

## Special Article – Family Caregivers

# Tailor Made Care-mix in Dementia

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**Received:** February 06, 2017; **Accepted:** March 02, 2017; **Published:** March 03, 2017

## Abstract

The WHO names Dementia as the biggest challenge for Europe in the next 50 years. The Disease affects several cognitive and psychological functions and leads to a great need for care. Often this care is provided by a main caregiver. Caregiving for people with dementia is very challenging - often it goes along with depression and physical impairment. In this article two emerging trends are put into focus that will shape the field of dementia in future: Gender diversity and complex care and case management. Both trends show a development from single main caregiver constellations to a much more complex and tailor-made care mix that includes the whole caregiving family, several kinds of professions and professionals as well as volunteers.

**Keywords:** Dementia; Family caregiving; Gender; Caregiver burden; Health services development

## Abbreviations

AD: Alzheimer Dementia; WHO: World Health Organisation; Pwd: People with Dementia

## Introduction

According to the Alzheimer Europe Association and the UN's demographic prospect an increasing number of older adults in Europe will be facing dementia in the next few years [1]. Currently there are over six million people with dementia living in the European Union. The syndrome affects approximately 5%-8% of the individuals aged 65 years and over, 15%-20% of the individuals aged 75 and over and 25%-50% of the individuals aged 85 and over. Approximately 40% of people with late-stage Alzheimer's disease (AD) live at home, while 60% live in healthcare establishments [2]. Often the families have to care for the affected person, which is a challenging experience for them. Apart from that, managing dementia in the elderly will be the greatest challenge that Europe will have to face in the next 50 years, due to the ageing of the baby boomer generation [2].

## Dementia

There is several different types of dementia. The most common ones are described in short as follows. The Alzheimer's disease is still the most common type of dementia, accounting for 60%-80% of the cases, with a greater proportion in the higher age ranges (age 85+). While early symptoms are impairments of basic cognitive functions (e.g. remembering recent conversations, names or events) and psychosocial matters (e.g. apathy and depression), later symptomatology include impaired communication, disorientation, confusion, poor judgment, behaviour changes, difficulties in speaking, swallowing and walking. Against this background, it is obvious that in later stages care management becomes increasingly challenging. Another type of dementia, which is probably the second most common, is Vascular Dementia. Nevertheless, its prevalence remains unclear, since Alzheimer's as well as Vascular Dementia are affected by cardiovascular events. In contrast to the initial symptoms of Alzheimer's the first signs of Vascular Dementia is an impaired judgment or difficulties to make decisions, to plan or organize

things. The remaining types (e.g. Dementia with Lewy Bodies (DLB), Frontotemporal lobar Degeneration (FTLD), Mixed Dementia, Parkinson's disease dementia (PD)) only account for a much smaller fraction of dementia diseases [3]. On the one hand, there is a bunch of risk factors known to increase the probability of developing Alzheimer's disease, including smoking, cardiovascular diseases, hypertension, Type II diabetes and obesity [4,5]. On the other hand, factors like a higher level of education, physical exercise as well as a Mediterranean diet show a decrease in the risk of developing an AD [4]. Taking all this into account, it is no wonder that the disease is an extreme burden for older adults with a neurodegenerative disorder as well as for the caregivers. In order to lower this burden there has been launched some medication in the US and the European countries (e.g. Memantine), that is helpful in dealing with certain aspects of the disease. The cholinesterase inhibitor appears to slow down cognitive decline, although the improvements are very modest.

As mentioned before, the disease constitutes a challenging burden for the different caregivers due to its capricious progression.

## Family Caregivers

From the medium stages of the disease on, the symptoms go along with a growing need of assistance and care which is mainly met by family caregivers in a home care setting. At the beginning of the disease, home care by relatives is preferred by both the caregivers and people with dementia (pwd) [6]. In general one caregiver bears the main responsibility. Commonly spouses become the caregiver for younger pwd while older pwd are usually cared for by their children. In most cases daughters become the main caregivers. Although the number of caregiving sons is increasing [7] they are still a minority [8].

This growing amount of tasks leads to an increase of stress and strain and also the disease itself also induces a typical cluster of emotions. Dementia caregivers experience the suffering and personality changes of a beloved person. This leads to emotions of grief [9-11] about the fact that the person with dementia who will never be the person he or she has been before. Furthermore, caregivers often feel anger towards the situation, the felt injustice

of the disease and sometimes the person with dementia due to symptoms of the disease [10,12]. This in turn can lead to inner conflicts, when caregivers believe they should not feel angry towards their ill relative [10]. Often the caregiver feels left alone by friends and family members [9-11]. In public they sometimes experience shame due to inappropriate behaviour of the person with dementia. Another typical emotion is the feeling of guilt about being unable to prevent the situation, taking care of their own needs or getting angry towards the person with dementia [10]. Often they are without hope, that there can be improvements to the situation [11]. The daily 24-hour-long care is perceived to be extremely challenging [11]. But people caring for relatives with dementia do not only experience negative emotions. Sometimes they experience personal growth and develop a more intimate relationship with the pwd. However these positive feelings neither are as frequent as the negative ones nor are they well researched [13].

The burden of care leads to an increased risk of developing cardiovascular illnesses and an increased probability of consuming drugs [6]. Dementia caregivers suffer particularly often from depression and their well-being is reduced [14].

Caregiver burden does not only affect the main caregiver but also the whole caregiving family and the interaction between family members. Perceived role conflicts between the family and the caregiver role have a high impact on Depression of the caregiver [15]. For the other family members there are ambiguous outcome variables. While grandchildren for example often perceive a worsening relationship with the person with dementia and a decrease in emotional closeness [16] it is also found that they develop more sympathy for older adults, spend more time with their siblings and have higher bonding with their mother because of the disease [17].

## Interventions for Family Caregivers

Many interventions have been established to address these difficult situations. While some therapy concepts for dementia caregivers have been developed [18] most programs belong to the field of psychoeducation. The REACH (Resources for Enhancing Alzheimer's Caregiver Health) Program [19] and the New York University Counselling and Support Intervention for Caregivers by Mittleman [20] are among the best evaluated programs leading to a decrease of caregiver burden and delayed nursing home placement for the person with dementia. Both programs underline the importance of involving other family members in the care to sustain the home care setting [21,22]. Meta-analyses by Pinquart, Sörensen & Duberstein [23,24] show that most interventions lead to medium effect sizes, which has been confirmed by newer analyses [25]. But not only professional interventions, also interventions carried out by volunteers can lead to an enhanced quality of life [26]. Typically these interventions address the relationship with the caregiver and the caregiver networking. In most cases they carried out by former caregivers who want to pass on their own experiences and improve the situations of other caregivers [27]. The provision of professional support to these volunteers has proven to be helpful. Also interventions that primarily address the pwd, like day care, lead to a reduced burden for the caregiver and the caregiving family [12].

## Emerging Trends

What are the emerging trends that are going to influence and

shape the field of dementia care by family members? Considering the demographic change, the change of lifestyles und family forms (patchwork families, divorced couples, single parents) and uncountable breakthroughs in technology the future of informal care will clearly differ from today's status quo. What changes can be predicted? Eifert et al [28] recently chose the theoretical lens of the life course perspective for their systematic review of the caregiving literature, asking what characteristics of the baby boomers separates them from previous caregiving cohorts and how these characteristics will affect family caregiving. They identified six trends:

1. Increasing use of digital technology for information gathering and support
2. More diversity among caregivers and care recipients
3. Strained finances and loss of entitlements
4. More complex care and care management
5. Demand for public politics related to caregiving
6. Balancing work, family, chronic disease and caregiving

Two of these trends will be introduced here, therefore revisiting some of the topic that have been addressed in the previous paragraphs: the baby boomer's rising number, the number of caregivers involved in a caregiving situation and the gendered nature of informal care.

## Diversity

Research (and health care professionals accordingly) usually concentrates on one main caregiver as being responsible for the care arrangement on her own. This "primary caregiver" is typically described as female, white, married, middle-aged and caring for her mother (mostly in the same household or nearby). Considering care as a "family affair" [29], as a challenge not only for one person but for a network of family members with different tasks and approaches is seldom taken into account [30,31]. Studies that explicitly asked for the number of people additionally involved have revealed that in 26% of the familial arrangements two caregivers are involved and in 37% of care arrangements three or more persons are involved [32], thus the burden is spread on several shoulders [33].

Eifert et al. [28] remind us to think of caregivers (and care recipients) in the 21<sup>st</sup> century as individuals of a diverse background – differing not only in race and ethnicity, sexual orientation, age or gender. As unique as each caregiver is – as unique is his or her caregiving situation and the resulting challenges and needs. Looking deeper into only one of those aspects – the gender – it is revealed that the majority of caregivers is still female – and care is usually considered as „ a woman's job“. Nonetheless, the number of men caring for an ailing relative is growing: Results of the EUROFAMCARE-study show that 68% of the caregivers in six European countries are female [34]. The MuG-III-Study of Potential and Limitation of Independent Living in Private Households in Germany [35] came to the result that 27% of the caregivers in Germany are men: from 1992 to 2002 the number of sons caring for a parent increased from 3% to 10%. Data of the "socio-economic Panel"/SOEP/BBR 2007 identified an overall percentage of 37% male caregivers in Germany. The numbers differ according to the definitions of care and caregiving and might be even higher if men who are not primary caregivers, but secondary

or supporting caregivers, were taken into account as well [36]. The percentage of men among adults caring for a family member with Alzheimer's disease or dementia in the USA doubled between 1996 und 2011 from 19% to 40% [37]. Studies show that "the experience of caregiving men has been largely neglected, and their contributions have been often marginalized" [38]. Given the smaller families and the rising number of employed women, the importance of men in the family care becomes obvious. The way they handle caregiving situations, experience challenges and burdens and find ways of coping is specific and unique – and affords new and different ways of support [39,40].

## Complex Care and Care Management

Trend number 4 identified by Eifert al al. [28] the development of informal care towards more and more complex situations and settings, especially regarding long-term chronic diseases that lead to the need of locating, managing and monitoring multidisciplinary professional support – for a long period of time. Coordinating and orchestrating a network of formal and informal support becomes a major task in caregiving. Another impressive and upcoming example is the following: The baby boomers and following generations are increasingly mobile, moving away from their hometowns when their family, education or careers require spatial flexibility. Caring from a distance "adds additional complexities and responsibilities" [41] – approximately 15% of all caregivers in the United States of America is living at least one hour away from the care recipient [42]. This growing group which faces specific challenges and has particular needs is another "blind spot" in the body of caregiving-literature, - there is only sparse research and hardly any interventions have been developed [43,44]. In a study about family members caring for pwd Thompsell and Lovestone [45] showed that the "impact of having a relative with dementia does not lessen with distance. The wider family needs support and information as well as the 'primary caregiver'." They experienced the same stress as proximal caregivers while reporting significantly higher levels of dissatisfaction with the amount of information they received.

## Conclusion

Professional approaches for relatives caring for a person with dementia should consider family as a system and network of interacting family members, supporting each other and the person with dementia. In the context of growing diversity, health care services and programs have to offer a variety of approaches, tailor-made for the individual needs and settings. As a guide line we see the vision of a "Caring Community" [46- 48]: a new culture of caring together for the elderly embedded in the community. The aim is to share the responsibility between families, volunteers and professionals that support each other in a "Care Mix" as we outlined for the FABEL-project [27].

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