**Title: The impact of an educational program by using group discussion on perceived stigma among the family caregivers of people with Alzheimer’s disease**

**Running Title:**  **Stigma among the family caregivers**…

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**Acknowledgement**

The authors wish to express their gratitude to the Research Administration of Tehran Faculty of Nursing and Midwifery, Iranian Alzheimer’s Association , and all caregivers who participated in the study.

**Conflicts of Interest**

The authors declare that there is no conflict of interest.

ABSTRACT

The objective of the present study was to determine the impacts of an educational program by using group discussion on perceived stigma among family caregivers of people with Alzheimer’s disease.

This non-equivalent non-randomized controlled trail was made in 2015. A sample of 66 family caregivers of people with Alzheimer’s disease was recruited conveniently. The caregivers were allocated to a control and an experimental group. Initially, the perceived stigma of all participants’ was measured by using the Stigma Impact Scale. Then, a five-session educational program by using group discussion was implemented over five weeks for the caregivers in the experimental group. The caregivers in the control group received no intervention. The level of caregivers’ perceived stress was reassessed both immediately and one month after the intervention.

Immediately and one month after the study intervention, the mean score of perceived stigma in the experimental group was significantly lower than the control group (P < 0.05).

The findings of the present study showed the noticeable effects of the educational program by using group discussion on the perceived stigma of family caregivers of people with Alzheimer’s disease.

**Keywords:** caregivers, disease, education.

**Introduction**

Alzheimer’s disease (AD) is a chronic progressive and debilitating brain disorder which has profound effects on memory, intelligence, cognition, speech, physical functioning, activities of daily living, and orientation to place and person, as well as self-care, planning, innovation, organization, and abstract reasoning abilities. A tentative or definite diagnosis of AD causes great fear for the afflicted person and his/her family members and significant others (1). The negative effects of the disease are so much profound that AD is often described as “an endless funeral” (2). Epidemiological studies on elderly people confirm a pandemic of AD (3). According to the statistics provided by the World Health Organization, the number of people with dementia in the world was 35.6 millions in 2012 which is estimated to reach 65.7 and 115.4 millions by 2030 and 2050, respectively (4).

Due to cognitive and behavioral alterations, people with AD are unable to fulfill their own needs and hence, they are greatly dependent on the help of others for fulfilling their needs. On the other hand, studies show that seven out of each ten persons with AD are cared for at home settings (5), denoting the fact that the most important source of care giving to people with AD is the family (1). Care giving to people with AD is an awesome and challenging task for family caregivers so much so that they are entitled as “the hidden victims of AD” (2).

Given the need of people with AD to long-term care services, their family caregivers are indisputably at risk for higher levels of stress, strain, and psychological problems compared with family members of elderly people with physical health problems (6). Moreover, AD can cause its sufferers to show different abnormal and strange behaviors such as forgetfulness, emotional outbursts, aggression, anger, and violation of social norms. Such abnormal states and behaviors give family caregivers feelings of shame and fear for others’ judgments (7). According to Riley (8), abnormal behaviors of AD sufferers such as anger, aggression, violation of social norms, personality alterations, poor self care, and incontinence affect AD caregivers’ identity and prestige and expose them to stigmatization.

Goffman (9) considered stigma as a spoiled identity in which a characteristic is attributed to a person or group and hence, the person or the members of that group are devalued and differentiated and are no longer considered as healthy and efficient individuals. Stigma can cause patients/caregivers to hide the illness. The burdens of keeping such a secret, being always cautious, escaping from others, and lying to others cause AD caregivers emotional damages. Besides, hiding a disease from others is equal to losing their social and emotional support (10). Therefore, AD family caregivers usually suffer from lack of social support and relationships and experience a sense of social isolation. They gradually move toward sacrificing their own leisure times, limiting their relationships with friends and relatives, and leaving their employments (11). On the other hand, due to the attached stigma, most patients/caregivers do not ask for help and thus, they fail to receive early healthcare services. Such practice may aggravate their health conditions and put them at risk for disability. Consequently, stigma is considered as the biggest and the most important barrier to help seeking, effective care delivery, continuation of treatments, and rehabilitation (12).

One of the strategies to improve family caregivers’ ability to give care to their ill members is education. Family caregivers need to receive educations about the underlying conditions of their ill members and how to give care to them (13). Patient and family education is one of the most basic responsibilities of healthcare providers, particularly nurses, the fastest and the most effective strategy to attain the goal of social justice, and a key strategy for supporting family caregivers and improving their conditions. It also helps nurses facilitate family members’ engagement in care giving to their ill members (14). Consequently, a wide range of supportive and educational programs has been developed and implemented in some countries for AD family caregivers, the effects of which have been assessed in several studies (15).

One of the studies on AD family caregivers was a mixed method research made by Liu (16) to investigate perceived stigma among 51 AD caregivers and its impacts on their depressive symptoms. That study revealed a significant direct correlation between perceived stigma and depressive symptoms irrespective of caregivers’ ethnicity, race, and reaction to their ill family members’ behavioral problems—the severer the perceived stigma, the stronger the feeling of depression. Pahlavanzadeh et al. (13) also made a clinical trial study into the effects of a family education program on the care giving burden of 50 AD family caregivers. Their findings revealed that care-giving burden gradually decreased in their experimental group and increased in their comparison group. They also reported that immediately after their intervention, there was a significant difference between the groups regarding the caregivers’ care-giving burden while one month after their intervention, the between-group difference was not statistically significant.

Iran is one of the ancient countries in the Middle East and its population is about 70 million, 5.2% of whom are aged over 65 years (17). Iranian culture emphasises altruism and strong family ties as two basic values. These characteristics of Iranian culture make the experience of giving care to a family member a unique one. Currently, there may be nearly 212,000 people living with dementia in Iran (18). Despite the large number of persons with AD in Iran, there is just one organisation to provide services, because there are obstacles to funding and organising such foundations. The Iran Alzheimer Association (IAA) is the only voice for people with the various forms of dementia, most notably persons with AD and their caregivers. The IAA, located in Shahrak Ekbatan in the western part of Tehran, Iran, was founded in 2001 and registered as a non-governmental organisation. The association is engaged in the following activities: rising public awareness, clinical and rehabilitative activities and other facet of activities such as counselling and education. However, there are limited support services for Iranian families caring for a person with AD (19).

The objective of the present study was to determine the impacts of an educational program by using group discussion on perceived stigma among AD family caregivers.

**Methods**

*Study design*

This was a non-equivalent non-randomized controlled trail. The trial was made in summer 2015 (Figure 1).

*Setting and samples*

Study setting was the Iranian Alzheimer’s Association located in Ekbatan, Tehran, Iran. Family caregivers of people with AD constituted the population of the study. Based on the results of a previous study and with a standard deviation of 11 (16), the sample size formula for comparing two means revealed that 66 family caregivers were needed for the study. Consequently, a convenient sample of 66 caregivers was recruited. The selection criteria included being a family member of the afflicted person, being the main caregiver of the person, giving care for at least six months, having no hearing problems, being able to read and perceive educational materials and answer to the study instruments, agreeing to participate in the program, actively participating in group discussions, and speaking Persian. The exclusion criteria were the death of the afflicted person, the change of the main family caregiver, and failure to participate in more than one educational session. The participants were non-randomly allocated to the experimental and the comparison groups. In other words, in order to prevent the leak of information from one group to another, we initially recruit all caregivers of the comparison group and then, started to recruit caregivers for the experimental group.

*Instruments*

The data collection instruments were a demographic questionnaire and the Stigma Impact Scale (SIS). The items of the demographic questionnaire were gender, age, educational and marital status, AD stage, number of caregivers, the kinship of the main caregiver with the afflicted person, the place where the afflicted person lives, the amount of time spent per day on care giving, the total length of care giving, the type of insurance coverage, caregiver’s employment status, and the financial status of the family. This questionnaire was filled by all participants during a general session held before the study intervention.

# The SIS measured perceived stigma in caregivers of persons with Alzheimer's disease that was used and validated by Liu et. al (16). The SIS comprises 24 items which assess AD family caregivers’ perceptions of stigma in the four dimensions of social rejection (9 items), financial insecurity (3 items), internalized shame (5 items), and social isolation (7 items). The items are responded and scored as follows: No idea: 0; Completely disagree: 1; Disagree: 2; Agree: 3; Completely agree: 4. The total score can range from 0 to 96—the closer the score to 96, the higher the perceived stigma (13).

The content validity of the SIS was approved by ten faculty members of T Faculty of Nursing and Midwifery, while its reliability was assessed via the test-retest method. Accordingly, ten caregivers filled out the scale twice with an interval of two weeks. The correlation coefficient between the test and the retest scores was .7, confirming the satisfactory reliability of the scale.

*Intervention*

One week before holding educational sessions, we held an inaugural session to explain the aim and the process of the study to the participants and also to ask them to complete the demographic questionnaire and the SIS. Then, a five-session educational program was implemented for the caregivers in the experimental group which had been already divided into 8–10-person groups. The sessions were held weekly and by using the group discussion technique. The researcher team attended all sessions and the group was guided by the researcher and professors. Also the meetings were held at the Alzheimer's Association in a calm and convenient environment.

The length of each session was about 90 minutes. Group discussion is one of the active teaching-learning methods. It is an organized dialogue about a topic which is of interest to all group members. Group discussion provides group members with the opportunity to share their ideas, beliefs, and experiences (11). In the first session, the caregivers got familiar with each other and provided a brief history of their ill family members’ conditions. Then, the aim and process of the study were briefly explained and a timetable was given to the participants which contained the titles, dates, and times of the sessions. Moreover, the importance of family’s role in giving care to people with AD was discussed. In the second session, a recreational tour was made for the participants. The aims of the tour were to familiarize the participants with each other, strengthen their relationships and interactions, boost their trust in each other, and thereby, facilitate their active participation in subsequent group discussions. In the third and the fourth sessions, the authors and the participants discussed AD, its prognosis, behavioral problems of the afflicted persons, stigma and its types, family caregivers’ experiences of stigma, strategies to prevent or reduce stigmatization, coping skills, and strategies to manage tensions and feelings. In these two sessions, the participants were also asked to share their own ideas and experiences of care giving. In the fifth session, the program was concluded and the participants were asked to share their experiences of using coping skills and feeling-management strategies in the face of stigmatization. Finally, a booklet containing the educational materials was given to each participant. Immediately and one month after implementing the program, perceived stigma of all patients in both groups was re-assessed using the SIS. Consequently, perceived stigma was measured trice namely before the intervention (T1), immediately after it (T2), and one month later (T3).

*Ethical considerations*

This study was approved by the Institutional Review Board of the Tehran University of Medical Sciences, Tehran, Iran (IRB approval number: 94S250802), and registered in the Iranian Registry of Clinical Trials (IRCT201502047212N6). In order to enter the study setting and start sampling, we initially obtained an introduction letter from the Research Administration of Tehran Faculty of Nursing and Midwifery, Tehran, Iran, and made necessary arrangements with the administrators of the Iranian Alzheimer’s Association. Moreover, we provided the participants with information about the aim and the importance of the study, confidentiality of the study data, and voluntariness of the participation. Then, their verbal and written informed consent was secured (Figure 1). Additionally, after the posttest, we provided the educational materials to the caregivers in the comparison group.

*Data analysis*

The data were analyzed through doing the Fisher’s exact, the independent-sample t, and the Chi-square tests as well as repeated measure analysis of variance (RM ANOVA) in the SPSS 20 software.

**Results**

The means of the caregivers’ age in the experimental and the comparison groups were 52±11.44 and 49.8±12 (*p* = .464), respectively. Most participants in both groups were female and housewife, held diploma degree, and gave care to people with third-stage AD. Moreover, they were mostly the daughters of people with AD (Table 1). The results of the Fisher’s exact and the independent-sample t tests illustrated no significant between-group differences with regard to the participants’ gender, age, educational and marital status, AD stage, number of family caregivers, main caregiver, caregiver’s kinship with the afflicted person, the place where the afflicted person lives, the amount of time spent per day on care giving, the total length of care giving, the type of insurance coverage, and the financial status of the family.

The Chi-square and the independent-sample t tests indicated that the difference between the groups in terms of pretest value of perceived stigma was not statistically significant (*p* = .146). However, immediately and one month after the intervention, there were significant differences between the groups in terms of the values of perceived stigma (*p* < .051). The results of RM ANOVA for the between-subject factor of group also showed that the intervention had significant effects on caregivers’ perceived stigma (*p* = .004). The Bonferroni’s post hoc test revealed a significant difference between T1 and T2 as well as between T1 and T3 in both groups with regard to the mean scores of perceived stigma (*p* <.001). The trends of variations were downward in both groups (Figure 2). Although perceived stigma decreased after the study in both groups, the amount of decrease in the experimental group was greater. Nonetheless, the groups did not significantly differ from each other in terms of the pretest-posttest mean difference of perceived stigma score (*p* = .412).

**Discussion**

The objective of this research was to determine the impacts of an educational program by using group discussion on perceived stigma among AD family caregivers. The study findings revealed a significant between-group difference regarding the mean scores of perceived stigma both immediately and one month after the intervention, implying the effectiveness of the educational program on AD caregivers’ perceived stigma. Bastani et al. (20) also did a study to investigate the effects of group discussion and telephone counseling on female AD caregivers’ perceived stress. They found that before their intervention, respectively 50.7% and 53.7% of their participants in their experimental and comparison groups had high levels of perceived stress. In line with our findings, they also found that the mean score of perceived stress in their experimental group decreased from 62.8±38.28 to 55.5±45.22 after their intervention ([1](#_ENREF_1)). The results of a study by Lindstrom Bremer (21) also indicated a significant decrease in the level of perceived stress among AD caregivers after implementing a psycho-educational intervention similarly (21), Pahlavanzadeh et al. (13) found that their family education program was effective in significantly reducing the burden of care giving among family caregivers of people with dementia.

In agreement with the findings of previous studies, our findings indicated that most caregivers were under the strain of care giving while educational program was effective in alleviating such burden. Lewis et al. (22) reported that giving care to a person with AD is a chronic stressful process which undermines caregivers’ physical and mental health. Therefore, protecting caregivers’ health and empowering them for care giving are essential. Caregivers need to learn techniques which facilitate their coping with care-giving stress. Moreover, providing them with educations about communication skills can reduce their psychological problems and facilitate their coping with care-giving difficulties.

Our findings showed that group discussion can reduce AD caregivers perceived stigma. Psychological interventions can be used for enhancing caregivers’ abilities, empowering them to manage their conditions and give effective care to their ill family members, and alleviating their care-giving stress. Such interventions include, but are not limited to, emotional release, group therapy, cognitive therapies, and counseling. On the other hand, educational interventions not only are helpful in enhancing knowledge and problem-solving skills, but also can improve ill persons and their caregivers’ quality of life. Carretero et al. (23) noted that official psychological interventions can alleviate caregivers’ perceived stress, relive care-giving burden, provide them with comfort, and reduce the negative effects of care on the afflicted persons.

**Conclusion**

The findings of the present study showed the noticeable effects of the educational program by using group discussion on AD family caregivers’ perceived stigma. These findings can denote the importance of experience sharing to the psychological well-being of AD caregivers. Group discussion and experience sharing help caregivers learn necessary skills for coping with their own problems. Also nurses, as a big part of the system, can play an important role to manage this problem. Nurses must be educated and sensitive of stigma, as a missing subject in nursing curriculum.

Health authorities and policy makers and healthcare providers are recommended to use group discussion and other educational interventions to reduce perceived stigma among AD caregivers. Given the multidimensionality of the concept of perceived stigma, we recommend future studies to investigate the effects of other interventions on perceived stigma among the caregiver of people with AD as well as other chronic health conditions.

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Figure 1 The Flow of The Study

Explaining the aim of the study and securing informed consent

Completing the SIS before the intervention

Inclusion criteria

Being the main family caregiver of the afflicted person

Having a care-giving experience of more than one year

Having no hearing problem and being able to read and perceive educational materials

Being able to actively participate in group discussion and answer to the study questionnaires

Being able to read and speak Persian

Obtaining permissions from the Research Administration of Tehran Faculty of Nursing and Midwifery

Referring to Iranian Alzheimer’s Association

Explaining the aim and the method of the study to the participants

Recruiting eligible participants and allocating them to the groups

Completing the demographic questionnaire and the SIS

Non-random allocation of caregivers to the 33-person control and experimental groups

Experimental group

Control group

In total, five caregivers were excluded due to frequent absences from the educational sessions, transfer of their ill family member to nursing homes (three ones), or voluntary withdrawal from the study (two ones). Consequently, final analysis was performed on data collected from 61 caregivers

Explaining the aim of the study and securing informed consent

Completing the SIS before the intervention

Implementing the educational program by using group discussion in five sessions

Completing the SIS immediately after the intervention

Completing the SIS immediately and one month after the intervention

Data entry into the SPSS

Data analysis by using the tests of inferential statistics

Exclusion criteria

Voluntary withdrawal from the study

The death of the afflicated person

More than one absence from the educational sessions

The change of the main caregiver

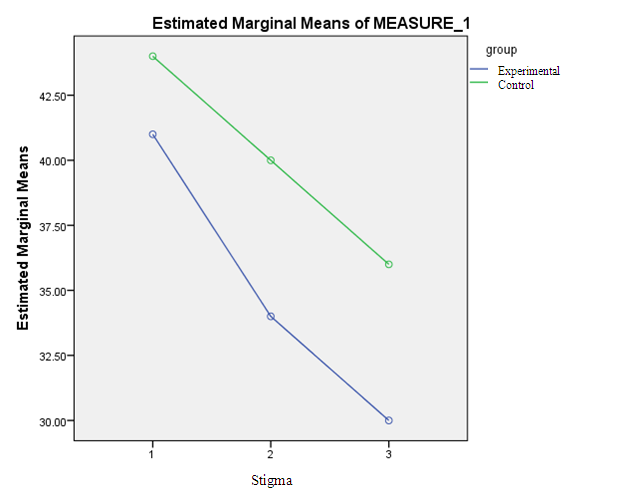


Figure 2 Variations Of Perceived Stigma Scores In Both Groups At Different Measurement Time Points

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Variables |  | Experimental group  n(%) | Control group  n(%) | Statistical test |
| Total |  | 30(100) | 31(100) |  |
| Gender | Female  Male | 26(86.7)  4(13.3) | 23(74.2)  8(25.8) | *p*  .221 |
| Number of caregivers | One  Two  Three and more | 18(60)  5(16.7)  7(23.3) | 12(38.7)  10(32.3)  9(29) | *p*  .428 |
| Place where the afflicted person lives | Private home  Caregiver’s home  Both | 24(82.8)  4(13.8)  1(3.4) | 21(70)  7(23.3)  2(6.7) | *p*  .553 |
| Length of daily care | Less than 24 hours  A whole 24-hour day | 3(10.3)  26(89.7) | 3(13)  20(87) | *p*  .805 |
| Types of the afflicted person’s insurance | Social security  Military  Therapeutic services  Others | 8(27.6)  8(27.6)  9(31)  4(13.8) | 4(18.2)  6(27.3)  12(54.5)  0 | *p*  .162 |
| Type of caregiver’s insurance | Social security  Military  Therapeutic services  Others | 9(36)  7(28)  6(24)  3(12) | 7(33.3)  3(14.3)  10(47.6)  1(4.8) | *p*  .378 |
| Income | Sufficient  Insufficient | 18(60)  12(40) | 13(41.9)  18(58.1) | *p*  .158 |

Table 1 The Demographic Characteristics of The Participants

Table 2 Perceived Stigma in Both Groups at Different Measurement Time Points

|  |  |  |  |
| --- | --- | --- | --- |
| Group  Time | Experimental  M±SD | Experimental  M±SD | The results of the independent-sample t test |
| Before (T1) | 41.02±9 | 44.35±8.6 | t=1.47  df= 59  *p* = .146 |
| Immediately after (T2) | 34.78±6.5 | 40.33±6.9 | t=3.23  df= 59  *p*< .001 |
| One month after (T3) | 30.76±7.84 | 36.3±8.96 | t=2.57  df=59  *p* =.013 |
| The results of RM ANOVA | Within-subject effect | Greenhouse test F= 34.94  *p* < .001 |  |
| Between-subject effect | F= 8.77  *p* = .004 |  |

*Note.* M = mean; SD = standard deviation.

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