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What causes grief in dementia caregivers?

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ABSTRACT

Alzheimer's disease (AD) is the most prevalent neurodegenerative disease in the world. Most AD patients become dependent on their relatives, i.e. family caregivers. Providing care to a person with AD influences caregiver's life and leads to feelings of grief, which often precede caregiver depression. The purpose of the article was to evaluate the Meuser and Marwit Caregiver Grief Inventory (MM-CGI-50) for use in Polish family caregivers and to find out determinants of grief of family caregivers of AD individuals living in Poland. A sample of 151 spouse and adult child caregivers of community-dwelling AD patients (95 females and 56 males) was interviewed to determine the influence of such factors as caregiver's age, gender, family relation to the care recipient (CR) and caregiving-related changes in caregiver's working time, leisure time and material status to find out the impact of caregiving role on intensity of caregiver grief. Caregiver grief was measured by means of MM-CGI-50. Additionally, carers were administered a questionnaire including patient's and caregiver's demographics. Also, CR's dementia assessment was informant-based and determined with investigator-administered clinical dementia rating (CDR) scale. Of all analyzed factors, only caregiver's informant dementia rating significantly influenced caregiver grief. To conclude, the effect of caregiver's age, gender, family relation to the CR and caregiving-related changes in caregiver's working time; leisure time and material status could not be found. To add, MM-CGI-50 can be effectively used to assess grief in Polish family caregivers of AD patients.

1. Introduction

AD is the most prevalent neurodegenerative disease in the world. Current epidemiological estimates indicate in the U.S, for example, that one in eight individuals over 65 years of age will develop AD. What's more, the total number of persons afflicted with AD in the world is expected to exceed 107 million by 2025 (2012 Alzheimer's disease. Facts and Figures, 2012; Grand, Caspar, & Macdonald, 2011; Grossman et al., 2010; Ozarowski, Kupsz, & Torlińska, 2006). The symptoms of the disease include not only progressing memory deterioration and cognitive impairment but also depression and behavioral symptoms such as aggression, sleep disturbances or wandering. In the course of the illness most AD patients become dependent on their relatives (spouses, adult children or, much less frequently, members of extended family), i.e. family caregivers.

Providing care to a person with dementia of Alzheimer's type is associated with emotional, physical and financial toll because of its influence on caregiver's lifestyle, professional career and financial status (Adams, 2006; Maslow, 2008). Recently, a number of investigations were devoted to psychosocial problems connected with providing care to a close relation with Alzheimer's. Being a family caregiver has been shown to be a risk factor for depression, anxiety and distress. According to several authors, the onset of caregiver's anxious depression depended on such factors as caregiver's age, gender and relation to the CR (Andrén & Elmståhl, 2008; Cuijpers, 2005; de Vugt, Nicolson, Aalten, & Lousberg, 2005; Epstein-Lubow, Duncan Davis, Miller, & Tremont, 2008; Mahoney, Regan, Katona, & Livingston, 2005; Melo, Maroco, & de Mendonca,

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2011; Schulz & Martire, 2004). Observations also indicated that depressive symptoms could be triggered by CR's behavioral disturbances.

Then Meuser and Marwit highlighted the concept of caregiver grief. Grief had initially been defined as a psychological (emotional, cognitive, functional and behavioral responses) response to a loss such as death (Prigerson & Maciejewski, 2008; Zisook & Shear, 2009). Meuser and Marwit, however, found out that family caregivers of persons with Alzheimer's disease grieved as they were observing "social" death and intellectual deterioration of their loved ones long time before the actual experience of their death (Marwit & Meuser, 2002; Meuser & Marwit, 2001). Meuser and Marwit also developed an inventory to assess caregiver (MM-CGI-50). Based on their analyses, which were carried with the use of MM-CGI-50, they indicated feelings of grief were related to caregiver's perceived personal sacrifice (adverse effect of care on caregiver's professional, social and family life), heartfelt sadness and longing (personal sadness and separation pain), social isolation and diminished perceived social support. Grief in dementia caregivers was distinct from depression and was associated with worse quality of life and mental health morbidity (Kiely, Prigerson, & Mitchell, 2008; Marwit & Meuser, 2005; Meuser, Marwit, & Sanders, 2004; Silverberg, 2008). Some investigators believed that the way an individual carer experienced and coped with caregiving-related grief could influence the quality of care, the process of mourning (grief work) and adjustment after the loved one's death (Gataric, Kinsel, Currie, & Lawhorne, 2010; Meuser & Marwit, 2001; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Silverberg, 2007). Caregiver grief reactions would fluctuate with time, were affected by the stage of the disease and could be determined by caregiver's family relation to the CR (Meuser & Marwit, 2001; Meuser et al., 2004). Simultaneously, it was noted that reaction to these agents could depend on caregiver's sociodemographic characteristics so factors affecting grief in America do not have to play an identical role in other countries (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Kiely et al., 2008; Marwit & Meuser, 2005; McLennon, Bakas, Habermann, & Meuser, 2014; Meuser & Marwit, 2001; Meuser et al., 2004). So far, there were only few studies of grief in reaction to dementia caregiving, most of which, were carried out on samples of caregivers living in the American society. Findings from these studies cannot be generalized to caregiver populations living in other countries because of socio-economic and cultural differences between societies, to say the least (McLennon et al., 2014). Consequently, considering both theoretical and practical importance of the impact of grief on dementia caregivers, our aim was to explore agents influencing caregiver grief in a sample of Polish caregivers of individuals with AD with the use of 50-item MM-CGI-50. In order to achieve that goal we decided to develop Polish version of that inventory. We wished to find out determinants of caregiver grief so caregiver grief measures in the sample were taken and related to such variables as caregiver's age; gender; family relation to the CR; caregiver's and CR's living arrangements (living together or in separate households); caregiver's informant assessment of CR's level of dementia and caregiving-related changes in caregiver's working time, leisure time and material status.

We hypothesized that these factors would influence grief but we believed their role would not be identical due to relevant socioeconomic and cultural differences between Poland and the U.S.

2. Method

One hundred and fifty one current spouse or adult–child caregivers participating in the study were recruited through Day Care and Rehabilitation Center for AD Patients in Poznan (Poland), via a special website designed for the purpose of the study, by an internet advertisement and by word of mouth. Demographics and care-related characteristics of all subjects are presented in Table 1.

3. Procedure

All subjects were interviewed individually and anonymously by the author of the paper either at their homes or in a separate room at day care center facilities. Each participant was informed about the purpose and importance of the study and voluntarily gave their consent to participate. The investigator also made sure subjects knew they could stop the interview at any moment. None of the participants stopped the interview or withdrew from research.

4. Measures

Informant dementia assessment: patient's dementia level was determined by way of CDR (Morris, 1993). Six cognitive-functional domains (memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal affairs) were measured. CDR was carried out as a semistructured interview with the caregiver. The interviewer used scoring rules (0 – normal, 0.5 – very mild, 1 – mild, 2 – moderate, 3 – severe) to determine functional impairment rating and used an algorithm-based composite score as the final rating as suggested by the author of the test (Morris, 1993). In the present study, respondents provided their own assessment of their CR's intellectual and functional impairment. Caregiver's subjective evaluation of CR's functional status was favored because, as MM-CGI-50 authors indicated, it was a more appropriate way to estimate caregiver's grief. It was believed participants' own individual perceptions and assessments of their loved one's health status were more important for their feelings of grief than doctor's diagnosis (Marwit & Meuser, 2002; Morris, 1993). In CDR, informant impairment rating is thought to be comparable to clinician's rating.

Caregiver grief: following CDR, all subjects filled in validated Polish version of MM-CGI-50 to assess the intensity of caregiver grief (Marwit & Meuser, 2002).

5. Validation MM-CGI-50

The procedure of validation of MM-CGI-50 consisted of two stages. The first step involved its cross-cultural adaptation while the second step involved determination of test's reliability. First, the questionnaire was translated into Polish by five independent bilingual translators without medical or clinical background about the concept of caregiver grief. Then the translation was synthesized and translated back into English by a professional translator who did not know the original version of MM-CGI-50. The resulting translation was then cross-examined with the original English version and discrepancies were corrected. This version was later pilot tested on ten healthy individuals with background in psychology who were native speakers of Polish and fluent in English. They were asked to provide critical feedback on vocabulary used and clarity of test items to ensure questionnaire's cross-cultural validity. All participants completed the questionnaire within 35 min and reported that all items were easy to understand and adequate in addressing caregiver grief issues. Then the test was ready for further statistical evaluation of its reliability.

To determine the reliability of MM-CGI-50 the test–retest method was used (Rousson, Gasser, & Seifert, 2002). First, the test was administered to twenty-five volunteers who were family caregivers of AD patients. After twenty-one days' interval the same group of caregivers was retested again. The total score reliability got an $r_s = 0.87$ Spearman-rank correlation coefficient ($p < 0.01$). The internal consistency was determined by Cronbach's alpha