (GHQ-28) was developed by Goldberg used to measure the general health of the participant. The scale consists of four subscales i.e., severe depression, anxiety and insomnia, somatization and social dysfunction, each constitute of seven items. The test-retest reliability and internal consistency was found to be 0.70 or higher.²¹

The State-Trait Anger Expression Inventory-2 (STAXI-2) is a 57-item inventory comprised of six scales, developed by Spielberger CD²² was used to measure the state and trait anger. Except for the Trait Anger Scale/Angry Reaction, the internal reliability is high for all the subscales (0.73-0.76).²² Concurrent validity of the original STAXI is strongly presented with correlations with the Multiphasic Inventory, Eysenck Questionnaire and Buss-Durkee Hostility Inventory.

Setting

The data was collected from private clinics and hospitals of Lahore, Pakistan. The prime teaching hospitals were contacted to get the participants but no participant was referred from the teaching hospitals for a period of three months as patients with dementia were rarely reported in out-patient departments. Finally, the private psychiatry clinics and neurology clinics of Lahore, Pakistan were approached and the data collected from there. After taking the written consent from the eight participants, they were initially assessed on GHQ-28, Burden Assessment Scale and STAXI-2 for pre-treatment scores and the intervention was conducted at those clinics. The structured therapeutic sessions were conducted twice a week and after the completion of the therapy, the research participants were reassessed on the same measures to test the efficacy of the protocol and to identify the differences between the groups (Table 1).

Ethical considerations

The participants were briefed about the outline of the implementation of the complete procedure i.e., the assessment phases, nature of the therapeutic intervention and the gap between the sessions. After ensuring the confidentiality, permission for the recording of the therapeutic session was taken and written consent forms were filled by the participants. They were informed about their right to withdraw at any point. No monetary compensation was awarded to them.

Statistical analyses

The 17.0 version of the Statistical Package for Social Sciences (SPSS-17.0) was used to measure the descriptive statistics for demographic variables and the independent samples t-test to compare the two groups of participants after the implementation of the therapeutic intervention. A graph is also displayed in order to depict the comparison of the efficacy of the protocol between the two groups on account of gender.

Results and Discussion

The above mentioned (Table 2&3) provides the information regarding demographic variables. The total number of participants was ten. The mean age of the research participants was app 52 years with SD of 13 years. The table clearly depicts that the mean educational level of the participants was app 13 years but vary approximately three years. However, the average income level earned was about 52800

with *SD* of 27518. The number of family members was seven but vary up to two. The duration of the received treatment by the patient was around 42months with a variation of 20months. The duration of the caregiving services received by the parents were 40months on an average with *SD* of 21months.

Table 1 A structured intervention program for caregivers of patients with dementia

| Sessions | Objectives | Therapeutic Interventions |
|------------|--|---|
| Session 1 | Interview | Diagnostic interview ²³ A-B-C technique ²⁴ |
| | Case conceptualization | Socialization ² , deep breathing ²⁵ |
| Session 2 | | |
| Session 3 | Verbal reattribution | Analysis of ABC, identify and elicit cognitive distortions, triple column ²⁴ |
| Session 4 | Managing Anger | The assault cycle ²⁶ Advantage-disadvantage analysis ²⁴ the traffic light routine ²⁷ |
| Session 5 | Relaxation exercise and solution focused therapy | Progressive muscle relaxation ²⁸ solution focused ²⁹ |
| Session 6 | Managing stress | Dealing with stressful situations: The 4 A's ³⁰ guided imagery ³¹ , coping statements ²⁵ |
| | | |
| Session 7 | Assertiveness training | Communication styles, assertive agreement, assertive irony, defusing, assertive delay, broken record, circuit breaker ²⁵ |
| Session 8 | Managing time | Saboteur time styles, time management grid setting priorities ³² |
| Session 9 | Improving physical health | Regular physical activity, dietary guidelines ³³ sleep hygiene principles ³⁴ |
| | | |
| Session 10 | Relapse prevention | Therapy blueprint ³⁵ , bibliotherapy ³⁶ |

Table 2 The following table summarizes the basic information about the participants

| | |
|---|--------------------------------------|
| Number | 10 |
| Age | 29-74 years (mean 52.38 ± 13.90) |
| Gender | 5 females, 5 males |
| Religion | All Muslims |
| Education | 10-18 years |
| Occupation | Job:4, retired:1, homemakers: 5 |
| Monthly Income | 25000-1lakh (52800±27518.19) |
| Marital Status | All married |
| Number of Family Members | 9-Mar |
| Duration of Treatment of Care-recipient | 1-6 years (3.6 years ± 2 years) |
| Duration of Caregiving | 1-6 years (3.4 years ± 2 years) |
| Medical Condition/Health Status | Healthy: 3, minor health concerns: 7 |

Table 3 Descriptive Statistics of Demographic Variables

| | N | Minimum | Maximum | M | SD |
|--------------------------------------|----|---------|---------|-------|----------|
| Age | 10 | 29 | 74 | 52.3 | 13.9 |
| Education | 10 | 10 | 18 | 13.2 | 2.53 |
| Income | 10 | 25000 | 100000 | 52800 | 27518.88 |
| Family Members | 10 | 3 | 9 | 6.6 | 1.71 |
| Treatment Duration of Care-Recipient | 10 | 12 | 72 | 42.1 | 20.65 |
| Duration of Caregiving | 10 | 11 | 72 | 40.3 | 21.72 |

Table 4 Descriptive Statistics and Results of Independent Samples t-test for Mean Differences on BAS, GHQ-28 & STAXI-II

| Scale | M | SD | T | P | 95 % CI | |
|-------------|------|------|-------|------|---------|-------|
| | | | | | LL | UL |
| BAS | 9.4 | 2.75 | 3.41 | 0.01 | 2.92 | 15.87 |
| GHQ-28 | -0.2 | 1.62 | -0.12 | 0.9 | -3.94 | 3.54 |
| State Anger | 0.33 | 4.47 | 0.07 | 0.94 | -9.99 | 10.66 |

CI: Confidence Interval; LL: Lower Limit; UL: Upper Limit

The above mentioned (Table 4) provided the analysis through Independent samples *t*-test, to test the significant differences across gender on different levels such as caregivers' burden, anger and physical health. Though the analysis done indicated that the statistically significant difference between the two groups was found on burden among the caregivers ($t=3.41, df=8, p=0.01$). It meant that the results confirmed that women tend to have low burden level after going through follow-up phase. The results showed that no significant difference was found on general health ($t=-.12, df=8, p=0.90$), and state anger ($t=0.07, df=8, p=0.94$) across the two groups. Hence it is concluded that the therapy was effective equally on both the genders except that the burden level among the women was alleviated more rather than men. (Figure 1).

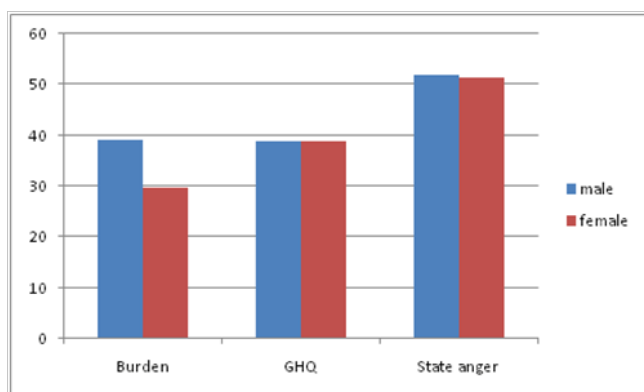


Figure 1 Graph showing post intervention scores on BAS, GHQ-28 and STAXI-2 across the gender.

In this study, the hypothesis regarding the difference of efficacy of therapy between both the genders in alleviating burden, anger and improving the general health of the participants was partially accepted as the findings showed that the women had low burden level in comparison to men. However, there was no gender difference regarding anger and general health. In 1990s, the role of gender in treatment through CBT gained the focus of attention.¹⁸ Few studies indicated that women rather than men acquire more advantage from therapy.^{15,16}

In a study by Brabban A et al.,³⁷ on the efficacy of CBT for anti-psychotic resistant patients, it was concluded that women had a much better insight and showed an overall reduction in symptoms.³⁷ Similarly, Peterson AL & Halstead TS³⁸ evaluated the efficacy of group CBT on 44 men and 94 women and found significant gender differences.³⁸ Further evidence regarding gender difference was reported by Chen S et al.,³⁹ who conducted group session of CBT of 7 men and 23 women outpatients in a hospital and concluded that gender came out to be a predictor of outcome in favor of women.³⁹

Contradictory findings have also been reported in the literature that both the gender had comparable response but the women have higher scores on depressive symptoms before implementation of protocol, thus they had poor outcome on CBT⁴⁰. A number of other studies also reported contradictory findings regarding gender differences that men responded more favorably on Tricyclic Antidepressants (TCA's) or the psychological intervention along with TCA's) as compared to women.⁴¹

Moreover, in a study conducted by Ogrodniczuk JS et al.,⁴² the efficacy of two psychotherapies (supportive therapy and interpretive therapy) with respect to the gender of the patients was examined.⁴² The patients were assessed on anxiety, depression and symptomatic

distress and results indicated that both the genders depicted a significant interaction effect at the post therapy level. Women patients tend to have better results on supportive therapy while men on the interpretive therapy.

The empirical findings also showed that no differences in gender were reported in community outpatient setting evaluating 58 men and 134 women on BDI after employing individual CBT.⁴³ In a study conducted by Sotsky SM et al.,⁴⁴ the severity of depression improved through CBT applied on 37 participants but the post treatment outcome was not predicted by gender.⁴⁴ In another study conducted by Jarrett RB et al.,⁴⁵ 14 men and 24 women received CBT for depression but it was found that post-treatment scores was not predicted by gender.⁴⁵

Overall, the findings of the study seem to be in line with the existing literature as there was gender difference in one parameter only.

Conclusion

Hence, in the light of the above mentioned facts and figures, it might be concluded that CBT was quite effective in reducing the anger and burden and improving the general health of the caregivers. However, CBT couldn't discriminate gender differences except for caregivers' burden. From the cultural perspective, the phenomenon of caregiving has deep roots because the family institution is very strong in Pakistan. There is a dire need to conduct such studies in the future to discriminate gender differences on larger samples to devise an indigenous intervention plan.

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Conflicts of interest

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