



EFFECTIVENESS OF SELECTED INTERVENTIONS ON THE QUALITY OF CARE AMONG FEMALE
PRIMARY CAREGIVERS OF ALZHEIMER'S PATIENTS DURING CAREGIVING

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Abstract: In the present paper, the researchers have attempted to study the effect of three different interventions selected to be role-play, psycho education and biofeedback on the Quality of Care delivered by 30 Female Primary Caregivers for their Alzheimer's patients. The results show that all the three selected interventions are equally effective in increasing the Quality of Care. Furthermore, an improvement in the Levels of Quality of Care was observed among all the 30 caregivers; it was found that there was an increase in the overall Quality of Care from average to good, after the intervention.

Keywords: *Alzheimer's disease, female primary caregivers, Alzheimer's care giving, interventions, quality of care*

Introduction: Alzheimer's disease (AD) is a type of dementia characterized by progressive decline in cognitive and functional abilities (Alzheimer's disease International, 2011). Its symptoms often begin with memory loss and progress to an inability to perform basic activities of daily living (ADL) e.g., dressing, feeding etc. and thus AD patients eventually become dependent on third-party care (Burns & Illiffe, 2009). Alzheimer's disease (AD) is considered as the most common form of dementia (Hsiung, 2007) classified it as a neurodegenerative syndrome with an insidious onset and progressive course is implicated in a gradual loss of the patient's autonomy and Quality of Life (Whitehouse, 2006).

Review of Literature:

Alzheimer's disease care giving: Care giving is hard in Alzheimer's disease because usually the caregivers are family members, spouses who are "on call" 24 hours a day, 7 days a week (Caregiver: Medline Plus from <http://www.nlm.nih.gov/medlineplus/caregivers.html>). For some family members, care giving becomes a "career" (Pearlin & Aneshensel, 1994). Care giving is associated with increased morbidity and mortality among caregivers (Schulz & Beach, 1999). The care giving task is mostly done by the patient's relatives, especially spouses or children (Ferrara et al., 2008).

Other types of interventional strategies in Alzheimer's disease care giving: The researchers after thorough review could find many interventional strategies delivered among Alzheimer's disease patients and their caregivers in home or institutions related to AD and have presented below: The interventions included 1. Cognitive intervention, 2. Functional performance (ADL) interventions, 3. Environmental interventions occupation therapy, 4. Integration of self-interventions and pleasure inducing interventions, 5. Psycho educational, 6. Respite voucher-type grant, or their combination, 7. Psychosocial interventions, 8. Reminiscence and life review therapy, 9. Behaviour therapy (including behaviour modification and token economy), 10. Psychotherapy-counseling, 11. Multi-component, 12. Technology based and computer driven interventions, 13. Case Management, 14. Social support and community based interventions, 15. Spiritual interventions, 16. Role plays, 17. Biofeedback, 18. Validation therapy, 19. Reality Orientation Therapy and 20. Simulations.

Selected intervention: In the present study, the researchers have selected the following strategies for the interventions of the study: Role play, Psycho-education and Bio-feedback intervention.

a) Role-play: The definition of role-playing is "the changing of one's behaviour to fulfil a social role" (Oxford English Dictionary. Askoxford.com. Role play is defined as "where a person is asked to perform a role which is not normally his own role" (Yardley-Matwiejczuk, Krysia, 1997). Another definition states, Role play as "a psychological therapeutic technique designed for an instance or situation in which one deliberately acts out or assumes a particular character or role" (American Heritage Dictionary). Role play is "a form of experiential learning that gives participants the opportunities to have direct experience with content and to practice or develop new skills" (Smith, 2004).

b) Biofeedback: According to the National Center for Complementary and Alternative Medicine (NCCAM), biofeedback is considered an alternative medicine technique under the mind-body category of complementary and alternative medicine (CAM) practices (NCCAM, 2012). "Biofeedback, is a technique that enables an individual to learn how to change physiological activity for the purposes of improving health and performance" (Gilbert & Moss, 2003 and Schwartz & Andrasik, 2003).

(c) Psycho-education: Psycho-education is an educative and therapeutic strategy to improve the Quality of Life for the family. Psycho-education is systematic, structural, didactic information on the illness and its treatment; and includes integrated emotional aspects in order to enable patient as well as family members - to cope with the illness" (Bamul, *et al*, 2006).

QUALITY OF CARE: Alzheimer disease impairs multiple domains including cognitive, functional and behaviors therefore, it is very important to systemically and individually assess these impairments in each

domain and assess how and what extent the care is rendered to them by the caregivers. In a study in nursing paradigm showed that the majority of studies on Alzheimer disease were in other disciplines. Only 3% of these studies were on providing safety, communication and individualized care (Algas's, 2007). Some reviews highlight on Quality of care and Alzheimer's disease. Quality of Care is relative and neutral term (Donabedian, 1980). Quality of care is assessing certain property related to care exists and to what extent it exists (Donabedian, 1980). The concept "Quality of Care" is multidimensional and complex and comprises different perspectives and levels (Wilde et.al, 1993). Empirical findings based on model of quality of care measured dimension of care (Wilde et al. 1993). Holistic care involved treating a person as an integrated whole, not just caring for the physical body and humanistic care should use personal qualities and intuitive knowledge to build relationships (Coulon, *et al*, 1996).

Categories of care: The term "caring" refers to the process aimed at enabling people with disabilities to achieves and maintain optimal functioning (WHO, 2001). According to the International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organization in 2001, Caring is of 2 types: "therapeutic care", which restores and maintains the body functions and "compensatory care", which compensates for the impairment of body functions and thus enhance and maintains the level of activity and participation.

The results were found with two broad categories of intervention: 1. Activities of daily living (ADL) physiological and hygiene like eating, drinking, toileting, sleeping, bathing and dressing, and 2. With psychosocial and behavioral interventions related to agitation and aggression. Though some focused on environmental design modification, limited evidence was found to support the effectiveness of intervention in ADL. The review concluded that research is needed on interventions to improve care for people with dementia and should include focus on evaluation intervention to improve eating, drinking, and sleeping pattern areas (Reed & Tilly, 2004).

Physical care: Under the physical care, rather meant as physiological care, i.e. meeting the needs like nutrition, elimination, comfort rest and sleep, safety and security. There are difficulties in handling dementia patients pertaining to eating, drinking, using toileting, communication, and sleeping interventions.

Psychological Care: Under psychological care, it pertains to changes in behaviour including depression, irritability, repetitiveness, anger, confusions, agitation, sleep disturbances and hallucinations, mood

swings, expression of distrust, shows increased stubbornness, withdraw socially, becomes aggressive and anxious and behaves inappropriately.

Level of Quality of Care: Quality of older people's care is stressed in many countries as having high priority and being major importance (SOU 2008:51). Research has been conducted on what constitutes good quality in the care for older people in community setting (Ho, et al 2003; Puts et al. 2007; Bilotta et al. 2009 and Hasson & Arnetz 2011). The following areas of good care are reported to be important for older people to be respected as a unique individual, individual adjustment of care, influence of care, how and when they receive care and from which caregiver (Wilde et al. 1995). Two of the ten factors important for good quality of home care for older people include 1. Health participation and environment 2. Support to relatives (Josefsson, 2010). Another study projects the types of care of both good and bad quality (Haak, 2006). The quality standards for the care of older people are published in Sweden (Brava 2010).

RESEARCH QUESTION: The following research question is raised and answered in the present study:

What is the effect of role-play, psycho education, and biofeedback on the Quality of Care during Alzheimer's care giving?

OBJECTIVE: The following objective is set and achieved in the present study:

To study the effect of role-play; psycho education, and biofeedback on the Quality of Care during Alzheimer's care giving.

HYPOTHESES: In order to achieve the above objective the following hypotheses was developed and tested:

Hypothesis - 1: Total Quality of Care improves as a result of the effect of role-play, psycho education and biofeedback interventions during care giving.

Hypothesis - 2: Levels of Quality of Care during care giving by female primary caregivers improved as a result of all the three (role play, psycho education and biofeedback) interventions.

POPULATION AND SAMPLE: The population comprises 100 Female Primary Caregivers (FPG) of patient with Alzheimer's disease in home set up. The sample comprised 30 Female Primary Caregivers (FPG) of 30 patients of Alzheimer's disease. After obtaining the permission, ensuring from the medical records and confirming the diagnosis, a total of 100 patients were identified. The female primary caregivers of

the Alzheimer's patients were carefully selected from the list collected and they were matched in order to ensure comparability and selected randomly. They were matched for age, marital status, relationship, education, occupation, and type of family, reliever, and number of hours of care giving, duration of care giving, duration of illness, sex of the patient and health problem. Only those cases where the researcher could match with at least one similar comparability for all 3 cases of the female primary caregiver were selected and randomly assigned to three treatment groups using the lottery method. The female primary caregivers were individually contacted for answering the test and participating in the intervention. The researcher thus selected 30 female primary caregivers and allotted randomly to 3 different interventions based on personal data.

TOOLS AND TECHNIQUES: The following tools and techniques were used in the study:

Sl. No.	Tool	Developer
1	Personal data sheet of Female Primary Caregiver and Clinical Data Sheet of Alzheimer's patient	Researcher
2	Quality of Care Checklist	Researcher

INTERVENTION: The researcher used the day -1 for pre-test, day -10 for post-test immediate and day -40 for post-test follow-up-of one month interval. The intervention was executed for 10 successive continuous days. The researcher used for group I role play, group II psycho education and group III biofeedback respectively with 10 caregivers for each group comprising total of 30 female primary caregivers of Alzheimer's patients. For 10 days the intervention was executed. The researchers measured during the home visit for the presence or absence of care in different contexts provided by the caregiver for Alzheimer's patient and also recorded the extent of the care received by the patient using the tool Quality of Care Checklist on day -1 before the intervention and on day -40 after the intervention i.e. one month interval post test (follow-up).

RESULTS AND DISCUSSION: The data collected were scored, tabulated, and subjected to analyses. The results are as follows:

Hypothesis -1: Quality of Care significantly improves as a result of the effect of role-play, psycho education and biofeedback interventions during Alzheimer's care giving.

In order to test the above hypothesis the mean and Standard deviation of pre test and post test scores of quality of care are calculated along with the change scores.

Table 1: Mean pre and post follow up Quality of Care scores of Female Primary Caregivers in role play, psycho education and biofeedback intervention groups

Intervention Groups		Pre test Quality of Care		Post test Quality of Care		Change
		Mean	S.D.	Mean	S.D.	
I	Role-Play	90.70	14.38	117.00	25.66	26.30
II	Psycho-Education	108.50	30.51	131.50	24.89	23.00
III	Bio-Feedback	86.40	21.03	126.60	14.21	40.20
Total		95.20	24.19	125.03	22.290	29.83

An analysis of the above table indicates that irrespective of the interventional groups such as role-play, psycho- education and biofeedback, the mean Total Quality of Care of Female Primary Caregivers had increased from pre-test 95.20 to post-test 125.03. Thus, there is an increase in Total Quality of Care delivered by 30 Female Primary Caregivers.

From the mean table, it is evident that interventional group wise comparison revealed that first psycho- education group had a mean pre-test to post-test (108.50 to 131.50), biofeedback had mean pre-test to post-test (86.40 to 126.60) and lastly mean pre-test to post-test (90.70 to 117.00) Thus, it implies that the Total Quality of Care had recorded maximum increase from average level to good Quality of Care level in all 3 interventions such as psycho- education, biofeedback and role play. The mean change was seen relatively more among biofeedback (40.20) than role play (26.30) and psycho-education (23.00).

Figure-1: Mean pre-test and post-test follow up Total Quality of care scores of Female Primary Caregivers in role play, psycho education and biofeedback interventional groups

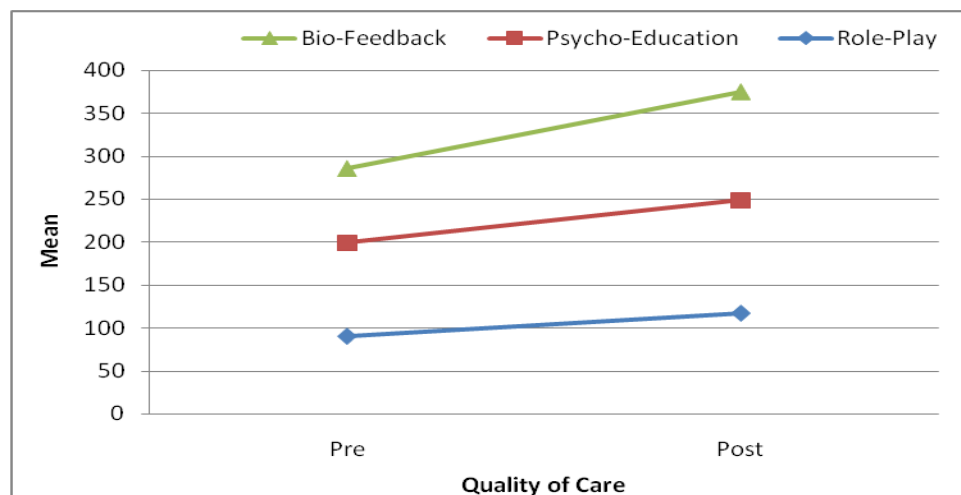


Table: 2: Results of repeated measure ANOVA for mean pre and post follow up Total Quality of Care of Female Primary Caregivers in role play, psycho education and bio feedback

Source of variation	Sum of Squares	df	Mean Square	F	Sig. (Non Significant)
Within subject effects					
Change	13350.42	1	13350.42	40.69	0
Change * group	833.23	2	416.62	1.270	0.30(NS)
Error (change)	8857.85	27	328.07		
Between subject effects					
Intercept	727540.82	1	727540.82	1051.24	0
Group	3000.63	2	1500.32	2.17	0.134
Error	18686.05	27	692.08		

Repeated measure ANOVA for mean pre and post follow up Total Quality of Care scores of Female Primary caregivers in role play, psycho education and bio feedback, revealed the following. Irrespective of the groups, there was significant increase in the pre test quality of care scores ($F=40.69$; $p=.000$). The overall pre quality of care scores were found to be 95.20, which had been increased to 125.03 in the post test session. The increase of quality of care scores of 29.83 was found statistically significant.

When increase in the Total Quality of Care scores was verified against the groups, again a non significant F value was observed ($F=1.270$; $p=0.297$). This indicates that there was statistically equality increase in the post scores of the selected groups under various types of intervention. From the mean table it is evident that biofeedback group had recorded an increase of 40.20 scores (pre 86.40; post 126.60), role play group had recorded a minimal increase of 26.30 (pre 90.70; post 117.00) and lastly psycho education group had recorded an increase of 23.00 scores (pre 108.50; post 131.50). F value clearly indicates statistically same for all the three intervention, thus inferred that all three are equally effective in increasing the Quality of Care.

With respect to delivery of both physical and psychological care, “Total Quality of Care”, Day, et al. (2000) found that behaviors during clothing were favorable and when clothes placed in sequential order enhanced AD patient’s independence in dressing. Murphy (2014) found the results among 14 Alzheimer patients of age 87, found that the caregivers reported a significant decrease in depression and agitation after the lights were installed for 4 weeks duration and had an increase in sleep quality (increase in 30 minutes per night). While, Mc Curray (2005) on exercise and physical activity Night-time Insomnia Treatment and Education for Alzheimer Disease (NITE-AD) with behavioral intervention among the 36 participants caregivers improved sleep and spent an average of 36 minutes less time awake at night and had 5.3 less nightly awakenings and also exercised significantly more days a week and had significantly lower level of depression. At 6 months follow up NITE-AD was effective. Yektatalab, Kaveh, Shariff, Fallahi, & Petramfar (2012) found that consistent promotion of the schedules, employment of trained staff and continued education can improve the Quality of care of caregivers and quality of life of patients. Hazzan et al, (2015) found that the caregivers identified a number of factors that researchers should consider when developing an instrument to measure level or quality of care. Ducharme, et al (2011) result indicated that at post-test and follow-up perception of caregiver during preparation of care giving situations was perceived to be better and effective.

Paradoxically, in regard to physical care, previous study findings did not support the findings of the present study. According to Els, et al. (2012) no significant effects were found on ADL performance in a trial of three sets of individually-tailored interventions, which involved behavioral and communication techniques to improve ADL function, psychosocial techniques, and a combination of first two sets of techniques. There are studies which had no significant effects with environment modification and did not match with the present findings which included as follows: Beck et al (2002) found no sufficient evidence on food quality supported with bright light therapy. Kim, et al., (2003); Forbes, et al, (2004) and Yamader et al. (2000) did not find that bright light improved or promoted sleep. Ancoli-Israel, et al., (2002) found that there was no significant change in sleeping patterns when light therapy was used. Likewise, on psychological care, studies which contradicted the present findings are as follows: According to Fortinsky, et al. (2009), there was no significant improvement result in depression and burden and Joling, et al. (2012), there was no significant improvement results in depression.

On the issue of selected interventions “*role play*” intervention on Quality of Care and Quality of Life, Belle, et al. (2006) found that significant improvement in quality of life among caregivers of AD patients. Another study by Lee, Czaja, & Schulz, (2010) found that reduction in depression and burden in Caregiver. However, there are study findings which contradicted the above results of this study and are presented as follows: Els, et al. (2012), Beck et al., (2002), Kim et al (2003); Forbes et al (2004), Yamader et al (2000), Ancoli-Israel et al (2002).

With regard to “*biofeedback*” intervention on Quality of Care and Quality of Life, Sung, *et al* (2000) & Pages *et al*, (2001) found that biofeedback with electrical stimulation produces subjective outcomes i.e., improvement in Quality of Life and higher contraction pressures of Pelvic Floor Muscle (PFM). Biofeedback alone seems to be more effective in controlling urge incontinence than Stress Urinary Incontinence (SUI). Jr, Valdemar Ortiz et al, (2006), a study reported non-pharmacological treatment of voiding dysfunction using biofeedback, and of urge syndrome by electrical stimulation, was effective for treating Lower Urinary Tract Dysfunction.

With regard to “*psycho education*” intervention on quality of care, some of the finding of the present study supports with the previous studies findings in the above said perspective of psychological care of Quality of care during care giving with the interventions like psycho-education. Coon, (2003) showed improvement in care giving i.e. self-efficacy through psycho educational and skill training. de Routrou, (2011), found improvement in patient activities of daily living(ADL) through comprehensive psycho education. Contradictorily, some of the finding of the present study contradicts with the previous studies findings in the above said perspective of psychological care of Quality of care during care giving with the interventions like psycho education as conducted by Cohen-Mansfield, et.al, (1997), and Hawranik, Johnston & Deatrich (2008).

Hypothesis 2: Levels of Quality of Care during care giving by Female primary caregivers improved as a result of all three role play, psycho education and biofeedback interventions.

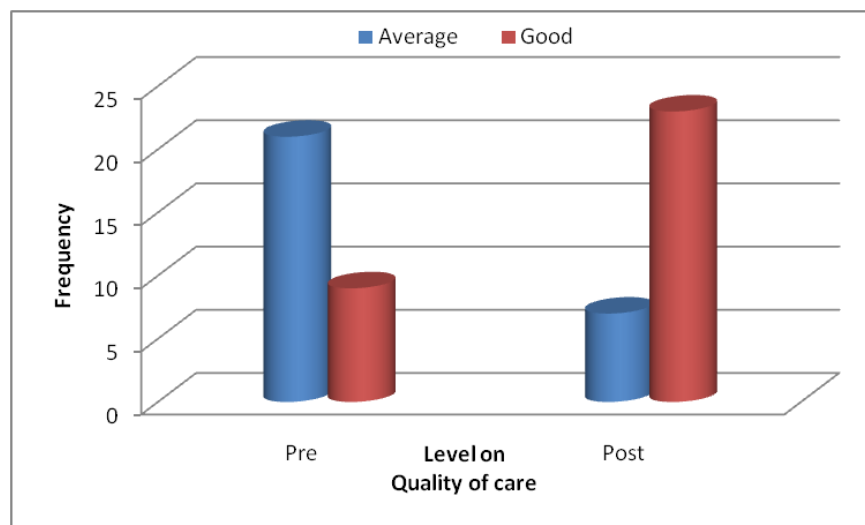
Table: 2: Frequency and percentage values on quality of care during pre test and post test sessions among 30 female primary caregivers and results of Chi-Square test.

Level on Quality of care	Pre-test (Before intervention) N=30		Post- test (After intervention) N=30		Total		Pearson's Chi-Square Value
	frequency	%	frequency	%	frequency	%	
Average 54-107 score	21	70	7	23	28	46	X ² =13.13 df=1 p=0 (Significant)
Good 108-160 score	9	30	23	77	53	60	

The above table shows frequency and percentage values on quality of care during pre test and post test sessions and the results of Chi-square test.

In the pre-test it was found that 70% of the female primary caregivers were in the average category of quality of care and 30% of them were under good quality of care. In the post test it was found that 23% of the female primary caregivers were in average category of quality of care and 77% of them were in the good quality of care. So there was significant increase in the frequencies from average quality of care to good quality of care from pre test to post test, which was further confirmed to be significant by Chi-square value ($\chi^2 = 13.13$; $P=0.000$). Therefore, among 30 female primary caregivers results found significant increase in the Level of Quality of care from average to good quality of care after intervention.

Figure-2: Frequency and percentage values on Levels of Quality of Care during pre-test and post-test sessions among 30 female primary caregivers and results of Chi-Square test.



With regard to “Levels of Quality of Care and Quality of Life “in Alzheimer’s care giving, Rebecca’s, (2007) review found 4 empirically derived components of good QOL for individuals with dementia on ADLs and physical functioning and mobility. Lawton, (1994) found that emotions judged from direct observations made possibility to assess response to interventions of dementia patients related to Quality of Life. Scholzel-Dorenbos et al, (2007) found improvement of Quality of Life and the type of care, setting, severity of dementia and specific quality of life domains focused the appropriate instrument related to Quality of Life.

Conclusions & Implications: The physical and psychological area of care giving, delivered by caregivers is indeed a challenging task. Caregivers need to be sufficiently equipped to handle them. This process of preparing the caregiver with different interventions becomes important. In the present study, one such attempt was made to study different interventions which can enhance care giving among female caregivers of Alzheimer’s. From the analysis, about the mind-crippling illness in relation to context of quality of care rendered by the female primary caregiver who had undergone interventions like role-play, psycho education and biofeedback the following conclusions can be drawn:

1. All three interventions are equally effective in increasing the Quality of Care.
2. Levels of Quality of Care among all 30 caregivers increased in the overall Quality of Care from average to good quality of care after intervention.

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