

Ways to Design Holiday Accommodations for People With Dementia and Their Family Caregivers

Abstract

The “graying” of the population is proceeding rapidly, and the prevalence of people living with dementia is rising. Dementia is a syndrome due to the disease of the brain, which is characterized by a progressive, global deterioration in the intellect including memory, learning, orientation, language, comprehension, and judgment. This entails an increased need for assistance with daily tasks. In most cases, family members perform the caregiving role. However, providing care and support for someone with dementia is associated with an enormous emotional, physical, and social stress. Therefore, it is necessary for caregivers to take periods of rest regularly and to take care of their own health. In Germany, assisted vacations have been established as an important type of potential support for family caregivers. They go on a vacation together with their care recipient. During their stay, professionals and volunteers assist with the care and, as a result, relieve the family caregivers. Unfortunately, few vacation accommodations meet the specific needs of the target group. Especially, a proper design of the physical environment can positively affect functionality, behavior, and well-being among people with dementia and, thus, also benefit the caregivers. Former research on designing dementia-friendly environments has been heterogenic, and little is known about how to design the built environment for people with dementia outside nursing homes. The purpose of this paper is to explore ways of designing holiday accommodations for people with dementia and their family caregivers.

The methods used were, first, a literature review on design and family caregiving for people with dementia. This aimed at identifying dementia-friendly physical features and at determining dementia caregivers’ characteristics. Second, a case study of existing holiday homes was carried out to detect strengths and weaknesses of their built environments. In combination, caregiver’s demands on the design of the built environment were assessed through qualitative interviews with caregivers. Consequently, design criteria were de-

veloped through a synthesis of the result of the previous steps. Finally, the resulting design criteria were transferred into a concept for a prototypical holiday accommodation.

Results suggest that a holiday accommodation, which meets the demands of the target group on the built environment, has to be barrier-free and dementia-friendly designed; has to offer situational orientation cues; and provides space for activities, communication, and retreat.

This paper represents a first approach of exploring ways to design dementia-friendly holiday homes. There is a need to further examine the resulting ideas.

Introduction

Increases in life expectancy combined with low birthrates have started a process of change in the age structure of the population in industrialized nations. The population is “graying” rapidly, and older people will soon represent a dominant segment of the society. However, older age is consistently associated with an increased risk of disabilities and diseases, especially dementia.

By definition of the American Psychiatric Association (APA, 2007), the essential features of a dementia are multiple acquired cognitive deficits that usually include memory impairment and at least one of the following phenomena in the absence of a delirium that might explain the deficit: aphasia (inability to speak), apraxia (disorder of motor planning), agnosia (inability to recognize objects, shapes, persons, etc.), or a disturbance in executive functioning (the ability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior).

In the World Alzheimer’s Report of 2009, it was estimated that about 35.6 million people worldwide will be living with dementia in 2010. Western Europe is the region with the highest number of people with dementia (7.0 million), closely followed by East Asia with 5.5 million, South Asia with 4.5 million, and North America with 4.4 million. These numbers are predicted to double every twenty years (ADI, 2009).

However, dementia does not only have negative outcomes for those who are diagnosed with it but also for their caregivers. It is estimated that about 73% of people with dementia are living at home and are cared for by a family member. In 57% of the cases, retired spouses function as primary caregivers (Wimo, Winblad, & Jönsson, 2007). Most dementia caregivers are thus at an advanced age

as well. Their mean age is about 60 years (Schneelkoth & Wahl, 2005). Providing care and support for someone with dementia is associated with an enormous emotional, physical, and social stress. In their study, Ory et al. (1992) found that dementia caregivers are affected more negatively by caregiving than non-dementia caregivers because they are confronted with an often overwhelming number of challenges. Eters, Goodall, and Harrison (2008) found several studies, which demonstrate that behavioral disturbances of patients with dementia are one of the largest factors contributing to caregiver's burden and depressive symptoms. Furthermore, dementia caregivers spend many hours per week providing care. As the disease progresses, providing care can sometimes become, literally, a 24-hour-a-day activity, and the caregiving role lasts many years or even decades. The impact on social and personal time is especially notable, with a great proportion of dementia caregivers reporting having to give up pleasurable hobbies or having less time for other family members (Ory et al., 1992). Additionally, a severe reduction in satisfaction with "time for self" in high-burden caregivers was found in a study by Coen, O'Boyle, Coakley, and Lawlor, (2002).

Family caregivers perform an important service for their relatives and society, but they do so at considerable cost of their own well-being. Therefore, interventions are needed, which help them take care of their own health, offer strategies to cope with their stressful everyday life, and support their social inclusion. There are many methods of trying to help family members providing care such as education and training programs, support groups, adult day care, in-home respite, and meal services. In the reviews of Brodaty, Green, and Koschera, (2003) and Schulz, Martire, and Klinger (2005), the authors found several studies, which indicated benefits of such interventions in the reduction of caregiver's morbidity, improvements in well-being, and a delay in nursing home placement of people with dementia. In Germany, assisted vacations have been established as an important type of potential support for family caregivers. They go on a vacation together with their demented relatives. During their stay, professionals and volunteers assist with the care and, as a result, relieve the informal caregivers. Few studies have evaluated assisted vacations of this type. However, results of the pilot study of Wilz and Fink-Heitz (2008) indicated that assisted vacations can have both immediate and longer lasting positive effects on caregivers' health.

Unfortunately, few holiday accommodations meet the specific needs of people with dementia and their caregivers. Especially, the design of the built environment is an important key element for a holiday to become successful. A therapeutic and dementia-specific adapted environment can positively affect the functionality, well-being, and behavior among people with dementia (Calkins, 2009; Day, Carreon, & Stump, 2000; Tilly & Reed, 2008). This benefits both the care recipient and their caregiving relative. Former research on designing dementia-friendly environments has been heterogeneous, and little is known about how to design the built environment for people with dementia outside nursing homes. The purpose of this paper is to explore ways of designing holiday accommodations for people with dementia and their family caregivers.

Methods

First, a literature review on design for people with dementia was implemented to identify physical features which are most important for a dementia-friendly environment. Research on family caregiving for people with dementia was the second topic included in the literature review to determine dementia caregivers' characteristics. Second, a case study in combination with qualitative interviews was conducted. Qualitative interviews with two caregivers, who had taken part in assisted vacations before, and four representatives from businesses, which offer vacations for people with dementia (welfare organizations, travel agencies, and nursing homes), were carried out. Two of the business representatives had formerly functioned as primary caregivers for a demented family member and had gone on assisted vacations with them. All four representatives were now actively involved in the execution of assisted vacations and acted as travel companions. The aim of the interviews was to assess the motives of dementia caregivers to go on a shared vacation, their demands on the design of the built environment, and their perceptions of deficiencies of exciting holiday accommodations they had visited. Furthermore, one Hotel, which is to date the only accommodation in Germany that particularly installed dementia friendly physical features in their hotel environment, was visited to detect those physical features that seem to work well for the target group in a holiday environment and those that do not. Consequently, design criteria for dementia-friendly holiday accommodations were developed through a synthesis of

the result of the previous steps. Finally, the resulting design criteria were transferred into a concept for a prototypical holiday accommodation.

Results

Target group characteristics and caregivers' motives to go on a shared holiday

Besides age-related bodily impairments, cognitive disturbances are a main characteristic of people with dementia and a crucial reason for their increased need for assistance. They need support with orientation in space, time, and situation. Unfamiliar surroundings, situations, and activities can be upsetting and frightening for them. Some have a high compulsion to move and tend to wander. Wandering is a very difficult factor for caregivers to deal with. Especially when the environment lacks safety, they are afraid of the care recipient falling or running away. This means an enormous stress for caregivers because they have to keep an eye on their care recipient frequently.

The main purpose of assisted vacations for people with dementia and their family caregivers is the caregiver's relief. Although a holiday alone seems to be the more relaxing alternative, most caregivers favor a holiday together with their care recipient over leaving them with another family member or in respite care. To understand this attitude, we need to have a look at the caregiver's characteristics: In most cases, dementia care is provided by spouses, who are also likely to be at an advanced age, followed by adult children. Especially, spouses experience difficulty turning care of their partners over to someone else. On the one hand, they might feel guilty to leave their loved ones behind. On the other hand, they are used to their caregiver role because of their intensive daily care practice and may value their own personal and caregiving routines. In addition, especially for couples, an assisted vacation represents a good opportunity to share relaxing and nice moments together and recharge energy for their stressful everyday life. Activating the partner with dementia, meeting new people, making friends, and sharing everyday problems with other affected families are further chances of assisted vacations. In contrast, most adult children providing care have less emotional difficulties turning care over to someone else. Because most of them are living in different personal circumstances than many spouses, with being employed and having to take care of their own family, they are more likely to take a break and go on a vacation with their family instead. Still, there

are some adult children who also prefer a holiday together with their parent and appreciate the chances such a holiday offers.

Demands of the target group on the physical environment

To satisfy the demands of the target group, the physical environment of a holiday home for people with dementia and their family caregivers has to pursue five objectives. These goals are as follows: (1) to compensate their age-related bodily impairments, (2) to take over as many tasks as possible on caregivers' behalf to give them the opportunity to experience a relaxing holiday, (3) to ease the problems of people with dementia with relocation to unfamiliar surroundings, (4) to offer couples opportunities to spend quality time together to improve couple's relationship, and (5) to support their social inclusion.

Strengths and barriers of existing holiday home environments

Unfortunately, few vacation accommodations meet the specific needs of the target group, and most of them display barriers for a holiday to become successful. The first major deficit of existing holiday homes is a lack of dementia-friendly physical features, which support the ability of people with dementia to remain independent. This gap is demonstrated by a predominantly non-barrier-free architecture and problems with providing spatial orientation cues for people with dementia. This entails that caregivers cannot be relieved sufficiently because people with dementia are still in great or, because of relocation, even in increased need for assistance. Moreover, none of the holiday homes offer safe outdoor environments for people with dementia to wander and, therefore, do not ease caregivers' concerns about their care recipients to go missing or getting injured. The hotel in the case study attempts to minimize such deficits, for example, by providing at least barrier-free bathrooms, differentiating the hotel-hallways through design motifs, and the inclusion of a small day care center within the hotel.

The second problem of existing holiday homes is the overall holiday atmosphere. Besides spatial disorientation, people with dementia have to deal with situational orientation problems and can get frightened through unfamiliar surroundings. Especially when assisted vacations are offered by health resorts or rehabilitation clinics, the holiday atmosphere tends to be very institutional. This leads to the risk of upsetting people with demen-

tia because they think they have been relocated to a nursing home. To comfort people with dementia with relocation, the hotel in the case study enables holiday makers to keep up with some of their daily routines. For example, by offering different room combinations, vacationists can easily adapt to their sleeping habits. They can choose between double bedrooms, two through a corridor connected single rooms, single rooms that are connected to double bedrooms or suites and, therefore, spend the night in room combinations that are similar to their homes.

One advantage of existing holiday homes for people with dementia and their caregivers is the wide range of leisure activities that are offered. Besides group activities, such as barbecues and assisted excursions to popular sights, the case study's hotel also provides a sensory garden. These offers represent a good opportunity for couples to spend quality time with each other, to activate people with dementia, and to meet new people. However, most accommodations offer dementia holidays only during a certain time of the year. At this time, the accommodations are not used by other holiday makers than the target group, which leads to a further separation of people with dementia and their caregivers.

Design criteria to develop dementia-friendly holiday homes

Based on the results of the previous steps, the built environment of a holiday home for people with dementia and their caregivers has to meet the following requirements: The built environment (1) has to be designed barrier-free to compensate people with dementia and also caregivers' bodily impairments. Additionally, it (2) needs to be dementia-friendly. A dementia-friendly environment compensates cognitive impairments and supports the independence of people with dementia. Important physical features of a dementia-friendly holiday home environment are, for example, a safe and accessible indoor and outdoor space, a clearly structured, small scale spatial layout, and at best intuitively understandable orientation cues. Furthermore, the built environment (3) has to provide situational orientation cues to alleviate the relocation to unfamiliar surroundings for people with dementia. On the one hand, an authentic and sensory environment, which includes regional design elements, can contribute to the creation of a holiday feeling that might explain the situation of being on vacation to people with dementia. On the other hand, familiarity can be created through

a holiday home, which is adjustable in respect to vacationists' daily routines, for example, through different room combinations. The built environment (4) needs to provide space for activities to offer couples the opportunity to spend nice and relaxing moments together. Such activity space can, for example, be a sensory garden or barefoot park. The built environment (5) should support the social inclusion of people with dementia and their caregivers. Therefore, space for communication, where vacationists can meet, and space for retreat are needed. At best, the holiday home would be an integrative type of accommodation to shift people with dementia and their caregivers to the center of society.

Design project: concept for a prototypical holiday home

Holiday at the seaside in a small resort town was chosen as an example to transfer the resulting design criteria into a prototypical, spatial concept because in Germany, the North Sea and the Baltic Sea are popular holiday destinations for young and old. Also, the accommodation type small resort town enables to develop a holistic and integrative concept for a holiday home, which involves indoor as well as outdoor space.

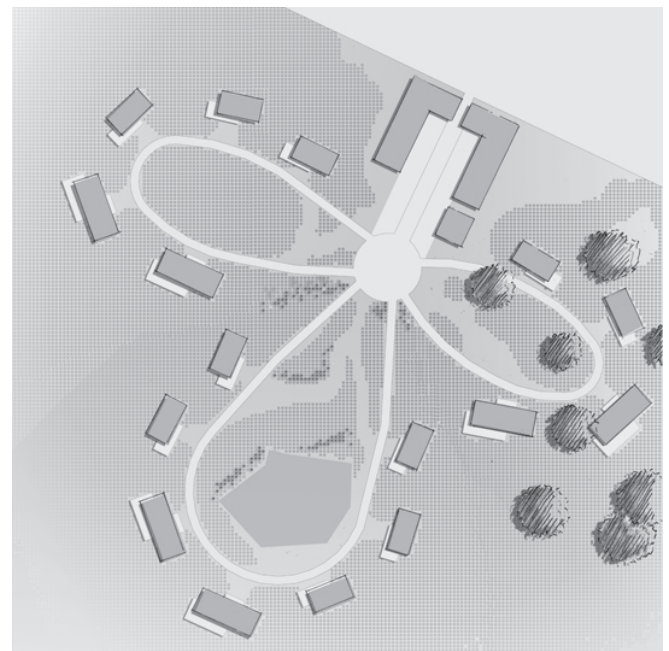


Figure 1. Map of holiday accommodation area

Special emphasis was devoted to the overall layout of the accommodation area. Access to the area is offered through a single, central entrance. The site is fenced in through natural boundaries, made of bushes, fences, and trees, to provide a safe and independently usable outdoor environ-

ment for people with dementia. As shown in Figure 1, route guidance works through paths that are shaped as horizontal eights. On the one hand, this can facilitate orientation because all paths lead back to a central meeting point. On the other hand, this layout enables to easily structure the small resort town. For the example, holiday at the seaside, the area could be divided into different regional landscapes like dunes, woods, dike, and town center. The differently designed spaces act as an intuitively understandable and sensory system for both spatial and situational orientation and also provide activity space for the vacationists.



Figure 2. Spatial layout of both types of lodges

Furthermore, two kinds of lodges were developed to attract various types of holiday-makers such as couples, families, or groups. Small lodges offer space for up to three people, and the bigger ones can host up to six (Figure 2). All lodges are single-floor, barrier-free, and clearly structured. The homelike layout and atmosphere is supposed to facilitate the relocation of people with dementia and support their independence.

Conclusion

Making assisted vacations available for people with dementia and their family caregivers is a worthwhile goal to reduce dementia caregiver's burden. To achieve this goal, there is a need to provide more dementia-friendly vacation accommodations. This paper represents a first approach of outlining key elements of a dementia-friendly holiday home environment. However, there is a need to further examine the resulting ideas of this paper. Therefore, future research should extend its in-

vestigations beyond the design of nursing homes. Interesting questions are how to design the environment of outdoor and public spaces and which situational orientation cues work for people with dementia. Furthermore, it is important to transfer research findings into practice. An increased awareness of the relationship between the built environment and people with dementia in society and the education of architects and designers about important features of a dementia friendly environment are key elements to achieve the goal of an overall dementia-friendly environment.

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