

life after care



A Report on Greek Former Carers



Athens Association of Alzheimer's Disease and Related Disorders

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Table of Contents



OVERVIEW REPORT – CARING AND POST-CARING IN GREECE

Introduction	5
Background	5
The population in Europe and Greece	6
The carers in Europe and Greece	6
Profile of family carers	7
Caring experience	7
Health impact	8
Psychological impact	8
Quality of life	8
Post-caring experience	9
The post-caring void	9
Closing down the caring time	10
Constructing life post-caring	10
Aim of the study	10
Methods	11
Sample characteristics	11
Assessment tools	12
Interview	12
Results	14
During Caring period	14
Post-caring period	17
Conclusions	19
References	20

OVERVIEW REPORT

CARING AND POSTCARING IN GREECE

Introduction

This overview report presents the outcomes in caring and post-caring in Greece within the framework of “Life After Care” Project. This project funded by the European Programme “Grundtvig” and carried out by the partnership of British, Irish, Italian and Greek non governmental organizations. The “Life After Care” Project aims at exchanging ideas and good practices about caring and post-caring experience in Europe, supporting the transition from the role of carer to the role of former carer on local and national level and aiding their reintegration into labor market or volunteering activities.

Background

The demographic developments in Greece and the European Union, including the ageing of the population, the rise of employment rates amongst the women over 45 years of age, the rise in single-person household, in divorce, in small families and geographical mobility from rural to urban areas, make the issue of health and social support of older people a key policy issue for Greece for the coming decades. Additionally the socio-economic changes occurring in Greece and other European countries suggest that if family carers continue to take on the responsibility for older family members, the state must offer some forms of support¹.

The support services for family carers vary considerably throughout Europe, being virtually non-existent in several countries and piecemeal and fragmented in a number of others. The Pan European Background Report, based on 23 national reports, suggested the existence of three main models of support: 1) Scandinavian model – typified by Sweden, where the emphasis has traditionally been on supporting the older person and dedicated services for family carers are beginning to emerge, 2) Southern European or family model – typified by Greece, where the primary responsibility for supporting older people rests with the family and where public services to support family carers are limited or non-existent, unless in cases of extreme economic hardship or the absence of family, 3) a smaller group of countries – where carers are recognized as citizens with specific rights. These include the UK, Ireland and Netherlands².

At that time, services for older people were very slowly developing and there was a little recognition of the needs of family carers for support³. Virtually family carers remain “invisible and undervalued” in many countries⁴, even though the unpaid caregiving contribute to the state in economic aspect⁵. The caregiving affects carers’ well being and quality of life, their health and socio-economic status and for those reasons the state has to develop supporting services for unpaid caregivers.

The population in Europe and Greece

In general, the population in Europe is living longer, expected to gain an extra five years in life expectancy by the year 2050⁶. It is estimated that the number of people aged 65+ will increase by 3-quarters between now and 2050. In the same period, the ratio of depended elderly is expected to double⁷. The proportion of the population over the age of 65 will almost double over the next 40 years, from 17% in 2005 to nearly 30% by 2050⁸. The very old (people over 80 years of age) in the EU will rise from 4,1% of the population in 2005 to 6,3% in 2025 and 11,4% in 2050⁹.

Greece has become the nation with the highest percentage of ageing population in the European Community. Although in 1993 12,3% of the Greek population consisted of citizens of 65+ years old, by the year 2050 it's estimated that this percentage will rise to 21,1%¹⁰. Similarly citizens 80+ years old will have risen from 2,2% of the entire population in 1990 to 5,2 by the year 2010¹¹. The WHO estimates that 5% of the total Greek population are in need of daily care rising to 7% and about ½ of those needing daily care are older people, although the proportions are predicted to rise within the next 50 – years¹².

The carers in Europe and Greece

The carer is a generic term referring to a person, either paid or voluntary, who helps an older person with the activities of daily living, health care, financial matters, guidance, companionship and social interaction. A caregiver can provide more than one aspect of care. Most often the term refers to a family member or friend who aids the older person¹³. Usually refers to informal, unpaid assistance for the physical and emotional needs of another person. Family members or friends frequently provide this type of care¹⁴. An informal carer has been defined by Eurocarers as “a carer that looks after family, partners, friends or neighbors in need of help because they are ill, frail or have a disability. The care they provide is unpaid”¹⁵

Estimates of the numbers of carers in the EU may vary due to a number of factors, such as different definitions of a carer and the methods used to identify carers. The most recent source of EU-wide data concerning carers is the second European Quality of Life Survey (EQLS)¹⁶, which does not estimate the actual number of carers in Europe, but it gives a picture of the activities of a significant number of the adult population¹⁷. In the EU 27, 3% of people state that they care for an elderly or disabled relative several times a week, 4% do it once or twice a week and 8% do so less than once a week. Altogether, a quarter of people report being involved in caring for an elderly or disabled relative; amounting to 125 million carers in Europe.

The family continues to be very important for the Greek society. Informal care is a common phenomenon across many countries. In Greece, there is a great number of informal carers but there is no official data about the accurate number of family carers¹⁸.

Profile of family carers

In all countries, women are more likely to be carers and are also more likely to provide more physically intimate, emotionally demanding and longer term care¹⁹. Most carers of those who report that they care for an older person every day are in the 50-64 age group (9%) followed by the 35-49 age group (7%). The vast majority of women in the middle years of life may assume care responsibilities for both elderly dependents and children, as well as possible paid employment²⁰. The concentration of carers in the 50-64 age group highlights that the majority of older people are care receivers and the role of adult children in providing that care²¹. Using data from England and Austria it is estimated that between 2% and 4% of all children and young people have care responsibilities, usually as a result of chronic illness or disability of a parent²².

According to the Eurofamcare results²³ the mean age of Greek family carers was 51,7 years though the actual range of carer ages was from 18-95 years. This made them slightly younger than family carers in other countries. Women were overwhelmingly the main providers of care, representing 80,9% to family carers and these findings are similar to the findings for other countries. The 76,4% of the sample of family carers were married or cohabitants, of whom the 17,1% were spouse carers, 6% were widowed, 5,7 were divorced or separated and 12% were single. In total 20,2% of the carer sample reported having no children. Of those who had children the main number were 2 with a maximum of 8 children. Of all family carers just 1,1% were of non Greek origins. The education level of carers was relative low, 37,4% had a low level of education, 40,6% had an intermediate level and 22,1% had a high level of education. In Greece 47,2% were still working for meanly 40 hours with a maximum of 140 hours a week. The findings showed that the family carers of a dependent person shared the same household in 50,7% of the sample. Additionally family carers were asked to add up all sources and give up an estimate of their total household income per month and the mean amount was 1093€. The mean number of hours of care given to the main dependent cared for person was 51 hours per week. Finally the majority of family carers (80,9%) cared for just one dependent older person, 16,8% were caring for 2 older dependent persons, while 2,3% were caring for 3 or more dependent older people.

Caring experience

The caring experience is a complex phenomenon and it can dramatically impact on all aspects of the family member or family. Caring negatively affects the physical, psychological, emotional, social and financial status of the caregivers, outcome commonly described as “caregiver burden”²⁴. It is well established that the caregivers of those with dementia have high levels of burden compared to other caregiver groups²⁵ and their caregiver role has been described as the “36-hours” day²⁶.

■ Health impact

Caring is associated with changes in physical health status through multiple pathways. Caregivers report poorer levels of health, a great number of physical symptoms and more chronic illnesses. In addition, they report slow cicatrization and hypertension. Several studies have found that caregivers, particularly those under considerable stress or a little opportunity to respite, have increased markers of nervous system activation and as a result of that they are vulnerable to stress and have increased risk of cardiovascular diseases. Furthermore they are complaining of exhaustion and distress. Caregivers are more likely to use drugs and they see a doctor more often than control groups. A prospective study found that the relative risk for all cause mortality among older spousal caregivers experiencing caregiver strain was 63% higher than that which was seen in non caregiving controls. Caregivers are less likely to engage in preventive health behaviors than their non-caregiving counterparts²⁷.

■ Psychological impact

Caregivers are more likely to experience depression and stress due to their caregiving role. They are anxious about the progress of the illness and they wonder if they would be able to deal with their new role. Family carers often report feeling anger and guilt about their behavior to demented relatives and their feelings. They also feel ashamed and disappointed of their relatives' socially unacceptable behavior or worrying about not taking care in the proper way. Additionally, loneliness is crucial to their life, especially in cases when the partner take care of the loved one. The caregiving experience includes a process of grief as the carer has to accept the loss of the premorbid period and the previous relationship with the relative and adapt to the new fact after the dementia onset^{28,29}.

■ Quality of life

Because a person with Alzheimer disease often loses the ability to perform the activities of daily living, caregivers devote time and energy to helping them with daily tasks. A caregiver may argue with a spouse or with other family members over how to manage the care receiver's needs. Caregivers sometime feel unappreciated and neglected by others. They may also have to limit the time and energy they invest in relationships or in their jobs. The caregiving role leads to social isolation and provoke difficulties in occupational responsibilities. The caregiving experience many times affects the financial status due to the expenses for patients' needs and/or decrease of income when the family cares are obligated to have a part time job or quit their job. Last but not least the patient's needs and his/her behavioral symptoms often causes sleeping disorders in the caregiver.^{30, 31,32,33,34}

The majority of findings show it is not the "objective" load from the patient that directly determines burden levels but the "subjective" interpretation by the carer and the subsequent coping of the carer. According to Campell et al.³⁵ the most important predictors of the caregiver burden are: caregiver overload, family disagreement, role

captivity, caregiver confidence, neuroticism, adverse life events, relationship quality, caregiver age and gender, kinship.

Post-caring experience

A former carer is someone who does not necessarily identify himself as a former carer but has experienced an episode of caring in the past that ended with the end of their dependant. This caring was not carried out on a professional basis benefits excluded, was unpaid³⁶.

There are few published reports on the post caring period, but there is strong evidence to show that the psychological, social and physical health consequences of caring may leave some family carers poor equipped for life after care. Ex carers experienced a variety of emotions in the post-care period. For those whose dependants had died, there was often an intense initial feeling of loss. The natural feelings of grief arising from the death of the parent were compounded by the intensity of the care that had been given.

A second consequence of the demands of caring can be a loss of confidence or self-esteem, which also carried over into the post-care period. The impact of caring in social contact and activity was noted by many carers. It was seen to be caused by the practical demands of caring, disengagement from employment, reduced income, loss of personal confidence, all of which had a major effect at the time of caring. For some people social networks had become too fractured, or they had lost the habit of socializing.

Certainly some of the ex carers had suffered from health problems whilst caring which had not received the attention or treatment they should have had. The most commonly mentioned problem is physical tiredness, exhaustion and back problems caused by regular lifting. According to McLaughlin, the ex carers deal with a reduced income from lowered or no participation in employment³⁷.

The Larkin's study³⁸ established that the post caring life had an identifiable trajectory with three phases, each of which involve a distinct set of experiences. These were "the post caring void", "closing down caring time" and "constructing life past caring".

■ The post caring void

The majority of those interviewed reported experiencing a void in their lives after caring ceased. This experience can be in part attributed to the death of the person who was their dependant. One dimension was a sense of a loss of purpose because the purpose in life had gone. Another dimension to this void caused by the cessation of caring was the experience of disequilibrium.

■ Closing down the caring time

During this transitional period routines changed and closure activities were undertaken. Such changes in routine involved changes in the sentient work caring had entailed. Routines in their social lives that had been established during caring also changed. Similarly some activities in this period involve closure tasks, such as sorting out funeral arrangements, paperwork and financial and legal issues that are inevitable after any death.

■ Constructing life post caring

This involved getting “life together” again, and “coming up to the surface”. The amount of time spent on hobbies expanded post-caring for the majority of those interviewed. These included sports activities, adult education classes, walking, gardening, taking holidays and voluntary work. Furthermore, the ex carers involved with carers group and carers centers associated with caring for people with illnesses and disabilities.

These phases in the trajectory were not experienced in a particular sequence and there was overlap between them. However, the “post caring void” and “closing down the caring period” were transitory for all and did seem to be followed by the “constructing life post caring” phase.

■ Aim of the study

There is no data concerning ex Greek carers. A deliverable of the Grundtvig Project “Life after Care” is to investigate this specific population. In this framework, Athens Association of Alzheimer’s Disease and Related Disorders, conducted semi-structured interviews to ex carers who have used the services offered by our organization. All data and reports are uploaded to project’s website www.lifeaftercare.eu

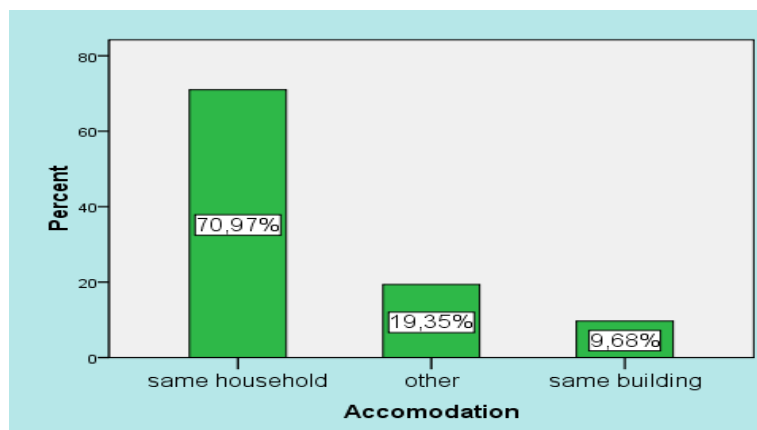
METHODS

Sample characteristics. 31 former carers have participated in this study. The participants were users of Dementia Day Care Centres and the Home Care Programme for dementia patients of Athens Association of Alzheimer's Disease and Related Disorders whose relatives have passed away.

87,10 % of ex carers are women and only 12,90% are men. Mean age of the participants was 59 years and mean years of education were 13.

48% of the sample are children of people with dementia, 41,9% are spouses and 9,68% are other relatives (nephews, brothers etc). 32,3% of former carers are in the range of age 55-64 and 22,6% are between 65-74 years of age. 48,4% have secondary education and 45,2% has tertiary education.

We didn't limit the post-caring period and we included all former carers that accepted to participate to this study. Mean time of relative death was 17 months, with a wide range from 2 months to 72 months. 58,06% of the participants has ended caring in a period between 1 – 12 months, 19,35 % in the range of 13-24 months, 19,35% in the range of 25 – 36 months and only a small percentage of 3,23% has ended caring after more than 37 months.



Graph 2. Percentages of accommodation for ex carers during their caring period

Assessment Tools

■ Interview

The interview was conducted by telephone scheduled appointments. Two psychologists with expertise in counselling and dementia conducted the interviews. The interviewers first completed a short form with epidemiological data: age, education, accommodation, financial condition, health problems, ex carers' period in months, external aid to the carer (annex I) and then they continued to the main body of the semi structured interview, which consisted of 3 parts:

Part 1 – Explore how the person became a carer. Most significant steps and most important changes in individual biography (4 questions)

- Which was your caring experience? What kind of problem / disease your relative had? How was the course of the illness?
- When did you start thinking that assistance might have been a commitment? Is there a specific episode that made you think: "it's my turn now!"
- Which were the reasons/feelings/thoughts that made you to take the responsibility for the care (e.x. only solution, duty, love, financial reasons)
- Could you divide the period of assistance in significant steps?
- Could you list the most significant change in your daily life due to caregiving (es. Concerning work, social life, hobbies...)?
- What have you done to feel better? How have you coped with these changes?

Part 2 – Explore the caring experience with BEI Method. Which were the most significant tasks of your caregiving experience? Could you please make a list? (8 subquestions)

- Which were your main tasks as a carer? Could you list them?
- Which had been the most critical events?
- Which was the situation? Who was involved? What did you think / feel / do in that situation? What did you want to do / or what were you motivated to do? What did you actually do? (*these questions can be repeated for more than one event*)
- Could you please tell me one or more episode in which you felt particularly effective?
- Which was the situation? Who was involved? What did you think / feel / do in that situation? What did you want to do / or what were you motivated to do? What did you actually do? (*these questions can be repeated for more than one event*)
- Who did you meet regularly in that period? (*Design a map of his / her relations, specifying intensity and type of contacts*).
- At the end of this experience, what do you feel you have learnt? Both in terms of feelings then concerning skills and knowledge? Which of these aspects you have used / you think can be useful in your life nowadays?
- How do you feel you have changed?
- Submit a semantic differential on prevalent emotions / behaviours referred to those days: In control / overwhelmed, Frustrated / stimulated, Depressed / active, Happy / sad, Useful / Not useful, Good / Bad

Part 3 – transition from the role of carer (4 questions)

- Which were the most difficult moment after the loss of your relative / friend / partner? What did you do / feel / think? What did you think about other people involved? What did you *want* to do? What did you do? How did it end? What happened? Who or what was more helpful?
- How has your life changed? How is your daily life / routine changed?
- Who are the people that you meet regularly? (*Design a map of his / her relations, specifying intensity and type of contacts*).
- Re-submit the semantic differential on prevalent emotions / behaviours referred to nowadays

This interview was provided by Anziani e Non Solo società cooperativa and Arco, the two Italian partners of the Grundtvig partnership “Life after care” and was back translated from English to Greek and Greek to English from expert in dementia with English language proficiency. There was a pilot phase where the interview was conducted to 3 ex carers and then adjusted to Greek Research Protocol adding to Part 1 two questions: “which was the reason/thoughts/feelings that made you decide to become a carer” and “what have you done to cope with the changes in daily routine?” and to Part 3 one question “what have you done to cope with the changes after the loss of your relative?”

Part 2 consists of BEI method. This method tries to identify skills acquired by carers during the caring experience (aka BEI Method). The basic principle of this method is that you can't rely on what people think or say about their own motivations or skills. But you can rely on what people actually do to face critical events. This interview also allowed us to collect general information about problems faced by carers in their transition to post-caring. This aspect was analysed in the Greek interviews and wasn't approached of the competences aspect.

RESULTS

62,1% of former carers are not facing any health problems and 37,9% of the sample have answered that they are facing health problems.

During Caring

When the interviewers asked the participants – which was your caring experience - 64,5% answered that they would describe this experience as difficult, 16,1% as depressive, 12,9% as stressful and 6,5% as useful.

“It is a quite difficult situation. Stress is the hardest part. You are hyper vigilant, as the disease is progressing”

“It is difficult. You must be there day and night”

At the question – which were the reasons/thought/feelings that made you take the responsibility for the care, 64,5% give as an answer that love was the main reason, 16,1% obligation, 9,7% financial reason and 9,7% answered then had no other solution.

“He was my partner in life. We lived together for 55 years. Emotional reasons made me look after him”.

“I have never thought that I could do anything else. It wasn't an obligation. I know he would do the same thing for me. I believe that emotional reasons made me decide to be a carer. I was with him 45 years, I wanted to be responsible for him”.

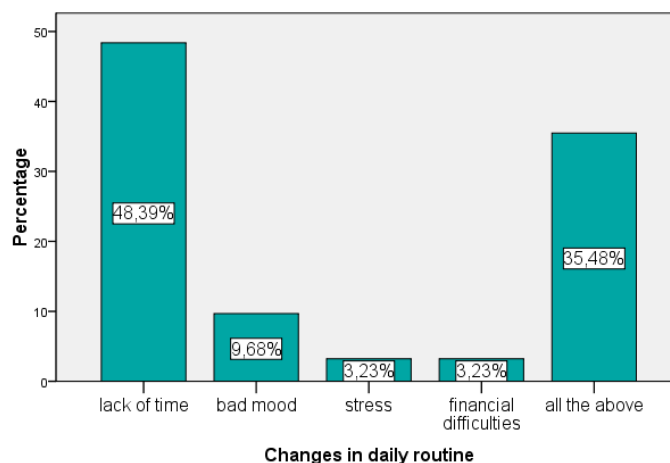
“There was no other solution. I was the only responsible”.

58% faced caring as commitment and 80,6% thought to be efficient as carers.

“I didn't feel insufficient. At the end stage there wasn't much I could do to help him. I just helped the paid carer. I didn't want to do anything else. People said that it is not regular for a wife to take so good care of her husband”.

“You can't ever feel efficient. Everything happens out of your control and you must accept. It would be different if we have seen it earlier and offer her help immediately. We did what doctors said, but with no improvement. You must have patience. Everything we said he never remembered”.

At the question - Could you list the most significant changes in your daily life due to caregiving (ex. concerning work, social life, hobbies...) - 48,4% answered that the major change in their daily life was the lack of personal time, 35,5% mentioned a combination of changes, as lack of time, bad mood, stress, financial difficulties. For 9,7% bad mood was the main change in their lives, for 3,2% stress and for another 3,2% financial difficulties (Graph 2).



Graph 2. Changes in daily routine during caring period

“My everyday life changed significantly. I had no personal time. We went everywhere together. I preferred to spend time with him and to help him socialise. My whole life had changed. I was sleeping with only one eye shut and with one ear stand by in case something would happen. I was all the time alarmed and I didn’t understand how tired I was feeling, something that I see now. After his death I collapsed”.

“Many changes... I was like a robot. I didn’t look after myself. I ought to check my blood pressure and take care of myself, but I didn’t have time to do that. I had no time. I didn’t sleep well and I had nightmares. I had hypertension and heart disease. One thing that didn’t change was our finances. We had taken in mind our expenses when we would become old. I couldn’t visit my grandchildren, or go to any fests. If somebody wanted to see us, he should visit us at home. I had no time to go to church, but instead of that I brought a priest at home”.

At the question-What have you done to feel better - 54,8% answered then hadn’t done anything, 22,6% started outdoor activities, 9,7% indoor activities, 3,2% activities with the patient, 3,2% voluntarism, 3,2% psychotherapy.

“I didn’t do anything. Caring was something I liked. Sometimes I went to church or I talked to my relatives. Children sometimes helped me with the housekeeping”.

“I didn’t do anything. There is nothing that can make me forget. Even when I was at work I held my mobile phone in my hand. I don’t believe that someone can escape of this situation. Only when we had a good paid careworker, the stress was less”.

At the question – Which were your main tasks as carer- 58% has answered that practical issues (hygiene, medication) were the main duties, 22,6% found reinforcement as the most important duty and 19,4% a combination of the 2 above answers, reinforcement and practical issues.

“Hygiene... He must be clean. His nutrition is important too. He must visit often his doctor and do all the required exams”.

“It was important for me to take care of his hygiene, to be close when he walked around, because I didn’t want him to fall. ... to shave him, feed him and all that”

At the question – which were the most critical events- 31% said the neuropsychiatric symptoms, 20,7% falls, 17,2 environmental factors, 17,2% severity of the disease, 13,8 physical health problems.

“He had hallucinations and sometimes he yelled. At other times he refused to go to Dementia day care centre. Often he went out to the balcony and asked for help because he was a hostage. I tried to calm him down. Another time when we walked in the metro station, I was afraid of him to start yelling and would make us look like fools. I tried not to isolate him. He would come with me everywhere I went”.

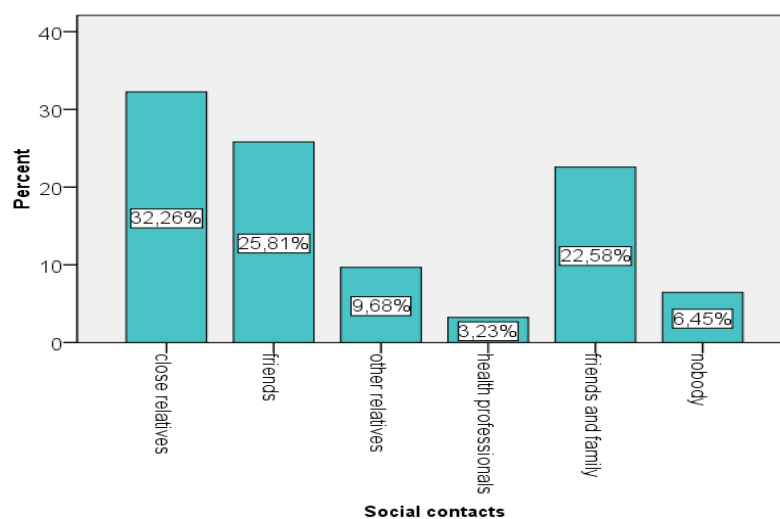
“She often fell. I was back at home once and I saw her on the ground in the toilette. I pulled her out and she was happy. I had no patience. I had edgy temper. When she answered me nonsense I would lose my temper and I yelled at her. I couldn’t do anything different. I was a human too”.

58,1% of former carers said that their relationship remained stable during the caring period, 25,8% stated that the relationships have worsened and 16,1% stated that the relationships have improved. 32,26% has continued to receive support from close family, 25,81% from friends, 22,58% from friends and family, 9,68% from other relatives, 6,45% from nobody (Graph 3).

“My uncle was there for me. I was also seeing a therapist, my friend, my husband. My relationships remained stable. My mother was in bad mood and had problems with her sleep”.

“I was seeing nobody. I had help from no one... Only me and my mother.... I tried with my relatives but no luck”.

“I met my friends once a week and of course my children and sister. My relationships remained stable. Everybody did everything they could. They were my support system. I knew that if I need help I could find it from them. I was always like that. He didn’t want me to have many friends and that didn’t change afterwards”.



Graph 3. Percentage of former carer’s social contact during caring period

Post - caring period

61,3% of the participants has answered that has recovered from the loss of their relative, 19,4% is in a transitional phase and 19,4% hasn't recovered yet

Former carers estimate in 54.8% positively the changes that they have experienced after their relative's death and only 22.6% negatively. They appreciate care management to be the greater gain (51.6%) and patience (38,7 %) of their caring experience.

"You gain knowledge of every experience you live. I have learned to handle difficult medical conditions and that is very important issue because I have seen my boundaries. I have also learned about Alzheimer's disease management, something that I didn't know".

"I have learned the importance of prevention. The things would be different, if I knew that earlier, probably the course of the disease would be slower. Now I go more easily to doctors".

"I have learned to be patient. It was a great joy for me not to get help from another woman. My children insisted to hire a paid carerworker but I didn't want to. I knew that my husband didn't want her".

The changes that former carers recognize in their daily lives are: loneliness (16,1%), bureaucracy (12,9%), leisure time (29%), negative feelings (19,4%), positive feelings (12,9%), no change (9,7%).

"I am in a transitional phase. I don't cry all the time now but I am angry with our Greek social system. We must take care of pensions etc. I haven't gone yet to live with my daughter, because I love this house and I am not ready yet. I admire voluntarism, but I cannot do that yet. I can't stand hearing about Alzheimer 's disease anymore. I am afraid about me and my children".

"Now I feel lonely...There is a new situation. I had learnt to live with my mother and I was always there. Now I don't know what to do with my time".

"...bureaucracy!. I have no time to do anything else. That helped me to get over things. I run all day. That's the first day without any obligations".

Persons that former carers meet regularly after the death of their relative are close family (29%), friends (29%), other relatives (6,5%), nobody (16,1%), both friends and family (19,4%).

"Now I meet everyone and more often that I used to. We go out and they encourage me to travel, to go to Leisure Time Activities Club (KAPI)".

"I see all my close friends, not so much relatives, because they didn't understand and then you stop talking to them".

They estimate that relationships with others have remained stable for 58.1% of the sample, have worsened for another 25,8% and improved only for 16,1%.

In order for former carers to feel better after the loss of their relative they participated in activities: outdoor activities (38,7%), caring for another frail person (25,8%), care for self (12.9). A 22,6% of the sample has done nothing yet to feel better.

"I have continued the gym and now I do things without stress because I have time".

"I try to be more sociable. Sometimes I succeed... but not always. I go to excursions but only when I am sure for the safety of other family members back at home. Now I have learned how precious my family members are".

Conclusions

The aim of this study was to investigate attitudes of Greek former caregivers. In Greece it is the first time that this specific population has been studied. Project “Life after Care” offered us the opportunity to learn good practices concerning this issue from other European countries: Italy, Ireland, United Kingdom.

Alzheimer’s associations in Greece provide support to carers, but they don’t foresee support for former carers. The transition of caring to post-caring has been interestingly analyzed by Larkin’s study³⁹, who discriminates: “the post caring void”, “closing down the caring time” and “constructing life past caring”. These phases in the trajectory, as Larkin says, are not experienced in a particular sequence and there is overlap between them.

Important issues that were highlighted of the former carers’ interview were the psychosocial dimension of burden, the neuropsychiatric symptoms as main carer’s issue and the isolation and changes in everyday routine they have experienced during caring. In post caring period, issues as loneliness, bureaucracy, leisure time, gain knowledge of dementia management and patience, the need to care for another frail elderly (serial carer) were subjects that former carers have discussed.

Alzheimer’s associations in Greece could provide support at this transitional phase of caring to post-caring period. This kind of support could be achieved by preparing carers of end stage patients and by educating health professionals of Home Care programmes for dementia patients.

Limitations of this study are the size and the heterogeneity of the sample. In future studies it would be interesting to investigate subgroups of this specific population (spouses and children). It is also important to include former carers, that they have closed the clinical period of mourning (2 years).



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life after care


Life After Care partnership brings together organisations involved in training, support and advocacy of family carers to address the issues faced by such carers after they have ceased in their caring roles.

The partnership aims to exchange ideas, experiences, good practices and tools in order to learn from each other. We aim to strengthen local and national strategies concerning informal training of former family carers to help their reintegration into society after they have ceased in their caring roles.



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