Attitudes and Understandings of the Grandchildren of People with Dementia

Evdokia Nikolaidou[1,2], Magda Tsolaki[2,3], Dimitris Niakas[1], Konstantia Ladopoulou[1]

[1]Healthcare Management, Hellenic Open University, Patras, Greece
[2]Greek Association of Alzheimer Disease & Related Disorders, Thessaloniki, Greece
[3]3rd Department of Neurology, Aristotle University of Thessaloniki, Greece
Email: nikolaidou.ev@gmail.com

Abstract

Objectives: The aim of this research is to explore the attitudes and understandings of the grandchildren of people with dementia regarding: health, dementia, their relationship with their grandparents and their emotional state. The same factors are examined with regards to the children's mothers. Finally we investigate the emotional interaction between grandchildren and mothers. **Method**: Grandchildren (n=50, 14-21 years old) and their mothers (n=40, 40-65 years old) participated in this study. We used the Burden Interview Scale (Zarit) for the mothers, while for the grandchildren we constructed a questionnaire examining the relationship satisfaction, the quality and frequency of contact with grandparents, and the children's emotional state. **Results**: Grandchildren and their mothers living with the patient experience a greater emotional impact and burden than those who do not. The clinical stage of the patient and the nature of their relationship with her/him contributes substantially. There is a positive correlation between the emotional state of the grandchildren and the emotional burden of the mothers. Regarding their own health assessment there is correlation with the gender of the grandchildren. **Conclusion**: Grandchildren understand and accept the symptoms and the health state of their grandparents. There is a particular emotional interaction between mother and child.
Keywords: Dementia, Grandchildren, Satisfaction, Emotional State, Emotional Burden

Introduction

Dementia is a chronic and usually progressive degenerative syndrome (DSM-5 2013). There are several types of Dementia, such as Vascular, Frontotemporal, Parkinson's Disease Dementia and Alzheimer's Disease Dementia. According to the signs and symptoms of the Dementia and their severity, there are 3 stages: the early, the moderate, and the severe stage (Perneczky et al. 2006). Dementia has a major impact on the patient, as well as on his family and close relatives, bringing to the surface further moral, social and financial issues (Luengo-

Fernandez et al. 2011). Currently, in Greece there are not any specialized care centers for moderate and severe stages of Dementia and the existing mainstream model is that a family member or a close relative takes over the role of the caregiver (Miller & Cafasso 1992).

In many cases, the grandchildren of a patient are about to experience or they already experience Dementia through their parents. This experience has a full impact on their emotion as well as on their extended family environment, with a corresponding emotional effect and changes in the roles (Celdrán et al. 2011). The consequences derived thus, may vary from large to stronger scales during adolescence which "by nature" is a period of time where there are strong changes and fluctuations, anyway (Santrock 2003).

AIM

Although the scientific literature on dementia is particularly extensive, the international literature on the relationship between grandchildren and grandparents with dementia is minimal. Only over the last few years has there been an interest in this population. In particular, the trend in the international bibliography mainly focuses on the following areas: a) intergenerational relationships (Ross et al. 2005); b) perceptions of caring (Fruhauf 2006; Celdrán et al. 2011); and c) caring for grandparents (Hamill 2012; Monserud 2011). However, in Greece, the specific topic remains unexplored without corresponding publications.

This study investigates the attitudes and beliefs of grandchildren with grandparents with dementia, as well as their emotional state towards them. Also evaluates the relationship quality, the duration of the contact and how this contact may be affected by Dementia.

The aim is to evaluate a) if the grandchildren and their mothers –as a caregiver- are affected or are emotionally charged by the actual disease, b) if the level of the Dementia and the level of the emotional charge are related, c) whether the emotional burden and the quality of the mother's relationship with the patient affects the emotional situation and the quality of the relationship between the grandchild and the grandparent, d) how much the quality and quantity of the contact is affected by the presence of the disease, e) how the level of the relationship satisfaction is affected, g) at what extend the experience of the Dementia affects the grandchildren's cognitive perception on their own vulnerability and their evaluation of health and g) which demographic factors play an important role. Finally, perceptions over their evaluation of their own health and others' are investigated, as well as the severity class they attribute to Dementia as a chronic disease.

The originality of this research coupled with the absence of relevant literature is twofold: on one hand, it studies the attitudes and feelings of grandchildren in the care of grandparents with dementia and the shaping of their future stances towards their parents when they age; on the other hand, it examines the effect of the role of their mother in the care of the patient with dementia.

Experimental Hypotheses

The experimental hypotheses are summarized as: a) the grandchildren are emotionally affected by their grandparent disease, b) the quality and quantity of the contact are affected by the disease, c) the effect is associated with the stage and the type of Dementia and the burden of the grandchildren mothers, and the quality of the previous relationship, d) the mothers and the grandchildren who reside together with the patient show heavier burden.

Design And Methodology

For the sample collection there was cooperation with the "Greek Association of Alzheimer's Disease and Related Disorders". Questionnaires were distributed amongst teenagers and young adults, all grandchildren of people with Dementia, aged 14-21years old, and their mothers respectively. Fifty grandchildren participated in the study; however 40 of them were selected for the statistical analysis as 10 grandchildren were casted out randomly, one out of each pair of brothers and/or sisters.

Procedure

The participants were given 2 questionnaires each. The first questionnaire was conducted based on the questionnaire by Celdrán et al. (2011), which was revised and renewed adding some more questions. This questionnaire assesses the demographics of the grandchildren, their relationship with their grandparents, the estimation and evaluation of the severity of the disease, as well as their evaluation of their own health and their grandparents' health. The second is the Emotional State questionnaire which assesses their emotional condition towards the diseased grandparent.

The mothers who participated to the study, were given the Zarit Caregiver burden Interview Scale (Zarit et al. 1980), revised (Iatraki 2005). This questionnaire assesses anxiety and the emotional burden of the caregiver. The second questionnaire includes demographics and questions which investigate the quality of the relationship between the caregiver and the patient, the effect of the Dementia on an emotional level and relationship level, and the evaluation of their own health as well as their patient health.

The investigator kept a fact sheet where he/she recorded the cognitive perception of the patient, from the MMSE task (Folstein et al. 1975; Tsolaki et al. 1996). The valid neurological diagnosis of the patient and the clinical condition of the patient was classified in three stages according to the severity of the symptoms. This information were valuable in order to compare whether the relatives are aware of the valid diagnosis and whether there is a statistical significance to the quality of the relationship and the emotional state of the relatives towards the clinical condition of their patient.

The questionnaire of the emotional state of the grandchildren and the Zarit's questionnaire were controlled with Cohen's kappa coefficient. The reliability of both questionnaires was valued by Cronbach's alpha. The coefficient for the first questionnaire equals 0.808, which is believed to be a good score, and for the Zarit questionnaire the coefficient is 0.910 which is believed to be very good score.

Design

Forty (40) grandchildren participated, 19 boys and 21 girls, aged from 14 - 21years old (average 17 years). The mothers who participated, were also 40, aged from 40-65 years old (average 48 years) and years of education 11 years on average. The family relation with the patient was formed as: 37.5% of the cases were their mother, 32.5% were their father and 30% was their father/mother-in law. Thirty three (33) of the mothers were living in their own house whereas the other 7 of resided in the same house with the patient. The people with Dementia (PwD) of the grandchildren which participated in the study, were also 40 (19 men and 21 women), aged from 65-95 years old with average 78.4 years. Their clinical condition was: bedridden (27.5%), ambulatory (26%) and functional (7.5%), with average score on MMSE, 10,76.

The biggest percentage (48% of grandchildren, 56.7% of mothers) of the sample raised as diagnosis Dementia. The valid diagnosis of the patient was correlated with those declared by the mothers and grandchildren. The Cohen's Kappa coefficient was measured to be κ=0.359 which means that there is a small coordinance between the grandchildren's and the mothers' answers (p=0.004). At independent correlations, there was a moderate coordinance (κ=0.528, p<0.001) and between the mothers, a small coordinance (κ=0.285, p=0.001).

Statistical Analysis And Results
The data sample was interpreted by using SPSS 21.0 (Statistical Package for the Social Sciences, IBM Inc., Armonk, NY). On the grandchildren's emotional state, Principal Components Analysis and Factor Analysis were applied.

Each of the questions representing each factor could separate into 8 groups: The first group contains the emotions, such as anger towards the patient, impatience, irritability, shame and embarrassment. All 6 of the variables of this group were answered by the grandchildren as non-representative (70.8%). The second group contains emotions, such as anger towards Dementia and the relative loneliness, where the majority of the grandchildren replied that, were not representative as well (78.7%). The third group contains emotions of insecurity, fear, sadness which comes from the clinical condition of the patient, curiosity, mental confusion, disappointment, guilt and fear for the future. The fourth group contains sadness that comes from the memory of the previous condition of the grandparent, the need for care, the need for love, the satisfaction for understanding these needs, the sense that he/she is useful and the sense of absence of the previous relationship. The fifth group contains the feeling of rejection, the sixth group contains envy, the seventh contains fear that someone may fool their grandparent and the eighth contains the satisfaction from the aid he/she offers (Table 1).

Descriptive Results
The duration of contact did not show a significant difference, but there was a small decline to the present situation of the disease. Before Dementia onset, high percentage of the grandchildren (45.7%) stated that was contacted "daily" to "few times a week", but to the present situation was "few times a week" (28.6%) to "few times a month" (22.9%). On the quality of the relationship there was a change varying from "very good" (95%) to "good-typical" (77.5%). The satisfaction level of the relationship before the Dementia onset, was stated as "very much" (45%) to "very satisfied" (32.5%), and in the present situation, was stated as "enough satisfied" (30%) to "less" (27.5%). Also the majority of the grandchildren replied that their relationship was affected "enough" (35%) to "less" (25%) due to the Dementia, and this change was characterized as negative (85.7%).

Half of the grandchildren sample reported that they participate to the care of their grandparent with average 10.26 hours per week. They dedicate their time to offer company to their grandparent (65%), they help with the groceries (32.5%), they accompany them to their walks (20%), they help them to take their medicines (20%) and they help their parent to the care given to the patient (27.5%).

From the 27 emotional states of the questionnaire used by the grandchildren, the emotions mentioned as non-representative which gained the higher scores were mostly negative and dismissive, such as anger (57.5%), shame (75%), disappointment (42.5%), and guilt (42.5%). On the other hand, they seem to be represented by positive emotions that show acceptance such as love (65%) and satisfaction (35%).

Both the grandchildren and the mothers graded with a 4.18 ave. to the 10-factor scale. This score shows a total agreement to the perception of the health of their beloved one. The perception of the grandparents' health did not seem to affect the emotional condition of their grandchildren, as they scored an average 5.7 on the corresponding scale and, on contrary, there is an emotional effect to the mothers which they scored an average 7.03.

The Relationship With The Patient And The Emotional State Of The Grandchildren
On the statistical analysis the p-value was defined as p<0.05.
There was no difference in the emotional state of the grandchildren between the factors of the question regarding the frequency of contact (p=0.309). Also there is no significant difference between the group of the grandchildren who reside together with their grandparent and the emotional charge this might have compared to the grandchildren who do not reside with their grandparent (p=0.291).
On the quality and satisfaction in the present situation, the results obtained, showed that there is no significant difference to the emotional state of the grandchildren in between the factors of these two variables (quality: p=0.614 and satisfaction: p=0.367). Also, there is no significant difference to the change of the relationship and the emotional state, either (p=0.528). The same applies when t-test was performed between two groups: the group that reported that the relationship was changed in a positive way, to the group that reported that the relationship was changed in a negative way (p=0.088). Finally, in the correlation of the variables of the emotional state and the effect these had to the family liaisons, there was no difference (p=0.604).

The Mother's Burden And The Emotional State Of The Grandchildren
Pearson correlation was applied, resulting to the fact that the emotional state of the child increases when the emotional burden of the parent increases as well (r=0.346, p=0.029). This rapport is illustrated with a linear regression (Table 2).

Demographics And Clinical Condition Of The Patient
The clinical condition of the patient affected the emotional state of the grandchildren (0.038), as well as their mothers' burden (0.027). Grandchildren gave greater scores to their emotional state, in cases where their grandparent was bedridden (Mean ±Std. Deviation: 37.1±14.2) compared to cases where the grandparent was functional (Mean ±Std. Deviation: 18.0±5.0) (p=0.041). The score of the grandchildren's emotional state where the patient is ambulatory, is greater (Mean ±Std. Deviation: 35.6±6.9) compared to when the patient is functional (Mean ±Std. Deviation: 18.0±5.0) (p=0.046) (Table 3).
Respectively, the mothers' emotional burden scores were greater in cases where the patient was bedridden (mean ±Std. Deviation. 38.6±14.1) than functional (Mean ±Std. Deviation: 14.0±1.0) (p=0.036) (Table 4).
There was a significant difference between the grandchildren's evaluations on their grandparent health and their grandparent clinical condition (p<0.001). The score was lower when the patient is bedridden (Mean ±Std. Deviation: 1.7±1.8) compared to the ambulatory patient (Mean ±Std. Deviation: 4.9±1.6) (p<0.001) and the functional patient (Mean ±Std. Deviation: 6.3±1.1) (p<0.001) (Table 5).
Finally, there was a significant correlation between the clinical condition of the patient and whether the relationship changed due to the disease. The grandchildren, whose grandparent was bedridden, stated that their relationship was significantly altered (Table 6).

Discussion

Grandchildren seem to be affected emotionally from their grandparent health condition (Celdrán et al. 2011). What is the most important for the grandchildren has been expressed to be their love –as it is- towards their grandparent, the satisfaction they receive when they care for them, when they manage to understand what their grandparent needs in a certain situation, the sadness they feel when the relationship constantly modifies, and the fact that they are missing the previous relationship with their grandparent. Emotions like anger, fear, insecurity and reject were not stated by the grandchildren as representative.

An important role to the emotions seems to play the quality and the satisfaction level of the previous relationship with the grandparent. An emotion, like love, remains unaltered and untouchable despite the disease. This means that the relationship, which is emotionally important and is dominated from mutual support, constitutes an important pleat to the shaping of their identity, as well (Ross et al. 2005). These dominant emotions which are representative of the particular age group basically indicate that the relationship is characterized by unconditional love. This is confirmed by the emotional notion "I love my grandfather/grandmother as he/she is" (65%).

The satisfaction derived from the aid the grandchildren offer towards their grandparent and the understanding of what their grandparent needs, refers to the quality of their previous relationship. The grandchildren state that they feel useful for their parent to the care of their grandparent (37.5%). These findings seem to be consistent with the findings of the Spanish study, on these three variables (Celdrán et al. 2011).

The grandchildren come face to face with a type of loss. Grandchildren are challenged to constantly adjust to the new conditions and through the experience of loss to give meaning. They get sad with the changes and they recollect the previous relationship with their grandparent. The greater emotional charge was seemed to be when the beloved one was in an advanced stage of Dementia. The majority of the grandchildren replied that their relationship was affected due to the Dementia, and this change was characterized as negative. This parameter is not consistent with the results of the Spanish study where the majority reported that did not note any significant changes (Celdrán et al. 2011).

The grandchildren who reside together with the patient did not show great scores in their emotional state compared with those who reside apart. These results contradict the initial hypotheses of the study. Those who live together with the patient, experience, on a daily basis, the symptoms and the course of the disease, as well as the impact of the disease into the family system. The grandchild plays the role of the indirect caregiver so he/she has a bigger sense of responsibility and that plays a key role to the shaping of his/hers identity both for the role as a caregiver as well as his/her future position into the family (Ross et al. 2005).

Emotional Interaction Between The Mother And The Child

As the burden of the mother gets heavier, the child's relationship towards its grandparent gets further emotionally charged, too. The emotions of a child can be affected by the emotional environment inside the family system, by the type of the relationship, and by the way these emotions are expressed by the child (Morris et al. 2007). The mother's emotions and how she handles the management of stressful situations seem to affect both the child's emotional state as well as the way he/she involves with his/her grandparent (Simpson & Rholes 1998).

Perception Of Health

Dementia is a disease with no actual "visible" signs, at least during the early stages of the disease. The grandchildren's evaluations were deeply affected from the stage of the disease their grandparent was in. For example, they would evaluate their grandparent health as "poor" when the stage of Dementia was advanced, with visible signs. The form that grandchildren evaluate other peoples' health could be related to the functioning of that person and his/her abilities to correspond effectively to his/her social needs (Parsons 1979). Interestingly, the evaluation of the patient's health, as well as the diagnosis of the grandchildren was consistent with the evaluation and diagnosis of their mothers. This could probably indicate that basic issues such as the attitudes one has towards health issues, are defined by learning and effectiveness of the important close relative. For a teenager or young adult, family and peers are significant influences to his/her perceptions and beliefs (Lau et al. 1990). In this particular case, the mothers' perceptions on the evaluations of health and diagnosis of the patient influenced, also, the perception of their children on the same matters. Regardless the age, the child is capable to review and recognize the nature and gravity of a disease (Papadatou and Anagnostopoulos 1999).

Limitations

Several factors limited the flow and process of the study. The number of the questionnaires that were actually filled in completely was limited, mostly because the participants were not accustomed to the methodology of the study. Other important factors were the difficulty of finding grandchildren to participate aged 14-21 yrs., as well as the valid diagnosis of the patient. So, the sample assessment was obtained only from the "Greek Association of Alzheimer's Disease and Related Disorders". The conclusions of the study, thus, cannot be generalized and they drive to the need of further investigations and studies.

Conclusions

The family dynamics are affected when the roles and the balance change. Family relationships are interconnected and every change in the family system has the subsequent effect to every of its member separately. Grandchildren have naturally, emotions of their own and so they perceive Dementia through these emotions. However, they seem to be affected by their mothers' burden or by the progress of the disease of their beloved grandparent. Grandchildren have an active role to the care given to their grandparent without limiting their own activities. In many cases, adolescents and young adult grandchildren of patients with dementia, whose mothers are caregivers, participate in the care of their grandparents and are emotionally affected by the disease but also by the burden on their mothers. Nonetheless, this experience may be an opportunity for maturation. This emotional effect and sequence is related to the type of the previous relationship and the current relationship, which were evaluated according to the quality, the frequency and the satisfaction from the relationship. In order to better serve the family, it is suggested to create support and psycho-educational programmes for the grandchildren of patients with dementia, especially for those living together, as part of the overall patient and family support. All the grandchildren's thoughts, behaviors and emotions as well as their attitude, perception, beliefs and stereotypes related to Dementia, remain a very interesting field for future research. The international literature on the matter is limited and in Greece is minimal to none. The next generation is a very useful source of information which can teach to older generations. Further research is required as

grandchildren with their attitude may have to teach a lot to elder family members as far as the acceptance of the patient with dementia and the behavior towards them are concerned.

References
Celdrán, M., Triadó, C. & Villar, F. (2011). "My Grandparent has dementia": How adolescents perceive their relationship with grandparents with a cognitive impairment. *Journal of Applied Gerontology*, 30(3), 332-352.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198.

Fruhauf, C.A. (2006). Grandchildren's Perceptions of Caring for Grandparents. *Journal of Family Issues*, 27(7), 887-911.

Hamill S.B. (2012). Caring for Grandparents with Alzheimer's Disease: Help From the "Forgotten" Generation. *Journal of Family Issues*, XX(X), 1-23.

Iatraki, E. (2005). I frontida ton asthenon me anoia se epilegmenes astikes kai agrotikes periohes tis Kritis: anaphora stin epivarinsi ton frontiston [The care of patients with dementia in selected urban and rural areas of Crete: reference to caregiver's burden (postgraduate research)]. Medical School, University of Crete, Heraclion.

Lau, R.R., Quadrel, M.J., & Hartman, K.A. (1990). Development and change of young adults' preventive health beliefs and behavior: influence from parents and peers. *Journal of Health and Social Behavior*, 31, 240-259.

Luengo-Fernandez, R., Leal, J., & Gray, A.M. (2011). Cost of dementia in the pre-enlargement countries of the European Union. *Journal of Alzheimer's Disease*, 27(1), 187-196.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or Artifact? *The Gerontologist*, 32(4), 498-507.

Monserud M.A. (2011). Changes in Grandchildren's Adult Role Statuses and Their Relationships with Grandparents. *Journal Family Issues*, 32(4), 425-451.

Morris, A.S., Silk, J.S., Steinberg, L., Myers, S.S. & Robinson, L.R. (2007). The Role of the Family Context in the Development of Emotion Regulation. *Social Development*, 16, 361–388.

Papadatou, D., & Anagnostopoulos, F. (1999). *I psichologia sto horo tis igeias [Psychology in the health care system* (3rd ed.)], Ellinika Grammata (pp. 215-241). Athens.

Parsons, T. (1979). Definitions of health and illness in the light of the American values and social structure. In Jaco, E.G. & Gartley, E. (eds) *Patients, physicians and illness: a source book in behavioural science and health*. Collier – McMillan, London.

Perneczky, R., Wagenpfeil, S., Komossa, K., Grimmer, T., Diehl, J., & Kurz, A. (2006). Mapping Scores Onto Stages: Mini-Mental State Examination and Clinical Dementia Rating. *The American Journal of Geriatric Psychiatry*, 14(2), 139-144.

Ross, N., Hill, M., Sweeting, H., & Cunningham-Burley, S. (2005). *Grandparents and teen grandchildren: Exploring Intergenerational Relationships*. Centre for Research on Families and Relationships and The Economic and Social Research Council, University of Glasgow .

Santrock, J.W. (2003). *Psicología del desarrollo en la adolescencia [Adolescence]*. New York: McGraw-Hill.

Simpson, J.A., & Rholes, W.S. (1998). *Attachment theory and Close relationships*. Guilford Publications, New York.

Steinberg, L., & Morris, A.S. (2001). Adolescent development. *Annual Review of Psychology*, 52, 83-110.

Tsolaki, M., Fountoulakis, K., Chanzi, E., & Kazis, A. (1996). The Cambridge Cognitive Examination for the elderly (CAMCOG). A validation study in demented patients from the elderly Greek population. *Encephalos Journal* (Εγκέφαλος), 33, 57-75.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*, 20(6), 649-655.