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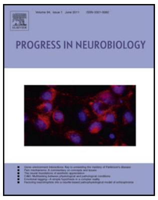

The impact of early dementia diagnosis and intervention on informal caregivers

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ABSTRACT

In the absence of disease modifying therapies for dementia, the question rises what the benefits are of an early dementia diagnosis for patients and their caregivers. This paper reviews the caregiver perspective in dementia and addresses the question what the consequences are of promoting earlier dementia diagnosis.

An early diagnosis offers caregivers the opportunity to advance the process of adaptation to the caregiver role. Caregivers that are better able to adapt to the changes that characterize dementia, feel more competent to care and experience less psychological problems. However, drawbacks of an early diagnosis may outweigh the benefits if people are left with a diagnosis but little support. There is convincing evidence that multicomponent caregiver interventions in the mild to moderate dementia stages are effective to improve caregiver well-being and delay institutionalization. However, there still exist a gap between the improved possibilities to diagnose people in the predementia stage versus the scarce knowledge on intervention effects in this very early stage. This stresses the urgent need for more research on early caregiver interventions that enhance role adaptation and that include long-term follow-up and cost-effectiveness evaluation. Early interventions may help caregivers in anticipating and accepting the future care role and transitions, with the increased possibility that caregivers can still involve the patient in the decision making process. As levels of stress and burden are still low in the predementia stage it provides excellent opportunities to empower the resources of caregivers.

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1. Introduction

The rising prevalence of people with dementia worldwide (Wimo and Prince, 2010) will make an appeal to many new families to engage in care for a person with dementia. The terms 'primary caregiver' or 'informal caregiver' have been used to denote a relative who takes on the principal role of taking care for the dementia patient at home. The person most likely to take on

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Abbreviations: MCI, Mild Cognitive Impairment; AD, Alzheimer's disease; FTD, Fronto-Temporal Dementia; RCT, randomized controlled trials.

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the caregiving role will be the spouse. If the person with dementia is widowed or not in a relationship, then an adult child will most likely become the caregiver. In cases where there is no family member, a friend or neighbor may provide care (Quinn et al., 2010). Informal caregivers provide care because someone needs help, out of love or out of a sense of moral duty. This is often not a conscious choice but a gradual adaptation to changes in their family member. The relationship between caregiver and the person with dementia can affect whether caregiving is perceived as natural or as an obligation. Informal caregivers often provide years of extensive care and must be able to adapt to a continuously changing and demanding situation. This requires a wide range of skills, such as: supervising or taking over daily tasks, managing cognitive problems, interpreting and managing behavioral changes, adapting to new social and economic circumstances, coping with relational and emotional consequences, and participating in care and treatment decisions.

Informal caregivers can experience a subtle onset and gradual increase of caregiving tasks due to a slow progression of the disease, even long before receiving a dementia diagnosis. A study conducted by van Vliet et al. (2012) showed that the average duration between caregiver reports of symptom onset and dementia diagnosis was almost 3 years in late onset dementia and even longer (4.4 years) in young onset dementia. Promoting an early diagnosis is widely advocated and has priority in several recently launched national dementia strategies, such as the National Dementia Strategy for the UK, the French Plan Alzheimer, and the US National Alzheimer's Project Act.

New biomarkers are playing an important role in the improvement of early detection and diagnosis of Alzheimer's disease (AD). Biomarkers are used to detect manifestations of AD in the very early phase, characterized by limited cognitive symptoms and preserved functional abilities, also referred to as the Mild Cognitive Impairment (MCI) phase. This biomarker development and acknowledgment of the very early phase of AD offers new important opportunities for early detection, diagnosis and interventions. But in the absence of disease modifying therapies for AD, the question rises what the benefits are of an early diagnosis and if these outweigh the possible drawbacks for patients and their caregivers. This paper will focus on the caregiver perspective in addressing the question what the consequences are of promoting earlier diagnosis in dementia in terms of benefits, drawbacks and opportunities for interventions. The importance and consequences of informal care will be reviewed to guide the discussion.

2. Importance and consequences of informal care

2.1. Economic importance of informal care

Of the 35.6 million people living with dementia worldwide, the majority is living at home and cared for by a family member. In the future informal care will be increasingly important as the number of people with dementia will rise to 65.7 million by 2030 and 115.4 million by 2050 together with a decrease of the working population (Wimo and Prince, 2010). The economic impact of dementia is enormous. Globally, costs for people with dementia amount to more than 1% of gross domestic product (GDP); if dementia care were a country, it would be the world's 18th largest economy (Wimo and Prince, 2010). Informal care is indispensable to keep dementia care payable, particularly with the rising costs for the upcoming years. This underlines the importance of investing in informal care. Furthermore, the main cost driver in dementia is the cost of care provided in nursing homes. Investing in early effective caregiver interventions may save costs in the long-term, particularly when institutionalization can be postponed.

2.2. Burden of informal care

The concept of burden has been applied to the dementia context to capture the complex negative consequences of caregiving (Verhey et al., 2007). Caregiver burden is a multi-component construct, influenced by the characteristics of both the person with dementia (e.g., behavioral problems) and the caregiver (e.g., perceived stress, psychological wellbeing, lack of knowledge, immature coping), as well as the social context (e.g., finances, social support, family help). A distinction can be made between objective and subjective burden. Caregivers differ in their competence and skills to successfully manage the day-to-day problems. Those who feel that the demands of caring exceed their capacities will feel stressed, whereas those who do feel equipped will not (Donaldson et al., 1998). Objective burden refers to aspects like the amount of time spent on caregiving and the type and number of caregiving tasks that are performed (Brouwer et al., 2004). Subjective burden refers to the emotional reaction of the caregiver to the demands of the situation, such as feelings of incompetence or exhaustion. Subjective burden can be distinguished from psychiatric symptoms in the caregiver, such as anxiety and depression. The distinction between objective and subjective burden is important because the association between the severity of impairment in the dementia patient and caregiver well-being is not straightforward (Montgomery et al., 1985).

2.3. Positive aspects of caregiving

The onset of dementia is associated with negative consequences but it can also bring positive experiences (Horowitz and Shindelman, 1983; Murray et al., 1999; Spruytte et al., 2001). Caregivers often report a stronger emotional bond with their spouse after onset of dementia (de Vugt et al., 2003), which can be explained in a variety of ways. First, both caregiver and patient come into the same situation where they have to deal with the diagnosis dementia. Sharing this difficult experience may strengthen their bond. Second, the quality of the relationship between caregiver and patient can no longer be taken for granted. This may increase caregivers' awareness of their affection for the patient and makes them enjoy more of the time they still have together. Finally, the increasing difficulty of dementia patients to manage their day-to-day life may elicit feelings of empathy in the caregiver and the need to protect their spouse. This can make them feel closer to their partner while daily interaction becomes more difficult.

Caring in itself can be rewarding and provide a sense of self-efficacy and feelings of accomplishment (Carbonneau et al., 2010). Nolan (1996) described that the greatest source of satisfaction identified by caregivers was the act of giving to the care-recipient. Being able to give something back can be considered a basic social need (Vernooij-Dassen et al., 2011). Another key motivating factor for caregivers is affection (Iliffe and Manthorpe, 2004; Quinn et al., 2010), followed by a sense of duty or a sense of obligation. Early interventions that focus on enhancement of the positive aspects of caregiving might contribute to caregivers' well being and reduce the long-term negative impact such as stress or burden.

2.4. Negative aspects of caregiving

Caregivers of dementia patients are very vulnerable due to the chronic stress they experience in the caregiving process (de Vugt, 2004). More than 80% of the caregivers have a high risk of reaching their upper limits in burden during the disease process. An English study showed that 24% of caregivers had clinically significant levels of anxiety symptoms (Mahoney et al., 2005). In addition, caregivers have a four times higher risk of getting depressed compared to non-caregivers (Joling et al., 2010). Caregiving may