

Psychological needs perception and stress, depression, insomnia and medical problems in caregivers

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Abstract. A large amount of research has addressed the negative impact of caregiving among the caregivers of dementia patients. These consequences have both a physical and a mental impact; specifically, caregivers show depressive symptoms, stress, insomnia and medical problems.

The aim of the study was to analyze the relationship between the subjective feelings of psychological needs, and depression, stress, insomnia and medical problems in formal and informal caregivers.

A survey was conducted in order to collect the training needs of formal and informal caregivers in four European countries (Italy, Romania, Turkey and Spain) within the context of "RING: Transferring Support to Caregivers" project during December 2009 through January 2010. The sample consisted of 331 formal and informal caregivers (204 and 127 respectively) of people with dementia. For this paper only, data related to caregivers' perception of their own psychological needs and its relationship to psycho-affective disorders and medical problems in the last year were taken into account.

A chi square test of independence was calculated, comparing the psychological needs perception among caregivers and their stress, depression, insomnia and medical problems. A significant interaction was found between caregivers with stronger psychological needs perception and stress problems (chi square(2)=9.542, p<.05), insomnia (chi square(2)=7.499, p<.05) and medical problems (chi square(2)=6.043, p<.05). No significant relationship was found with depressive symptoms (chi square(2)=5.468, p>.05)

These results should be taken into consideration when developing training programmes for both, formal and informal caregivers. This is the purpose of the Ring project.

Keywords: caregivers, Alzheimer's disease, psychological needs, psycho affective disorders, medical problems

Introduction

The improvement of living conditions, although not equally distributed, is the main reason underlying the current ageing phenomenon worldwide. Europe is particularly affected by this global trend as it is the most aged continent of all the regions of the world: on average, 17% of the 501 million Europeans are aged 65 or older (Eurostat,

2010). Although ageing does not imply disability or dependency, it does bring along frailty and the probability of suffering from what is called age-related diseases and thus dependency. The ageing process of the European population has been also characterized by “the ageing of the aged” as the number of those aged 80 years and older increases in a disproportionate way (Marin & Zaidi, 2008). The age groups of 80+ are particularly at risk of facing dependency. As a result, even under the assumption of otherwise improved health conditions, European Union (EU) member countries will be faced with an increased number of people at risk of needing care, as the share of 80+ increases sharply. Indeed it has been estimated that the numbers of people with dementia (one of the age related diseases) will double every 20 years, if today’s age-specific prevalence rates persist (Brodaty, 2008). As the prevalence of dementia increases with age, it is estimated that it doubles every five years after the age of 65 and that nearly 50% of those aged 85+ have Alzheimer’s Disease (Eurostat, 2010).

Currently, Alzheimer’s Disease International estimates 30 million people have dementia in the world, most of them living in developing countries (66%). Moreover, 4.6 million new cases are expected to occur annually to reach 100 million people with dementia by the year 2050. According to the European Community Concerted Action on the Epidemiology and Prevention of Dementia Group (EURODEM study), there are estimated to be 5.5 million people with dementia in Europe.

Regarding the question of who cares for these elderly people, care provided by family members, friends or other informal carers still represents the bulk of care provision to the elderly in Europe. Results from the Eurobarometer surveys (2008) illustrate the continuing high percentage of families caring for older people who are in need of ongoing social support due to declining health, functional and cognitive capacity. Care giving may include caring for a loved one in the caregiver’s home, the care recipient’s

own home or in an institutional setting. It may include attending to an individual's emotional well-being and/or physical health. It may involve long-term care giving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness.

Caregivers may be both *informal*, a family member and other individual, who is an informal provider of in-home and community care to an older individual, or *formal*, a paid person caring in-home or in a long-term facility for an elderly person.

The impact of carrying out care giving among Alzheimer's informal caregivers has been shown in numerous studies that address the high prevalence of depression, stress and medical consequences (Schulz, Martire & Klinger, 2005), as well as psychological morbidity (Cooper, Katona, Orrell, & Livingston, 2006) among Alzheimer's informal caregivers. Informal caregivers commonly experience higher levels of depression, anxiety and greater utilization of psychotropic drugs than the general population (Fox, Kohatsu, Max & Arnsberger, 2001). Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non caregiver peers (Pinquart & Sorensen, 2003). Estimates show that between 40-70% of caregivers have clinically significant symptoms of depression, with approximately one quarter to one half of them meeting the diagnostic criteria for major depression (Zarit, 2006). Depressed caregivers are more likely to have coexisting anxiety disorders, substance abuse or dependence, and chronic disease. Depression is also one of the most common conditions associated with suicide attempts (Spector & Tempi, 2005).

Literature on caregivers stress shows that caregivers have higher levels of stress than non caregivers (Pinquart & Sorensen, 2003). As a response to increased stress, caregivers are shown to have increased alcohol and other substance use. Several studies

show that caregivers use prescription and psychotropic drugs more than noncaregivers (National Alliance for Caregiving & Evercare, 2006).

Concerning medical problems, caregivers have lower levels of subjective well-being and physical health than non caregivers (Pinquart & Sorensen, 2003). Caregivers suffer from increased rates of physical ailments (including acid reflux, headaches and pain/aching), increased tendency to developed serious illnesses (Shaw, Patterson, Semple, Irwin, Hauger & Gant, 1997), and have high levels of obesity and bodily pain (Barrow & Harrison, 2005). Studies demonstrate that caregivers have diminished immune response, which leads to frequent infection and increased risk of cancer (Kiecolt-Glaser, Dura, Speicher, 1991) and higher level of stress hormones and lower level of antibody response (Vitaliano, Zhang & Scanlan, 2005).

Referring to sleep deprivation, a host of studies demonstrate that sleep deprivation is rampant in caregivers. There are some predisposing and precipitating demographic and medical risk factors for insomnia (age, gender, medical problems...). In addition, a growing body of research suggests that the unique psychological circumstances faced, and their emotional and behavioural responses to these circumstances, may perpetuate caregiver sleep complaints. Caregivers are often awakened by the care-recipients at night (McCurr y& Teri, 1995) and caregivers sleep better when they avail themselves of respite beaks away from the care-recipient (Lee, Morgan & Lindsay, 2007). There is also evidence that caregivers objective sleep quality is not significantly different form age-matched non caregiver samples, although caregivers perceive their sleep to be worse (Castro, Lee, Bliwise, Urizar, Woodward, King, 2009). Thus, what may be important for the actual caregiving role in the development and maintenance of insomnia is the caregiver' personal interpretation or appraisal of their situation (McCurry, Gibson, Logsdon, Vitiello & Teri, 2009). In recent years, a number of

researches have begun to consider how modern theories of stress and coping inform our understanding of the relationship between caregiving and caregivers' health outcomes, including those important to sleep (Schulz & Martire, 2004).

It seems the subjective perceptions of caregivers play a key role in the negative consequences of the care work. It is shown that positive beliefs about caregiving can have an important impact on the mental health of caregivers. Regardless of the level of demand placed on caregivers, individuals who find meaning in their role and those who are searching for meaning express fewer depressive symptoms and greater self esteem than caregivers who do not find meaning in their caregiving role (Noonan & Tennstedt, 1997). The care giving appraisal model proposed by Lawton and colleagues (Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Lawton, Moss, Kleban, Clikman & Rovine, 1991) focuses on the relationship between the objective caregiving situation and the caregiver's constant appraisal and reappraisal of the situation. The results of this appraisal, in turn, are reflected in the expression of the total caregiving experience of the caregivers (Lawton et al., 1991), in other words, the positive or negative consequences of the caregiving. Subsequent research has shown the important mediating role these variables play between caregiving stressors and the level of psychological adaptation associated with patient care (Fox & Night, 1997; Pruchno, Peters & Burant, 1995).

Formal care to older adults includes care provided at home and care away from home. Formal carers are paid individuals who provide hands-on assistance to dependent adults, working either full-time or part-time, and hired privately, through an agency or sometimes provided by public assistance. Although there is a lack of studies that analyse the impact of care giving among formal caregivers, it has been addressed that paid caregivers suffer from burden (Zimmerman, et al., 2005). Research that has

studied the burden on formal caregivers, has focused on health care professionals working in long-term facilities and not on formal caregivers. Health care professionals are reported to experience a high rate of burnout (Bourbonnais, Comeau, Vezina & Gion, 1998) defined as a syndrome of emotional exhaustion and cynicism that occurs among the individuals in human services. Interpersonal relationship with clients, co-workers and supervisors has received attention as a predictor of burnout, besides work overload and job conflict (Edwards, Burnard, Coyle, Fothergrill & Hannigan, 2000). Professionally caring for people with dementia has been described as emotionally and physically draining (Morgan, Semchuk, Stewart, & D'Arcy, 2002) with a high physical and psychological work load (Fjelltun, Henriksen, Norberg, Gilje & Normann, 2009). But, conceptually, health care professionals (nurses, doctors, auxiliary staff...) are different to formal caregivers, as home care workers are engaged in private homes and nursing homes and are personally involved with clients and their families. Because of this, the relationship with clients and clients' families may play an important role creating psychological stress among formal caregivers.

One of the studies that analyzed burnout among home care workers in Japan concluded that interpersonal conflicts with the care recipients and their families were important indicators of emotional distress among home workers (Fujiwara, Tsukishima, Tsutsumi, Kawakami & Kishi, 2003). According to these findings, the conflicts with clients and clients' families may be strongly related to burnout among home care workers. No data has been found in relation to psychological needs perception and psycho-affective disorders and medical problems in formal caregivers.

Consequently, the aim of the present study is to analyze the relationship between the subjective feelings of psychological needs, and depression, stress, insomnia and medical problems in formal (non-professional) and informal Alzheimer's caregivers.

Method

Participants

A total of 331 questionnaires from caregivers were collected in four countries: Turkey, Romania, Italy and Spain. Caregivers were divided into two groups: formal or informal. A total of 204 formal caregivers and 127 informal caregivers were interviewed. The distribution of caregivers by country was the following: Turkey, only 60 formal caregivers; Romania, 10 formal and 6 informal caregivers; Italy, 117 formal and 107 informal caregivers; and, finally, Spain, 17 formal and 14 informal caregivers.

Formal and informal caregivers were defined as follows in the present study:

Formal Caregiver: a paid worker in a Nursing Home /Rest Home, a paid outworker, or a volunteer who cares for the elderly and is only paid expenses.

Informal Caregiver: a family member or relative who cares for the elderly at home or in a Nursing Home/Rest Home, and who is not paid for the care provided to the care recipient.

Figure 1-3 approximately here

Measurement Tool

The European project called RING (Transferring supports for caregivers) aims to gather formal and informal caregivers training needs. In order to collect this information and to detect psychological needs of the caregivers, an *ad hoc* survey was created for data collection. The questionnaire was composed of the following sections: *sociodemographic data* (age, sex, living arrangements, and relationship with the care recipient), *questions related to the amount of care provided* (hours per day and number of years caring), *type of support they had* (formal or informal), *psycho affective disorders* (stress and depression), *medical problems* (health related problems) and *drug intake, psychological needs, care organization needs and training needs*. For this paper

only, data related to caregivers' perception of their own psychological needs and its relationship to psycho-affective disorders and medical problems in the last year were taken into account.

Psycho affective disorders, medical problems and drug intake data were collected asking caregivers if "*in the last year, they had had any of the following problems: stress, depression, insomnia, medical problems*" and if "*they had needed medication for any of these problems*".

The Psychological needs section consisted of the following items: "*Do you think that meeting with other people in the same situation as you would be useful?*", "*Do you think it would be useful to have some kind of psychological or emotional support in the context of caregiving work?*", "*Do you think you have enough time for yourself?*" and "*Do you think you have enough time to spend with friends, acquaintances and family?*". Answer options were *yes* or *not*. The full questionnaire is shown in Annex 1.

Results

Socio demographic characteristics

Informal caregivers

Data was gathered from 127 informal caregivers; however, only 124 of the respondents answered this section. The mean age of informal caregivers was 55.62 years (SD=14.47), ranging from 20 to 82 years.

Being the range too large, it is better to re-distribute the data into age groups: one for the 20-40 years-old, a second group for the 41-60 years-old and a third group for the 61+ years-old. This will show a better description of the groups and will lower the deviation (14.47 years).

The largest group is the 41-60 years-old (43,5%), followed by the 61+ group (39,5%). The 20-40 group is the smallest one (16,9%). As can be seen, care giving is mainly a “grown-ups” thing, as young caregivers are not as numerous. Mean age for the 20-40 group is 32.76 years (SD=7.04), for the 41-60 group mean age is 51.94 years (SD=7.11), and for the 61+ groups, mean age is 69.47 years (SD=6.35)

Most informal caregivers were female (83.5%), lived with the care recipient (55.6%) and were either the care recipient’s daughter (42.9%) or spouse (23.8%). On average, caregivers had been caring for someone for four years, although the variability is great, ranging from 1 month to 27 years. They spend an average of 11.95 hours a day (SD=8.59) on care giving. The main help received when care giving was given by family or friends (50.5%) or by formal or volunteer staff (43.2%). A minor share of caregivers (6.3%) stated getting both formal and informal support.

Formal caregivers

Data was gathered from 204 formal care givers; however, only 199 of the respondents answered this section. Their mean age was 39.44 (SD=10.40), ranging from 20 to 80 years, although 80 years old is a “strange” age as the next younger age is 66. Let us recall the informal care givers’ mean age for comparison purposes: 55.62 years (SD=14.47). That is almost 16 years of difference, let alone that there were more frequent cases of 60+ caregivers in the informal group than in the formal group.

Being again the range too large, it is better to re-distribute the data into age groups: one for the 20-40 years-old, a second group for the 41-60 years-old and a third group for the 61+ years-old. This will show a better description of the groups and will lower the deviation (10.40 years) again.

We find in these group younger carers than the ones found in the informal group. For instance, the largest group is the 20-40 one (55.3%), followed by the 41-60 group (41.7%). The 61+ group is really small (3.0%), including six cases, all of them from Italy. Concerning their mean age, the results are as follows: for 20-40 group, it was 32.24 years (SD=6.21), for the 41-60 group it was 46.98 years (SD=4.93), and for the 61+ group it was 67.17 years (SD=6.52)

Psycho affective disorders

When asked if they had some psychological and medical problems (health related problems) in the last year, the results show a high frequency of these disorders among the caregivers that participated in this study. Thus, the informal caregivers interviewed pointed out the following problems: stress (60%), depression (32.8%), insomnia (41.9%), and medical problems (33.1%). They referred to taking medication to deal with those problems in 47.2% of the cases. Formal caregivers reported stress as the most frequent problem they had (54.2%), followed by insomnia (25%), medical problems (22.5%), and finally depression (11.1%). In relation to the drug intake for the treatment of these disorders, 19.4% answered yes when asked if they were in treatment for these psychological and medical problems.

Figure 4-5 approximately here

Psychological needs perception psycho affective and medical problems

A chi square test of independence was calculated, comparing the psychological and emotional needs perception among caregivers and their stress, depression, insomnia and medical problems. A significant interaction was found between caregivers with stronger psychological needs perception and stress problems (chi square(2)=9.542, $p<.05$), insomnia (chi square(2)=7.499, $p<.05$) and medical problems (chi

square(2)=6.043, $p<.05$). No significant relationship was found with depressive symptoms (chi square(2)=5.468, $p>.05$). Contingency coefficient for each association was .169 for stress, .150 for insomnia, and finally .136 for medical problems. Although low, these coefficients support the associations found within the chi-square tests.

Discussion

The aim of this study was to analyze the relationship between the subjective feelings of psychological needs, and depression, stress, insomnia and medical problems in formal (non professional care workers) and informal Alzheimer's caregivers.

Results in this study show a relationship between psychological and emotional needs perception of formal and informal caregivers and stress, insomnia and medical problems. This means that those caregivers with a subjective feeling of needing psychological and emotional support present stress, insomnia and medical problems. In this study no relationship has been found between psychological and emotional need perception and depression.

Previous research has addressed the fact that most caregivers are ill-prepared for their role and provide care with little or no support from others (Family Caregiver Alliance, 2006), yet more than one-third of caregivers continue to provide a lot of care. Care giving stress models (Noonan & Tennstedt, 1997) have argued that caregivers' subjective feelings in relation to the care giving process have a moderating effect on the negative consequences of care giving (depression, stress and medical problems). For instance, studies that have investigated anxiety and stress problems among informal Alzheimer's caregivers and noncaregivers has outlined that caregivers have higher levels of stress (Pinquart & Sorensen, 2003). In a National Survey carried out in the United States among informal caregivers, 16% of caregivers revealed feeling emotionally strained and 26% said taking care of the care recipient was hard on them

emotionally (Center on Aging Society, 2005). Factors associated with caregivers' stress vary considerably, but studies have addressed the mediator effect of caregivers' appraisals of the situation on the perception of stress. Caregivers showing higher role captivity present higher levels of stress (Bertrand, Fredman & Saczynski, 2006). These results support our findings that subjective psychological needs of caregivers are associated with their stress.

The results from our study support previous research that has highlighted caregivers appraisal of their situation, between others, as one of the predictors of insomnia among caregivers. Sleep disturbances are very common among caregivers of people with dementia. Approximately two-thirds of dementia caregivers report having trouble sleeping (McCurry, Logsdon, Teri et al. 2007). However, there is growing evidence that being awakened by the persons with dementia at night does not necessarily lead to insomnia. There are other factors such as caregiver's depression, burden, medical morbidity and appraisal of their situation, as well as, care-recipient's depression and functional impairment that may be more important in the development of the caregivers sleep problems (Mc Curry, Gibbons, Logsdon, Vitiello & Teri, 2009).

Regarding medical problems, a large number of caregivers report that caregiving has caused their physical health to worsen (Center on Aging Society, 2005). Caregivers who are at the greatest risk of negative health outcomes include individuals with very demanding caregiving responsibilities, chronic stress as a result of the caregiving role, and negative psychological outcomes such as depression (Schulz & Beach, 1999). These results support the findings from our study that psychological and emotional needs of the caregivers are related to medical problems. Indeed, association between emotions and health among caregivers has been widely reported in the literature (Shaw, Patterson, Sample, Dimsdale, Ziegler, Grant, 2003; Gallagher-Thompson et al., 2006).

Caregiving has been described as a chronic stressful situation. As a result, negative emotions are associated with this process such as feeling loss of self identity, lower levels of self esteem, constant worry, or feeling of uncertainty. Caregivers frequently describe to be frustrated, angry, drained, guilty, helpless (Center on Aging Society, 2005), and hostile (Marks, Lambert & Choi, 2002) as a result of providing care.

Negative emotions and less emotional expressiveness has been associated with higher hypertension in family caregivers. Uncontrollable life stress, hostility and emotional inhibition are three psychological factors that have been implicated in the development of essential hypertension (Shaw, Patterson, Sample, Dimsdale, Ziegler, Grant, 2003). Some studies have addressed the idea that suppression of hostility and anger may be an additional risk (Burns, Evon & Strain-Saloum, 1999; Vogeles, Jarvis & Cheeseman, 1997).

Negative emotions result in a cascade of physiological changes that weaken the immune system and, consequently, overall health. Stress impacts on the immune system of caregivers by charting the levels of IL-6 (a protein of the cytokine family). Researches have found that the stress of caregiving caused IL-levels to increase four times as quickly in elderly caregivers as in the non caregiving participants who were under less strain. This translates to a higher occurrence of infections and illnesses, putting caregivers at a greater risk of everything from colds and influenza to chronic diseases like heart disease, diabetes and cancer (Kiecolt-Glaser, Preacher, MacCallum, Atkinson, Malarkey, Glaser, 2003).

There is another physiological marker of stress responses such as cortisol. Results from different studies have underlined that cortisol levels are higher among Alzheimer's caregivers compared with non-caregivers (Davis, Weaver, Zamrini, Stevens, Kang & Parker, 2004).

Summarising, caregivers subjective feeling of needing emotional support and the association with medical problems outlined in the present study should be taken into account for further development of intervention programmes for Alzheimer's caregivers. Recent research has demonstrated that intervention programmes focused on the regulation of emotion among Alzheimer's caregivers have a positive effect on their subjective well being, emotion regulation, positive affect, negative affect and stress levels (Etxeberria et al, in press; Etxeberria, García, Iglesias, Urdaneta, Galdona, Yanguas, 2009). Taking into account the association between emotion and health, further studies should investigate the effect of emotion-focused intervention programmes on the improvement of emotional and health functioning among Alzheimer's caregivers. As described below, this will be one of the aims of the Ring project.

Psychological and emotional problems were not associated with depression among caregivers. One possible interpretation for this may be that separately formal and informal caregivers showed different percentages of having depression. Depression was present in 32.8% of the informal caregivers whereas only in 11.1 % of the formal caregivers was reported. Taking both groups of caregivers together for data analysis could influence the results in this variable. Indeed, empirical literature has addressed stress more than depression among formal caregivers, as is shown in this present study (Fujiwara et al., 2003).

Limitations found

The main goal of the RING project is to smooth the process of knowledge transfer between ten European organisations and then to provide care givers with up-to-date tools to improve both the quality of their work and their quality of life. Research comes second in these priorities as not all of the partners are research-oriented. Yet, fruitful

efforts have been made to take advantage of the possibilities to collect data from such a diverse collection of partners and countries.

Even though the samples gathered do not show a representative picture of the situation of care giving in the four countries, they do provide interesting data from carers on Alzheimer's- and/or dementia-related care work.

The results yielded from the Ring exploratory and initial survey show there is still a lack of enough knowledge on the needs of formal carers. It was difficult to have a unify approach in every country, especially when it came to the definition of what a formal care giver is and what it is not. In the end, the operational definitions paved the way to being able to apply a common questionnaire in four different languages. Yet there is still risk of disparities because questionnaires were translated from English into the country's language and then results came back in English. A great deal of scientific supervision was employed in order to control these deviations. We estimate the outcomes to be of a good quality.

Next steps

Not only are elderly people increasing their share as a heterogeneous population group, but care givers are also expected to become more numerous as the need for social and personal care is very likely to increase, too.

A vast body of evidence reveals that caring for someone suffering from a chronic disease can eventually have harmful and risky effects on the care giver. And then from the care giver to the one being cared for the consequences turn into a vicious circle of distress and discontentment.

Once the initial diagnosis is made, what is next for the Ring project? Based on the evidence gathered within the project, on the previous experiences of training from most partners and on the evidence-based literature reviewed, the steps to come are:

1. A Training tool for care givers will be developed by the end of 2010. The tool, called RING KIT, will pay specific attention to the different needs of formal and informal care givers' and those of trainers, too.
2. A post-analysis of those taking part in the training programme to measure actual impact on the care giver quality of life.

Concerning research, we aim to:

1. Further validate our caregiver education support programme focussing on emotional management
2. Determine the impact of an intervention such as the RING KIT to ease or reduce the care giver burden.
3. Identify the association, if any, between Emotional Expressiveness and objective health outcomes, such as other chronic diseases (cancer, hypertension, tumor growth).

Conclusions

Results from this study report the relevance of the subjective feelings of formal and informal caregivers and their association with stress, medical problems, and insomnia. Caregivers appraisal on their situation and on their psychological and emotional needs should be taken into consideration when developing intervention programmes for them. Little is done specifically with in-home formal caregivers at least in some European countries participating in this study. So, the RING project aims to detect the training

needs of both formal and informal caregivers, and to provide them with useful training programmes for enhancing their psychological and emotional health.

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Figure 1-3. Participants distribution per country and per type of caregivers

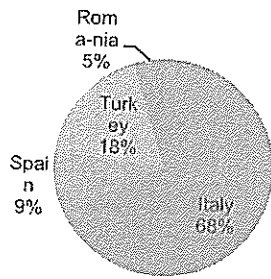


Figure 1. Total Caregivers by Country.

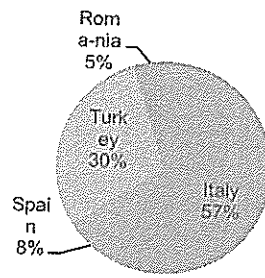


Figure 2. Formal Caregivers by Country.

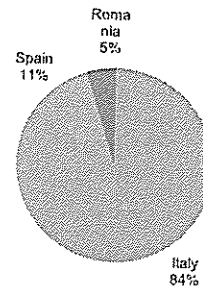


Figure 3. Informal Caregivers by Country.

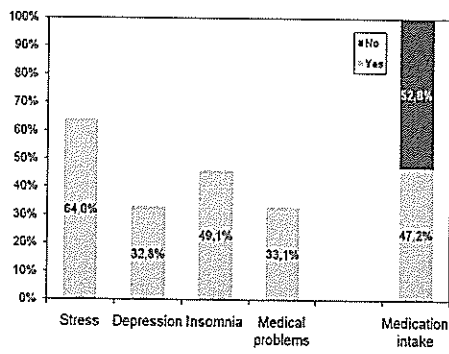


Figure 4 – Informal Caregivers. Psycho affective disorders and medical problems

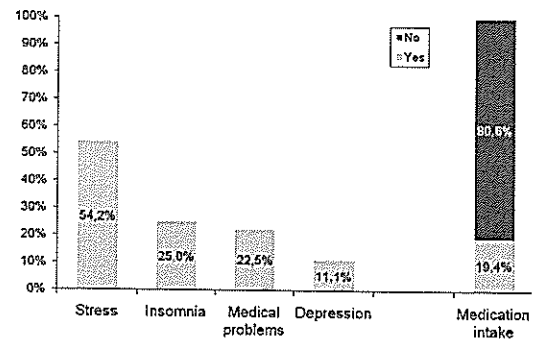


Figure 5 – Formal Caregivers. Psycho affective disorders and medical problems

Annex 1

QUESTIONNAIRE TO IDENTIFY THE NEEDS OF CAREGIVERS

European Commission - DG Education and Culture
Life Long Learning Programme – Leonardo Da Vinci call
RING: TransfeRing Supports for Caregivers
Project Number: LLP-LDV-TOI-09-IT-0446

PARTNER: _____

DATE OF COMPLETION: _____

This questionnaire will contribute to the realization of a European project called Ring. The project aims to lend support to caregivers like you, health professionals, family members, volunteers, etc. In particular, the project will allow us to develop and test tools to help you in your care giving relationship with elderly people suffering from dementia. Completion should require only a few minutes. We thank you in advance for your valuable cooperation.

Type of caregiving

- 1.a. Do you live with the person you care for? Yes
 No
1. b. How many hours a day do you care for someone?
 1-4 hours 5-8 hours more than 8 hours
2. Does someone else besides you care for this person?
 No Yes, professional or volunteer Yes, Informal
(family or friends)
3. In the last year, have you had a case of anxiety, depression or insomnia? Yes
 No
4. In the last year, have you needed medication for any of these problems? Yes
 No
4. In the last year, have you needed medication for any of these problems? Yes
 No
5. Do you have any training in caring for the elderly? Yes
 No
- 5.a. If so, please describe:

6. Are you connected with any support groups or other means of self-help? Yes
 No
- 6.a. If so, please describe what groups you have engaged with in the past or are engaged with now:

Identification of needs: psychosocial area

7. Do you think that meeting with people in the same situation as you would be useful? Yes No
8. Do you think it would be useful to have some kind of psychological or emotional support in the context of care giving?
 Yes No
9. Would you like to have more time for yourself?
 Yes No

10. Would you like to spend more time with friends, acquaintances and family?
 Yes No

Identification of needs: organizational area

11. Could you use help in your care giving work situation?
 Yes (n°11a) No (n°12)
- 11.a. What kind?
- Nursing
 - Housework (cleaning, shopping)
 - Administration (bank, doctors' appointments ...)
 - Personal hygiene care and help with activities of daily life
 - Other (e.g. help with child care, other elderly people), please specify:

Identification of Training needs

12. Would you like more information about the characteristics and evolution of the illness of the person you care for?

No Yes

13. Would you like more information about how to relate to the person you care for?
 Yes (n°14) No (n°15)

14. How would you like to be informed / helped?

- Meetings with professionals
- Booklets
- TV, radio
- DVDs
- Training courses
- Specific websites
- Other: _____

Other information

15. How old are you? _____ years old.

16. Sex: Woman Man

17. What type of caregiver are you?: Formal Informal

In general, Formal Caregiver is a paid worker in a Nursing Home /Rest Home, a paid outworker, or a volunteer who cares for the elderly and is paid only expenses.

A Informal Caregiver is a family member or relative who cares for the elderly at home or in a Nursing Home, Rest Home, and who is not paid for carrying such a job.

- 17a. Please specify

- Professional with vocational qualifications (Please specify your qualification _____)
- Spouse
- Child
- Brother/Sister
- Volunteer
- Other

18. What is your nationality? _____