The Impact of Neuman Systems Model in Reducing the Care Burden on Primary Caregivers of Dementia Patients

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Abstract

Aim: This research in order to evaluate the effectiveness of education and support group initiatives given to primary caregivers of dementia, before and after education, was done using a mixed single group quasi-experimental and qualitative methods.

Method: Research carried out to primary caregivers of 30 old people who fixed criteria. The data collected by researcher with using the Primary caregivers identification form, Primary caregiver burden inventory, focus group interviews in a planned way, to those who are primary caregivers were given education of caring which related to old people and what can do for themselves about their health while doing their works and support group interaction provided for them. Ethics committee approval and written informed consent form taken from individuals. While evaluating McNemar, Independent test and content Analysis were performed.

Results: Five-dimensional features (physiological, sociological, psychological, developmental, spiritual aspects) which created according to Neuman systems model, which expressed as negative before education, decreases after education and the decreasing first and second observations follow-up are also reduced or totally eliminated. Yet, during the focus group discussions primary caregivers's expression related the five dimensions detente between the before and after education statements also changes in a positive way draws attention. If we look at the distribution of scores on the inventory's five sub-size dimensions, between total score average (65.883±19.5) and sub-dimensions such as burden of time-dependence, developmental physiological and social burden's before and after education scores were found to be significant difference (p<0.001).

Conclusion: According to the results of this research, the education and support group interaction given to caregivers of demantia patients are pointed to be effective lessen their care burdens.

KeyWords: Nursing, public health, geriatric, caregiver burden

Background

Elderly care has social, psychological, physical, economic, and interpersonal effects on family members and primarily caregivers (Kasuya et al., 2000; Kucukguclu et al., 2009; Akgun Sahin et al., 2009). In literature, caregivers are defined as latent patients and it is indicated that caregiving families experience mental and physical health problems as they are unable to efficiently cope with stress (Wong, 2000; Laidlow et al., 2002; Barrowclough, 2005). Results of related studies show that caregivers of elders with dementia experience a higher rate of psychological distress and similarly, caregivers are affected more by depression and other psychopathological diseases than people who do not give care (te Boekhorst et al., 2008; Au et al., 2010). In the analytic study conducted by Bull, (1990) with 60 caregivers, there was an increasing rate of care burden and depression. Vitaliona et al. (2003) determined that caregivers had 23% higher stress hormones and 15% lower stress responses than people not providing care.

For these reasons, primary caregivers comprise one of very important groups that expect nursing care service from nurses. This nursing care service contains planning, applying and assessing the interventions required for protecting, sustaining or regaining all the dimensions of caregivers. Associating the issue with the
Neuman Systems Model (NSM) at this point; it provides a system-based and comprehensive conceptual framework for nursing as it considers human beings from a multidimensional and system point of view. The focus point of the model is to assess individual as a combination or a whole of five dimensions as physiological, psychological, socio-cultural, developmental, and spiritual.

It is indicated that giving information to primary caregivers about the condition of elders with dementia and using support group interaction are among factors decreasing or removing care burden and it is required to determine their efficiency. Thus, revealing the effect of giving information and using support group interventions to decrease care burden through a quasi-experimental study is thought to make a significant contribution to literature.

Method

Design and participants

This one-group quasi-experimental and qualitative study was conducted by the mixed method with primary caregivers of elders with dementia who were registered to a Community Center of Social Services Institution in the Province of Kırsehir before and after training.

The population of the study consisted of primary caregivers of 60 elders with dementia that were registered to a Community Center of Social Services Institution in the Province of Kırsehir between 1 January 2007 and 31 December 2010. The sample of the study, on the other hand, consisted of 30 primary caregivers who stated that they were voluntary to participate in the study, provided primary care for elderly patients with dementia, and lived with them.

Instruments

The data were collected by using “Introductory Form for Primary Caregivers”, “Caregiver Burden Inventory”, and “Focus Group Interview Form”.

Introductory Form for Primary Caregivers: Introductory Form for Primary Caregivers was developed according to the descriptive characteristics of the caregivers, questions about caregiving and five dimensions of the Neuman Systems Model (physiological, psychological, socio-cultural, developmental, and spiritual).

Caregiver Burden Inventory: Caregiver Burden Inventory was developed by Novak and Guest in Canada in 1989 for assessing the effect of caregiving on caregiver patient relatives. The fact that the inventory was developed specifically for relatives of patients with cognitive disorder provides a superiority for using it for caregivers of patients with dementia (Kucukguclu et al., 2009).

The inventory is a five-point Likert scale involving five subscales and 24 items (0-4). The subscales have titles like time-dependence burden, developmental burden, physical burden, social burden, and emotional burden. All subscales comprise of five items, whereas the third subscale (physical field) has four items. Each factor could be scored between 0 and 20 as; never defines (0) point, almost never defines (1) point, moderately defines (2) points, quite frequently defines (3) points, and nearly always defines (4) points. In the physical burden that comprises of four items; the score of each response to items is calculated through being multiplied by 1.25 and totally 20 points are obtained from this factor. Total score of each individual may vary between 0 and 100. While high score signifies a high burden; low score signifies a low burden (Kucukguclu et al., 2009).

Turkish validity and reliability of the inventory was conducted by Kucukguclu et al., (2009) in 2009. The Cronbach Alpha value was determined as 0.94 and the subscales: “time-dependence burden” (0.93), “developmental burden” (0.94), “physical burden” (0.94), “social burden” (0.82) and “emotional burden” (0.94).

In this study, on the other hand; the total Cronbach Alpha value was determined as 0.91 during 1st and 2nd follow-up before and after training, and the subscales: “time-dependence burden” (0.91), “developmental burden” (0.90), “physical burden” (0.89), “social burden” (0.84), and “emotional burden” (0.91).

The inventory was applied during 1st and 2nd follow-up before and after training.

Focus Group Interview Form

In focus group interviews, the size of group was determined as eight people. Among the primary caregivers, those who were open to communication and had a higher educational level were included in the group.
Focus group interviews were prepared according to five dimensions in NSM in Introductory Form for Primary Caregivers because Neuman (Neuma and Fawcett, 2002) sees human as an open system mutually interacting with their environment and continuously changing. As an open system, human has sequential lines/structures of defense protecting the basic structure (self-core). Each line of defense tries to prevent the basic structure (self-core) from damage by protecting the following one. From outer to core, these are flexible line of defense (FLD), normal line of defense (NLD), and line of resistance (LR). Each of these lines are equipped with five dimensions such as physiological psychological, socio-cultural, developmental, and moral variables. Individual responds stressor based on its potential with these variables. In case of not responding stressor, lines of defense are damaged. Thus, stressor reaches to dimension that can break down balance of the system (Neuma and Fawcett, 2002). According to NSM, individual is protected with these owned five dimensions (physiological psychological, socio-cultural, developmental, and moral) at the outermost FLD firstly against stressors confronted. If individual cannot be protected at this line (with five dimensions), he/she starts to reveal stress response against stressor. This first stress response is described as incapability of flexible line of defense of individual for buffering these stressors sufficiently and failure of NSM’s (line in the middle of defense) to satisfy. In case that NSH remains incapable, the innermost LR becomes active (with five dimensions) and prevents individual to give a response deteriorating core structure at negative/interruption of system with deterioration of basic structure/ self-core of the individual. In case that lines of resistance fails, such response occurs in individual.

Ethical Issues
In order to conduct the study, a written permission was obtained from Kırsehir Directorate of Social Services and Ethics Commission of Erciyes University (2010/155). Written and verbal consents were received from individuals who agreed to participate in the study.

Data analysis
Difficulties experienced by primary caregivers were firstly recorded with the interviewer and then deciphered by the researcher during focus group interviews conducted based on five dimensions of the NSM. The data were assessed by using two approaches. In the analysis, five dimensions of the NSM were used as a base and a template. And then the content was analyzed by both direct statements and the interpretation of meaning and was placed below five dimensions. A theory was formed following this phase.

Results
The primary caregivers of the elderly had an average age of 42.4±9.50 and they were in the beginning of middle adulthood, all female, housewives, mostly primary school graduates and married (70.0%). The primary caregivers were those who consciously chose caregiving (60.0%), were already living with elders (100%) and daughter-in-laws (53.3%).

A total of 21 physiological characteristics were defined by primary caregivers (self-care, attention, general mobility, fatigue, sleep order, health controls, dental care, eating order, appetite, weight, intestinal habit, drinking plenty of water, urination habit, back pain, low back

Development of Training and Support Group Programs
Two training programs were developed for the study. While the first one was related to the primary care of elders with dementia; the second one was related to what caregivers could do for their own health while providing care to elders. On the other hand, support groups were used as they had functions like providing additional knowledge and sense of belonging to caregivers, sharing their experiences, and developing the coping skills. The group involved four people for making the support group efficient. Group members consisted of a psychiatrist, a psychologist, a social worker and a nurse (researcher). In the support group program, three (psychological, spiritual and developmental) out of five dimensions that affected and balanced the function of system in the Neuman Systems Model were examined.

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pain, frequent diseases, smoking, drinking alcohol, sexual life, menstruating, relaxing time) and there was a “decrease” in the characteristics such as self-care, relaxing time, attention, general mobility and sleep order before training. These five characteristics that caused a negative change in the lives of primary caregivers were observed to be either completely removed or distinctly decreased after training and the same positive change was sustained in 1st and 2nd follow-up.

The primary caregivers stated that there was an “increase” in their physiological characteristics like fatigue, low back pain, and smoking. These four physiological characteristics that increased before training were either completely removed or significantly decreased after training and the same decrease was sustained in 1st and 2nd follow-up.

When results of focus group interview performed according to NSM in order to determine primary caregivers to be affected at the physiological dimension were examined; during the focus group interviews that were conducted before training, it was determined that primary caregivers experienced body pains due to the failure of using body mechanisms and strain.

Caregivers stated,

“My low back pains have increased and I can’t do anything; I can bend but never stand up” (Caregiver 1), which exemplifies their experiences.

During the focus group interview that was conducted after training, on the other hand, it was determined that body pains like back pain and low back pain decreased by means of exercises.

The caregivers stated, “I have headache, back pain, neck pain, but they have decreased a little after exercises, they are good for me, I feel relieved” (Caregiver 3), which exemplifies their experiences.

A total of 17 socio-cultural characteristics were defined by primary caregivers (being pleased with environment, relations with other people, neighborhood relations, number of friends, intrafamilial relations, intramural responsibilities, time allocated for family, private life, domestic arrangements, domestic right to speak, time allocated for favorite activities, reading newspapers-books, sustaining house chores, worshipping, income status, economic burden, support, and resources) and there was a “decrease” in seven socio-cultural characteristics before training as; relations with other people, neighborhood relations, number of friends, time allocated for family, private life, time allocated
for favorite activities, and reading newspapers-books. There was a numerical “increase” in all these seven socio-cultural characteristics after training and the same increase was sustained in 1st and 2nd follow-up.

When results of focus group interview performed according to NSM in order to determine primary caregivers to be affected at the social-cultural dimension were examined; in the focus group interview that was conducted before training, it was determined that primary caregivers receded from their environment and had a decreased interest in their family in the course of time.

The caregivers stated, “I can’t welcome guests at home. My mother-in-law is not comfortable with it”, which exemplifies their experiences.

In the focus group interview that was conducted after training, on the other hand, it was observed that they not only tried to take precautions against or control their socio-cultural characteristics, but also could transfer the protection exercises into behaviors.

The caregivers stated, “I certainly have less friends now, but I talk to them on the phone. I try to meet my neighbors in the evening or the mid-afternoon even for a short while.” (Caregiver 4), which exemplifies their experiences.

It was determined that among 12 developmental characteristics (desire of doing something, being able to do anything, feeling strong, feeling healthy, feeling successful, feeling mature, feeling old, self-admiration, being sensitive, sense of loneliness, feeling manipulated, sense of high expectation-low control) experienced by primary caregivers; 7 characteristics that were observed to either decrease or increase before training showed a numerically positive change (increased if decreased; decreased if increased) in 1st and 2nd follow-up after training. However, two (feeling manipulated, sense of high expectation-low control) out of five features of the caregivers who remained the “same” before training also sustained in 1st and 2nd follow-up after training. Other three (self-admiration, being sensitive and loneliness) showed a positive increase after training and this increase was sustained in 1st and 2nd follow-up.

When results of focus group interview performed according to NSM in order to determine primary caregivers to be affected at the developmental dimension were examined; in the focus group interview that was conducted before training, it was determined that primary caregivers expressed their differences and emotions perceived when they compared themselves with their peers with harsh statements.

The caregivers stated, “I feel older than my peers. I am more pessimistic compared to them……? (Caregiver 6), which exemplifies their experiences.

In the focus group interview that was conducted after training, on the other hand, it was observed that their perceived differences, emotions and statements were milder when they compared themselves with their peers.

The caregivers stated, “I am better than before; I did not want to do anything like getting dressed or wearing make-up when we last spoke. But I feel like doing them right now” (Caregiver 1), which exemplifies their experience.

It was determined that among 12 spiritual characteristics (conduct of life, control over life, self-belief, meaning of life, self-confidence, future expectations, life satisfaction, sense of peace, trust in others, trust in God, commitment to belief, fulfilling applications concerning belief) experienced by the primary caregivers; nine characteristics (conduct of life, self-belief, meaning of life, self-confidence, future expectations, sense of peace, trust in God, commitment to belief, fulfilling applications concerning belief) were observed to remain the “same” before training. Three (trust in God, commitment to belief, fulfilling applications concerning belief) out of these nine characteristics numerically remained the same or showed a little increase in 1st and 2nd follow-up after training. It was determined that the other six characteristics (conduct of life, self-belief, meaning of life, self-confidence, future expectations, and sense of peace) showed a numerically positive change in 1st and 2nd follow-up after training.

When results of focus group interview performed according to NSM in order to determine primary caregivers to be affected at the spiritual dimension were examined; in the focus group interview that was conducted before training, it was determined that the primary caregivers had an increased spirituality.
The caregivers stated, “I have an increased spirituality and I pray more as I constantly stay at home and see what time could make to a person. Our view of life changes so that God does not to end up like that” (Caregiver 2), which exemplifies their experiences.

In the focus group interview that was conducted after training, on the other hand, it was observed that they could find a meaning in these experiences.

The caregivers stated, “Bad experiences have made me stronger” (Caregiver 2), which exemplifies their experiences.

### Table 1. Diagram of Training Group and Support Group Plan

<table>
<thead>
<tr>
<th>Session</th>
<th>Trainings and Support Groups</th>
<th>Duration</th>
<th>Methods Used</th>
<th>Equipment/Material</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second Session (22-24-27 June 2011)</td>
<td>Difficulties encountered in the care of elders with dementia and things to be done to deal with these difficulties FIRST SUPPORT GROUP SESSION. Group rules and objectives are discussed.</td>
<td>Training 45 min. 15 min. break and then Support group 60 min.</td>
<td>Narration Question-answer Discussion</td>
<td>Training Manual and Video for Caregivers of Elders with Dementia</td>
</tr>
<tr>
<td>Third Session (29 June/1-4 July 2011)</td>
<td>Physiological dimension SECOND SUPPORT GROUP SESSION. Emotional dimension Effect of caregiving process on caregivers, feelings of caregivers toward elders during the caregiving process, negative and positive feelings regarding elders are shared.</td>
<td>Training 45 min. 15 min. break and then Support group 60 min.</td>
<td>Demonstration Question-answer Discussion</td>
<td>Training Manual for What You Can Do for Your Health</td>
</tr>
<tr>
<td>Fourth Session (6-8-11 July 2011)</td>
<td>Socio-cultural, emotional and spiritual dimension THIRD SUPPORT GROUP SESSION spiritual dimension Being “obliged”, meaning of life, commitment to life, life satisfaction, self-belief, self-reliance, belief in people, expectations from future and life control are discussed.</td>
<td>Training 45 min. 15 min. break and then Support group 60 min.</td>
<td>Demonstration Brainstorming Question-answer Discussion</td>
<td>Training Manual for What You Can Do for Your Health</td>
</tr>
<tr>
<td>Fifth Session (13-15-18 July 2011)</td>
<td>Developmental dimension FOURTH SUPPORT GROUP SESSION Developmental dimension. Sensibilities, sense of loneliness (when and how this feeling is experienced), states of feeling mature and old and strong and successful are discussed.</td>
<td>Training 45 min. 15 min. break and then Support group 60 min.</td>
<td>Narration Brainstorming Question-answer Discussion</td>
<td>Training Manual for What You Can Do for Your Health</td>
</tr>
</tbody>
</table>
Table 2 shows that there was a significant difference between the total mean scores of inventory before training (65.883±19.5) and after training (37.067±12.34) (p<0.001). Considering the distribution of the mean scores of inventory in five subscales beyond this general total difference; a very significant difference was also determined between the subscales of time-dependence, developmental, physical and social burden before and after training (p<0.001). On the other hand, there was no difference between the mean scores of emotional burden, which is another subscale of inventory, before and after training (p>0.05).

Discussion

In this study, it was determined that among 22 psychological characteristics used for determining the psychological state of primary caregivers according to NSM; twelve increased, six were never experienced, and four remained the same.

Domestic and abroad studies also reported similar results concerning the affected physiological dimension. According to the results of this study, researchers determined; an impairment in the sleep order, physical and mental health of caregivers (Koyuncu Yasar, 2009), fatigue, decrease in appetite, change in urinary system, decrease in attention (Ugur, 2006), headache, stomach complaints (Akca, 2003), back pain, change in immune system, hyperinsulinemia, hypertension, sleeplessness, chronic fatigue, change in appetite, gaining or losing weight (Gopalan and Brannon 2006), Silver and Wellman (2002), İnci and Erdem (2008) and Beaundreau et al. (2008), chronic fatigue, muscle pain, constipation, untidy clothes, and cardiovascular problems.

In this study, it was determined that among 22 psychological characteristics used for determining the psychological state of primary caregivers according to NSM; twelve increased, six were never experienced, and four remained the same.

One of the dimensions where the health of caregivers of elders with dementia is also affected is the psychological dimension. Results relevant studies revealed that caregivers had mental problems like temper and discomfort at
home (Kılıc Akca and Tascı 2005), moderate-severe depression (Gonzalez-Salvador et al., 1999), symptoms of clinic depression, depression or anxiety and stress about care. In the study conducted by Ugur (2006), it was observed that caregivers had weakness, fear and despair. te Boekhorst et al. (2008) and Au et al. (2010) also determined that caregivers of elders with dementia were affected by psychological distress, depression and other psychopathological diseases at higher rates.

In the phase before training in this study, an “increase” was observed in twelve psychological characteristics out of totally 22 psychological characteristics that increased with caregiving were determined as; being unable to cope, sadness, despair, tension, fatigue, anger-irritation, impatience, regret, sorrow-misery, disappointment, anxiety and questioning life before training. Among these characteristics; anger (Kılıc Akca and Tascı 2005), despair (Ugur 2006) and tension (te Boekhorst et al., 2008; Au et al., 2010) were also determined in previous studies. These results made us think that the primary caregivers experienced interpersonal stresses like new emotions and thoughts while providing care to the elderly. After training program and support group interviews, it was concluded that there were common emotions between individuals going through these new emotions and thoughts and the same experience and they tried to take precautions against or control them.

In this study, there were a “decrease” in nine and an “increase” in two among 17 socio-cultural characteristics, used to determine the socio-cultural state of the primary caregivers according to NSM. One of the dimensions that affected caregivers of elders with dementia is the socio-cultural dimension. According to NSM; this dimension mainly forms interpersonal and extrapersonal stressors. While aforementioned dimensions mainly reflected the interpersonal stresses of the caregivers; socio-cultural dimension was aimed at extrapersonal stressors of the caregivers.

According to the results of relevant studies; 76% of caregivers stated that they could not spare enough time for themselves and thus, this situation affected negatively family and social relations; whereas, 40.9% stated that the responsibility of caregiving obstructed other things. Dramalt et al. (1998) and Koyuncu Yasar (2009) indicated that caregivers failed in coping with problems of time and energy, occupational labor loss and daily life while providing care. In their study, Aksayan and Cimete (1998) stated that 66.2% of family members made changes in their domestic tasks due to disease and family members experienced fatigue, anxiety and social life changes.

In the study of Alpteker (2008), those having care burden (24.5%) stated that providing care to the elderly affected family life. Gopalan and Brannon (2006) stated that caregivers experienced social isolation and their domestic roles were also affected. Stetz and Brown (1997) reported that caregivers got usually isolated from previous relations and social interactions due to their responsibilities and roles.

The results of this study are compatible with and support the results of these studies. It was stated that primary caregivers experienced a “decrease” in their relations with others and neighbors, number of friends and time allocated for family, private life, favorite activities, reading newspapers-books, sustaining working life, and income status. This result was associated with the fact that interpersonal and extrapersonal stress were another stressor of the caregivers.

In this study, it was determined that among 12 developmental characteristics used to determine the developmental state of the primary caregivers according to NSM; five decreased, two increased and five remained the same. The caregivers had an average age of 42.43±9.50 and they were at the end of early adulthood (25-45 years) and in the beginning of middle adulthood (45-65 years). According to development theoreticians like Piagét, Erikson, Kohlberg; their most significant characteristics were as follows. Physical changes and familial diseases slowly start to emerge; they have an impaired sleep order, fatigue due to working – stress or decreased activity and mental maturity; consider events from a realistic perspective with their insight and perception; have the skill of arranging data and recalling them well; have efficiency and self-respect; feel isolated and lonely due to their psychological development; could separate themselves from rules and expectations and form their own principles; go beyond social rules; conflict with social values and rules.
In this study, it was determined that among 12 spiritual characteristics used to determine the spiritual state of primary caregivers according to NSM; eight remained the “same” and four “decreased” before training.

In relevant qualitative studies; researchers stated that caregiving enabled individuals to find a meaning. In domestic and abroad studies; researchers determined that the responsibility of caregiving had significant effects on caregivers (Yasar 2008). Oldnall (1996) stated that individuals needed some beliefs that would enable them to explain the meaning of life, troubles, health and diseases and they would start dying in their absence.

The results that are given so far are the results of the study data acquired as a result of questionnaires and focus group interviews. Following discussions are regarding the results acquired by using the Caregiver Burden Inventory for supporting these data and results (Table 2).

Care burden Inventory mean score of primary caregivers was determined as; 50.2 ± 8.7 in the study conducted by Yasar (2008) in Ankara. Total burden mean score was 54.63 ± 21.15 in the study conducted by Akpınar (2009) in İzmir and 43.01±22.99 in the study conducted by Kucukguclu et al. (2009) in İzmir. Care burden mean score was 58.56±16.21 in the study conducted by Koyuncu Yasar (2009) in Mugla. In this study, the total care burden mean score was determined as 65.883±19.5. This mean score shows that caregivers had a higher care burden compared to studies conducted in other cities. This result was associated with the fact that the study was conducted in Kırsehir that is dominated by the Central Anatolian culture.

An advanced significant difference was determined between the total mean scores of the inventory and the data concerning five subscales before and after training (p<0.001 and p<0.05). This result shows that care burden, which was higher before training, could be significantly decreased in all dimensions after training. These results also revealed that training and social support interventions were effective upon decreasing care burden (Table 2).

According to the Neuman Systems Model; primary caregivers constitute the “basic structure” (BS) of the model. In this study, it was determined that primary caregivers had experienced physiological, psychological, socio-cultural, developmental and spiritual stress before training. As resistance rings remained insufficient; these stressors proceeded toward the basic structure and caused caregivers to react in various ways. Secondary protection was provided by training the primary caregivers and third protection was provided by acquiring a support group interaction. As a consequence, the interventions became effective and the stressors were retracted to the flexible defense ring after training and during follow-ups.

In accordance with this study; it is recommended to adopt to use a holistic philosophy in sustaining and extending the training and support group interactions provided to the caregivers.

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