

# Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature

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*Key words: Caregiving, AD, institutionalization, caregiver role strain, caregiver burden*

*Parole chiave: Caregiving, Malattia di Alzheimer, caregiving stress, peso assistenziale, istituzionalizzazione*

## Abstract

**Background:** Informal caring or caregiving is very common in our postindustrial society. Caregiving burden grows with the worsening of cognitive impairment of the patient and is one of the factors influencing institutionalization. Alzheimer's disease (AD) is a type of dementia that is chronic and deteriorative. The symptoms of this neuropsychiatric disorder generally begin to manifest after the age of sixty and currently 8.9 million family caregivers provide assistance to someone with AD or a related dementia. As the patient's condition worsens, it increases the burden on the caregivers, due to the physical, psychological, and emotional stresses that result from caring for the patient.

**Methods:** A search of the literature was conducted on electronic database: PubMed, Google Scholar, Science direct, CINAHL in a exploratory way. Inclusion criteria were: articles in English and Italian published between 1999-2011 which mentioned Alzheimer's caregivers, burden, stressors, and institutionalization. The exclusion criterion was failure to mention the word "caregivers". About 100 titles were found and 30 articles abstracts with key words in the title were reviewed. Of the 30 articles selected for further review based on the relevance to the study purpose, 17 articles were finally selected for inclusion in this literature review.

**Results:** Results display that caregiver burden is influenced by patient behavioral and cognitive status, hours involved in care, stress, social isolation, gender, relationship to the patient, availability of support resources, and caregiver characteristics. Assessment tools available to assess and recognize risk factors and burden in caregivers are useful both in terms of caregivers health and decision on institutionalization.

**Conclusion:** Literature suggests to provide information for health care providers to reduce burden and support caregiver health and well-being. Assessment tools available to assess and recognize risk factors and burden in caregivers should be used more often to contribute to reducing caregiver stress and the impact of institutionalization.

## Introduction

Home care and informal care is an essential topic in Italy and worldwide. This is due to the fact that the number of persons who suffered from dementia and more

particularly Alzheimer's disease (AD) is growing continually (1). The role of informal caregivers is key in the framework of this kind of illness, especially in Italy where family is still the first and the most enduring informal caregivers in the

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health system. Several studies demonstrate that caregiving has a strong impact on caregivers' physical and mental health and well-being, due to many factors. For example, caregivers experience anxiety, poor sleep, exhaustion, and depression, (2, 4), and also sadness because the loved one is far from the person they previously knew, and it is difficult to deal with these facts. While the first stages of Alzheimer's disease involve some loss of memory or needing a little help, severe levels of AD push informal caregivers to deal with personality and mood changes and to look after a person who depends completely on them. Furthermore, it is important to not forget that often informal caregivers are the partners of the patient. This means that caregivers may be older than the patients as well and may not be really healthy. Even if the caregiver is a child of the patient, he/she can be also in middle age with many responsibilities. The major life impact of AD on the family means that care giving can be a very difficult and physically demanding activity that encompasses all of the caregiver's life. Caregivers not only lose their relationship, spare time, have problems with their job, but experience depression, anxiety, and social isolation, leading to poor health impact as a caregiver of AD. This article provides a discussion of the literature about factors that influence caregivers of patients with Alzheimer's disease and their adjustments to institutionalization of a loved one.

Alzheimer's disease (AD) is a type of dementia that is chronic and deteriorating. The symptoms of this neurological and neuropsychiatric disorder begin to manifest generally after the age of sixty (5). The disorder consists of several stages which eventually lead to loss of intellectual functioning, profound mental deterioration, and finally, death (6). According to WHO data (1) it was estimated that 35.6 million people were affected by dementia worldwide,

this number is projected to increase to 115 million by 2050. The countries with the fastest growth in elderly populations include China, India, South Asia, and their Western Pacific neighbors. The European Union (EU) reports 9.95 million persons with dementia, primarily focused on Alzheimer's disease. It is anticipated that the cases will double in Western Europe and triple in Eastern Europe in the next 30 years (5). According to Gallagher and colleagues (7), "approximately 20% of patients are institutionalized in the first year after a diagnosis of dementia" (p. 205); this rate increased to 50% during the following 5 years, and arrived at 90% after 8 years.

It is estimated that 8.9 million caregivers provide care to someone fifty years or older with AD or a related dementia (8). In the United States, a recent concern has been the high number of institutionalized elders that led to exceedingly high costs for Medicaid, a US government health assistance program (9). In Italy, 50% of patients with Alzheimer's reside now outside of the home (5). A major predictor of institutionalization is the continuing burden that caregivers experience as a result of the care process as the patient's condition deteriorates and care needs increase over time, in addition to the accumulated financial, social, psychological, and physiological impact of family caregiving (8). Thus, there is a dual feeling in caregivers with respect to institutionalization of their loved ones; on one hand they are overall relieved that somebody is now taking care of their relatives affected by AD, on the other they feel guilty having decided to institutionalize their loved ones (9, 10). According to Anderson et al. (11) nursing home units that encouraged family members to bring *memorabilia* (such as life pictures, and music enjoyed by the patient) decreased patient 'prn' medication needed and family members

reported feeling like they could contribute to patient's care by surrounding them with personal mementos, which created a positive interaction with the nursing home as well. At this moment in Italy, a new *phenomenon* is occurring, where migrants, mainly women, privately care for elderly at home. Surrounding institutionalization of the patient with AD, placement transition factors influencing caregivers' health and well-being are not consistently described, so they cannot be addressed in practice.

### Materials and Methods

A search of the literature was conducted in summer 2011 to review research articles on factors affecting Alzheimer's caregivers and role strain related to institutionalization of a loved one. This was done by searching the electronic database search engines of PubMed, Google Scholar, Science Direct, and CINAHL in an exploratory way. The search included articles from 1999 to 2011. The following key words were used: "Alzheimer's patients and institutionalization," "Institutionalization of Alzheimer patients," "Alzheimer's and caregivers," "Alzheimer cognitive impediment and institutionalization," and "Caregiving burden".

Inclusion criteria included research articles that mentioned Alzheimer's caregivers, burden, stressors, and institution-

alization. The exclusion criterion was failure to mention the word "caregivers" (Table 1). Articles were initially selected based on the applicable titles and then abstracts were reviewed to select articles for full text review. About 100 titles were found and 30 articles abstracts with key words in the title were reviewed. Of the 30 articles selected for further review based on the relevance to the study purpose, 17 articles were finally selected for inclusion in this literature review.

### Results

The review of the literature considered several factors influencing the impact that the placement transition experience has on the health and well-being of caregivers during institutional placement of their loved ones with AD. Summaries of study results are reported in the following subsections. The major evidence-based factors described in the literature reviewed included sources of caregiver burden, caregiver's relationship to the patient, predictors of caregiver response to institutionalization, programs available to support patients with AD, a review of assessment tools for caregivers, and caregiver activities after institutionalization. A summary of the Italian studies about caregiving and institutionalization is also included.

Table 1 - Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Articles from 1999-2011	Failure in mention Caregivers
Key Words	
Alzheimer's patients and institutionalization	
Institutionalization of Alzheimer patients	
Alzheimer's and caregivers	
Alzheimer cognitive impediment and institutionalization	
Caregiving burden	

Table 2 - Categorization of articles

Caregiver factors influencing Institutionalization Sources of Caregiver Burden	Immediate vs. Non-Immediate Family Caregiving	Quality of Premorbid Relationship, Gender, and Race	Programs available for Alzheimer's patients and caregivers	Assessment Scales to Measure Impact of Caregiving	Caregivers burden after institutionalization	Italian Profile of AD Caregivers
Sansoni et al, 1999 Tornatore and Grant, 2002 Vellone et al, 2002 Sansoni et al, 2004	Paulson and Lichtenberg, 2011	Vario and Sansoni, 2000 Schulz et al, 2004 Conde-Sala et al, 2010 Schultz et al, 2010 Winter et al, 2011	Marriot et al, 2000 Colvez et al, 2002 Gaugler et al, 2008	Vario and Sansoni, 2000 Van Durme et al, 2010	Tornatore and Grant, 2002 Yamamoto et al, 2002 Schulz et al, 2004 Schultz et al, 2010	Vario and Sansoni, 2000 Vellone et al, 2002

The 17 articles reviewed were categorized into seven areas that influence institutionalization of a loved one and caregiver responses: 1) caregiver factors influencing caregiver burden and institutionalization, 2) immediate vs. non-immediate family caregiving, 3) quality of premorbid relationship, gender, and race, 4) programs available for Alzheimer's patients and caregivers, 5) assessment scales to measure impact of caregiving, 6) caregivers burden after institutionalization, 7) Italian profile of caregivers of AD (Table 2).

## Factors influencing Caregiving and Institutionalization

### *Caregiver Factors Influencing Caregiver Burden and Institutionalization*

As a patient's cognitive status deteriorates, it makes it more difficult to care for the patient and, on average, placement occurs two years after the onset of AD symptoms (12). Stress occurs in the caregiver, particularly when the patient has symptoms of hallucinations, depression, insomnia, incontinence,

agitation, or cognitive decline; and can be more pronounced depending on the caregiver's personality type (12). The above mentioned behaviors, together with the level of cognitive impairment, directly relates to the level of the caregiver's anxiety and predominantly affects females (12). In addition, Stress, Anxiety, and Depression were positively correlated with caring hours and sleep problems in the caregiver, as well as the behavioral disturbances of the patient (2, 12). These same factors were negatively correlated with free time and time spent out of the home (Figure 1) (12). As figure 1 displays for the increase or decrease of the number of free time/caregiving hours, there is a opposite increase or decrease of burden in terms of self perceived *Stress, Depression and Anxiety*. Thus, caregiver predictors related to increased burden included stress, anxiety, depression, cognitive decline and problematic patient behaviors. Tornatore and Grant (13) summarized these cumulative influences as the length of time spent in the direct caregiving role before institutionalization as the most important predictor of caregiver burden. Furthermore the level of anxiety and

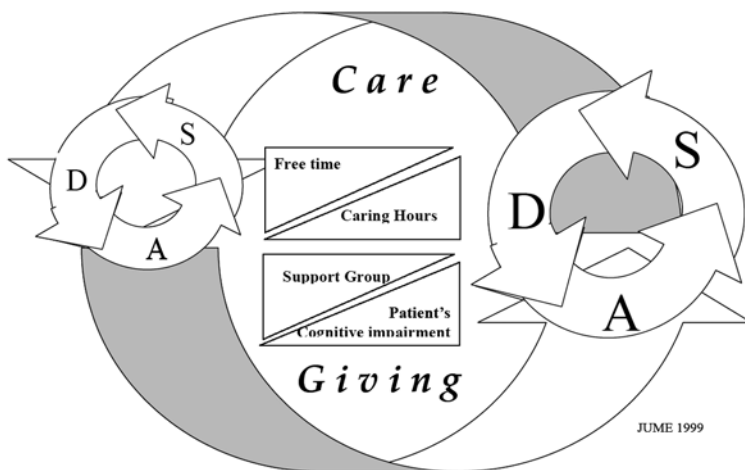


Figure 1 - Model of self perceived Stress/Anxiety/Depression on caregivers

depression among female caregivers is truly high, apparently with no correlation with status of the illness showing that caring for a person with Alzheimer's disease is really heavy independent of the level of the illness (3). In partial contrast with above said, Gallagher et al. (7) display in their research that quite often the decision to institutionalize a family member is not strictly related to the increase of the negative behaviors related to AD, but are somehow independent, despite that they point out a number of variables can accelerate the decision, such as coping style, caregiver self efficacy and presence of services which are aimed at helping both patient and caregivers with tasks.

*Immediate vs. Non-Immediate Family Caregiving*

Paulson and Lichtenberg (9) compared the caregiver's relationship to the patient, immediate family (spouses or adult children of the patient) versus non-immediate family, and whether or not this influenced the decision to seek long-term

care (9). Results showed that caregivers who were immediate family of the patient experienced more stress and sadness (9). Family members feeling guilty over seeking placement, experiencing grief related to their loved one's loss of ability for self-care, or giving up their care-giving role were reasons for the increased stress and sadness. Immediate family caregivers reported dealing with a greater degree of behavioral disturbance. They personally displayed greater affective disturbances, such as increased anxiety, phobias, and aggression when compared to the non-immediate family caregivers (9). In this comparative study, motives that led caregivers to seek institutionalization were depression, the patient's neuropsychiatric change in symptoms, caregiver employment status, and low frequency of socializing (9). Thus, immediate family caregivers' decisions about institutionalization were influenced by patient behavioral challenges, caregiver employment status, low frequency of socializing, and increased affective difficulties more than non-family caregivers.

### *Quality of Premorbid Relationship, Gender, and Race*

The quality of premorbid relationship, caregiver gender, and race were examined for both men and women, as factors affecting the desire to institutionalize a relative with dementia. Findings showed that a stronger decision to institutionalize was significantly associated with a lower quality of relationship for male caregivers, but not for female caregivers (14). This suggests that healthcare providers recognize poor quality of relationships as a risk factor for institutionalization, especially among male caregivers. Another study of 251 patients and their caregivers compared burden among spouses and adult-child caregivers of AD (15). The burden was higher among adult-child caregivers than spouses, especially for those children who lived with the patient and if they experienced other family obligations such as children or dependents (15). Also, in relation to gender and role performance, wife caregivers showed greater burden than husband caregivers, while sons also experienced greater burden than husbands (15). This last correlation might be because adult-child caregivers may view caregiving as a task and an important change in their lifestyle, while spouses regard it as part of their duty as a partner (15). It is interesting to note that Schulz and colleagues (4) report a protective factor for caregivers who felt useful, needed, appreciated, and important were more likely to experience a delay in desire to institutionalize, again emphasizing relationship quality. Race and culture also may influence institutionalization placement. In a study of 1222 family caregivers, whites are more likely to be placed in an institution than remain at home, when compared to African American or Hispanic patients (16). In Italy, patients with Alzheimer's are institutionalized after around 2 years of home care at onset of heavy mental

deterioration (10). Thus, these studies highlight that the level of relationship quality (particularly for males), a spouse role over an adult child role, and race factors into institutionalization decisions.

### *Programs available for Alzheimer's patients and caregivers*

Types of pre-institutional programming available may influence caregiver response in decreasing burden and delaying institutionalization. Marriott and colleagues (17) conducted a single-blind randomized controlled trial that analyzed the outcomes of a family intervention made up of 3 elements: caregiver education, stress management and coping skills. One of two control groups did not receive any intervention. The second one had only the possibility to be involved in a semi structured interview to assess the overall situation of the family both on economics, the social level, and more specifically, with respect to the illness. The intervention group showed that the 3 part intervention decreased burden in caregivers in comparison with the two control groups. The intervention decreased family burden; the semi structured interviewed had very little impact, and there was no impact with respect to the information given.

Another study compared five existing programs in the European Union and the influence of program services on caregivers. Fifty patients from each site including home social services (Denmark), day centers (Germany), expert centers (Belgium & Spain), group living/Cantou (Sweden & France), and respite hospitalization (France) provided both care to people with dementia of the Alzheimer's type and support to their informal caregivers (18). Different programs produced different outcomes. Caregivers of Alzheimer's patients experienced less burden using group living/Cantou and home social services, while the expert

center program alleviated concerned emotional reactions such as depression. Those who attended day centers were helped to reduce the feelings of social isolation. They also found that female informal caregivers expressed difficulties related to lack of energy, depression and sleep-related problems significantly more often than males. In addition, the caregiver's relationship with the patient had a major influence on subjective feelings of health and work burden (18). Based on this study's results, program services impact the patient and the caregiver, particularly with the problematic caregiver responses to previously described results. Support to caregivers during the care and institutionalization process of the Alzheimer's patient significantly helped reduce burden and depressive symptoms. A RCT of 406 caregivers examined whether counseling and support reduced the burden and depressive symptoms of spouse caregivers of Alzheimer's patients during the institutionalization transition (8). They found that six sessions of individual and family counseling, support group participation, and continuous availability of telephone counseling reduced burden and depressive symptoms among caregivers in the treatment group (8). Therefore, programs providing respite and care services in the institutionalization process alone can reduce caregiver burden and depressive symptoms, but counseling provides additional long-term benefits (8).

#### *Assessment Scales to Measure Impact of Caregiving*

A review study (19) identified 105 scales available for assessing the impact of informal caregiving of the elderly and provided a definition of 'informal caregiver.' These scales commonly measure the caregiver's burden, needs, and quality of life related to the impact of caregiving

on caregivers' health. The largest number of scales assessed the negative impact of caregiving (n = 55), exploring dimensions such as burden or determinants of burden, strain, stress, grief, loss of self. Positive impact of caregiving (n = 34) was explored by appraisal, competence, quality of life and well-being. Other scales measured more neutral dimensions, like coping, health, impact, and reaction (n = 16) (19). Van Durme and colleagues (19) concluded the Zarit Burden Interview (20) was the most useful tool, based on its extensive validation, brevity, user friendliness and its ability to detect changes over time. This scale is made up of a 22 item version which has been translated into 18 languages and "measures the perceived burden of the informal caregiver in its multidimensional aspects: social, physical, financial and emotional burden, as well as the relation with the care receiver" (10, p. 10). Use of these tools by health care providers to assess the impact of caregiving would allow more tailored interventions addressed to alleviate the identified burdens and influence life quality and health.

#### *Caregivers' Burden after Institutionalization*

Antecedent conditions which lead to placement of patients with AD by caregivers primarily are the focus of caregiver burden research. However, the influence on the health and well-being of the caregivers dealing with AD and caregiver burden does not always end after institutional placement. A study conducted in 2004 (4) found that spouses were more depressed before placement and even more depressed and anxious after placement than non-spouses, and that the percentage of caregivers taking anxiolytics increased from before to after placement. Once placement occurred, they found anxiety to be reduced after institutionalization, but not depression, often due to the caregiver's

perception of unmet needs at the institution (16).

Caregiver burden after nursing home placement also was found to increase, because caregivers took on additional tasks at the nursing home and sometimes they felt that their family members' needs were not being met (13). Yamamoto-Mitani, and colleagues (21) showed that being a spouse, having lower education, holding a close past relationship, expressing a strong sentiment against placement, and living close to the facility predicted more frequent and longer visiting times in institutionalized patients with AD. To sum up attention is needed to avoid exacerbation of continued negative responses in caregivers and facilitate their health and quality of life.

#### *Italian Profile of AD Caregivers*

Examination of caregiving in Italy in 2000 conducted by the Italian Association of Alzheimer disease outlined the following profile and characteristics of a sample of AD caregivers. Those affected by dementia in Italy were on average of 65 years for males and 76 for females; 83% lived at home and 17% lived with a relative, especially among children (10). The caregivers were mostly spouses and children, and occasionally another relative over 55 years; most were females and married. The caregiver assisted the family member 24 hours around the clock for an average of at least three years; only when the situation was unsustainable was institutionalization sought (10). Caregivers' quality of life is profoundly affected by caregiving itself, according to a phenomenological study on 26 Italian caregivers, where caregivers experienced profound changes in their lives because of the change of relationship with the relative-patient. With other relatives, fears, concern, and lack of information and support by the health system were reported (22). In addition to personal patient and caregiving

factors, the availability of programming to assist with caregiving also influenced institutionalization placement.

Thus, factors influencing caregiver responses surrounding institutionalization of loved ones with Alzheimer's disease include both patient and caregiver dynamics. The results from these studies highlight that increased burden due to stress, anxiety, depression, cognitive decline and problematic patient behaviors, caregiver employment status, quality of relationships, low frequency of socializing, gender, race, and availability of community programs to support caregivers, as significantly affecting the caregiver's experience of caregiving.

#### **Discussion and Conclusion**

This literature study outlines many different factors that influence the impact on caregivers caring for their family member with Alzheimer's disease and what predicts caregiver responses to the institutionalization of loved ones. In addition to the personal factors detailed in the review, health care system policies can influence choices. In the United States, coverage for institutionalization and day care is based on health care needs, health care coverage, and personal wealth. Medicare in U.S., health care provided for the citizens 65 and over, may cover a portion of the costs of institutionalization. Day care centers are available for adults and programs that help reduce caregivers' burden, but again availability is governed by health care reimbursement and personal wealth. In Italy, for some regions it is difficult to obtain support for caring for patients with AD and increasingly family members are dealing with the difficulty in caregiving. This may lead to increase burden for caregivers and precipitate opting for placement in a public nursing



facility for their family member, since the state would cover the costs.

The literature highlights several factors which require attention from nurses and health care providers when providing care for patients with Alzheimer's disease and their caregivers. As the patient with Alzheimer's condition deteriorates, more stress is placed on caregivers, who are predominately females. Caregivers who must deal with increased cognitive decline, aggression, incontinence, and increased caregiving tasks demonstrate more depression, anxiety, loss of sleep, and stress, which impacts the caregiver health status and quality of life as well as their ability to provide quality care for their loved ones and themselves. Attention to the stress level and health of caregivers needs to be the focus of care in the family with Alzheimer's, in addition to care of the patient. Many assessment scales are available that can be used to assess and identify the negative impact of caregiving on the caregiver's life and suggest timely interventions to reduce burden, with the Zarit Burden Inventory (19) recommended highly.

Female spouses showed greater burden than husband caregivers in the majority of the articles reviewed. As expected, immediate family members experience more stress than non-immediate family members; for male caregivers, a lower quality of relationship led more frequently to institutionalization. Compared to spouse caregivers, adult-child caregivers reportedly experience higher burden, since some may see the role as an additional task and causing important changes in their already busy lifestyle. Caucasians are more likely to be institutionalized than African Americans or Hispanics; it is thought that culture and family values explain this. Thus, burden is seen differently by gender, race/ethnicities, quality of relationship, and with spouses vs. child or not-related

caregivers. It is important for nurses and health care providers to assess the dynamics affecting each patient and their caregiver to individualize interventions to address areas of need, burden, and caregiver health and well-being. Since caregiver burden is identified as a multifactorial dynamic and a major influence ongoing in the process of institutionalization of a loved one, using assessment scales in practice regularly will give voice to change the nature of distress experienced from caregiving.

Institutionalization is frequently seen as a relief from the stress of caregiving. However, after placement, spouse caregivers experienced more depression and an increase in anxiolytics use prior to placement. Often spouse caregivers that have lower education, had a close past relationship, strong sentiments against placement, and live closer to the facilities were found to visit the institutions more frequently. Many caregivers continue their caring and vigilance for their loved ones, even after institutionalization by spending their entire or the majority of the day at the institution continuing to be involved in care. Reasons can be varied from inability to let go, grief, monitoring of care, dedication, or wanting to be near. For these caregivers, helping them to be a part of the care and monitoring attention to their own health risks becomes part of the health provider care of these families.

This care mandate extends to programs for patients with Alzheimer's such as day centers, expert centers, group living and respite hospitalization that have shown to decrease burden and alleviate depression among caregivers. Health care providers should not only assess the patient with Alzheimer's, but also the caregiver and emphasize the available resources in the community to help them care for their loved ones and receive assistance to deal with the stresses of caregiving and the need for support. Recognizing risk

factors in caregivers and patients of AD allows health care providers to provide timely interventions and can further delay institutionalization. Furthermore, additional support to the caregiver such as counseling or group support is often helpful after institutionalization occurs. Attention to these caregiver responses and factors that predict responses about institutionalization are critical to consider when providing quality care to caregivers of Alzheimer's patients and their loved ones.

Caring for a family member with Alzheimer's disease is not a simple task. Dealing with AD can have a positive and/or negative effect on a caregiver's physical, psychological, emotional health, social life, and financial life (8). Stress, anxiety and depression of caregivers are correlated with caring hours, sleep problems, behavioral disturbances of the patient, amount of free time and time spend out of the home(2, 3, 12). The research articles reviewed revealed the following profile of caregivers of AD more at risk of burden: a patient with more behavioral and cognitive decline; Caucasian; care provided by immediate family caregivers and female spouses; conflictual behaviors and cognitive problems, lack of support; caregiver negative disposition, and values and beliefs of doing it alone. Using services such as home social services, day services, group living/Cantou, expert centers and respite hospitalization decreases depression, social isolation and burden among the caregivers of an Alzheimer's patient. Creating a balance in life after institutionalization where institutional visitation does not become burdensome is advised.

Therefore, health care providers should assess AD caregivers, their health, and recognize the individual dynamics and risk factors outlined in this literature review associated with early placement

and psychosocial *sequelae*. It is critical to inform caregivers what are the available resources in the community for their loved ones and themselves. During placement and even after, caregivers do best with counseling and support groups to alleviate the feelings of depression and burden. Further research should focus on programs to help caregivers cope with stressors, burden, and depression during and after institutionalization to assist them to maintain their health and quality of life during caregiving.

### Riassunto

*I caregivers dei pazienti con Malattia di Alzheimer (MA): fattori che influenzano l'istituzionalizzazione. Qualche considerazione in base alla letteratura esistente*

**Obiettivi:** Il caregiving è sempre più presente nella società post industriale, il peso e lo stress assistenziale è direttamente proporzionale al grado di compromissione cognitiva del paziente. Questa è spesso una delle cause che richiamano l'istituzionalizzazione. La malattia di Alzheimer è una malattia dementigena cronico - degenerativa. I sintomi di questo disordine neuropsichiatrico iniziano a manifestarsi dopo i 60 anni; al momento vi sono circa 8.9 milioni persone investite del ruolo di caregiver. Nel momento in cui le condizioni del paziente peggiorano, il peso da tollerare per i caregiver aumenta, questo dovuto allo stress psicofisico ed emotivo che deriva dal prendersi cura di una persona con demenza di tipo Alzheimer (DtA).

**Metodi:** Si è studiata la letteratura esistente consultando le banche dati elettroniche: PubMed, Google Scholar, Science direct, CINHALL. I criteri inclusivi erano: articoli in lingua italiana o inglese, pubblicati tra il 1999 e il 2011 che contenessero: caregivers di pazienti affetti da malattia di Alzheimer, peso assistenziale, fattori stressanti, and istituzionalizzazione. Fattori di esclusione erano che non vi fosse contenuta la parola "caregiver". Sono stati trovati circa 100 articoli, di questi 100, 30 sono stati criticamente valutati, selezionandone infine 17 più coerenti con gli obiettivi dello studio.

**Risultati:** L'esperienza dei caregiver in riferimento all'istituzionalizzazione rivela che il peso assistenziale del caregiver è influenzato dal comportamento e dal livello cognitivo del paziente, dalle ore che

lo coinvolgono nell'assistenza, stress, isolamento sociale, genere, relazione con il paziente, possibilità di sostegno e caratteristiche personali. La letteratura dimostra che strumenti per valutare e riconoscere fattori di rischio ed il peso assistenziale dei caregiver hanno una forte utilità ed hanno riscontro anche sulle decisioni sull'istituzionalizzazione.

**Conclusioni:** la letteratura suggerisce una maggior informazione degli operatori della sanità rispetto a come limitare il peso assistenziale e le sue conseguenze. Tutti gli strumenti per valutare e riconoscere fattori di rischio ed il peso assistenziale dei caregiver dovrebbero essere usati più spesso al fine di ridurre il peso assistenziale e migliorare il livello di salute e benessere del caregiver, riducendo anche il ricorso all'istituzionalizzazione.

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