

## *Caring Communities – Ready for a Collaborative Approach to Dementia?*

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### **Abstract**

Old age, care dependency and dementia pose particular challenges to those affected and their families. This paper presents participatory approaches to face these challenges, both theoretical and practical, focusing on the concept of the Caring Community. One form of a Caring Community is the dementia-friendly community where people with dementia and their families find the acceptance and support they need. These communities are characterized, among others, by efforts to enable social inclusion and overcome stigmatization as well as an open approach to dementia in general. Several conditions need to be fulfilled for the successful social participation of a disadvantaged group (e.g., people with dementia) in a Caring Community. Among others, communities need to develop a fundamental social (e.g., dementia-inclusive) attitude which then translates into corresponding actions and behaviors. In addition, community members' understanding for and acceptance of people's needs and lived realities need to be improved. This paper discusses the experiences from a project in a small town in Austria which implemented awareness-raising, support and relief activities to improve the town's dementia-friendliness as well as dementia-inclusiveness. Highlighted are challenges with sustaining newly established meeting spaces and with activating people to engage in community efforts in times of the COVID-19 pandemic. Finally, the paper also touches upon the results of the participatory evaluation regarding the effectiveness of the project's activities.

Keywords: Caring Communities, Dementia, Dementia-Inclusiveness, Participatory Approaches

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## **Introduction**

Demographic change, different age structures, and the associated issues of health, illness and social participation up to a very high age require considerations about ways to maintain a good life for all people in a community. As the members of a society grow older, the risks for illness and caregiving issues also increase. Traditionally, care in Austria has been provided and is still provided to a high extent by family members. This, in addition to the social, economic and emotional burdens of predominantly female family caregivers, is subject to future changes as life courses and employment histories increasingly change. With facing a rising number of dementia-related illnesses, questions how to handle this as a society become important. According to the latest data, approximately 55.2 million people all over the world were living with dementia in the year 2019 (World Health Organization, 2021). Caring Communities, a practical concept with a strong theoretical background, could lead to a collaborative approach to dementia. In line with this, the research question of this paper is how Caring Communities can create the necessary structures for a community to be ready for a collaborative approach to dementia.

First, this paper will give an overview on the concept of Caring Communities and the latest data about dementia. In addition, the social aspect of dementia and the signs on how to identify dementia are presented. The next part focuses on a participatory approach which was used and evaluated in a practical project designed to help establish a dementia-friendly municipality in the South of Austria. The findings from this project and its evaluation are discussed and summed up afterwards in the conclusion.

## **Caring Communities and Dementia**

Under the term Caring Communities there are manifold approaches and international best practice examples summarized that differ depending on national structures in social and health sectors. The term Caring Community refers to a community of solidarity that includes formal networks but is built on informal and solidarity-based structures. Therefore, it is necessary to define what is meant by a Caring Community in each region, in each place. This definition depends on the type and nature of the region, on the specific circumstances and needs of the people in that region. The term Caring Community is therefore to be understood as a collective term for communities of solidarity (Wegleitner & Schuchter, 2021).

Caring Communities or community-based approaches are built on solidarity and empowerment. Caring Communities have a responsibility for all people within a community, the aim is shaping care for and together with citizens in difficult life situations. This could be very different life situations which are challenging for people in the community (e.g., health and social issues, like dementia). Caring Communities are also addressing the question of the conditions of a good life and a good life together with other people in the community. It must be analyzed what a good life means individually as well as in the context of a community. Abilities and opportunities for a good life for all members of a society have to be discussed. Caring Communities are about individuals and the communities as well as the network between these two positions (Wegleitner & Schuchter, 2021).

Topics of Caring Communities are mindfulness and justice for others and the whole, which means the individual person in the context of society. Creating a helpful culture as well as supplying structures is very important in the neighborhood. An essential question is: where is the community located and what stakeholders are in this neighborhood? This is also related to

different opportunities in a certain region depending, e.g., on rural or urban circumstances, infrastructure, the living conditions in a region (e.g., industrial), access to education, professional care etc. Furthermore, the different generations are very important: the topics of Caring Communities are intergenerational exchange as well as intergenerational justice. With keeping the different generations in a community in mind, this concept could also prevent loneliness especially in an older age. An active care culture in different places and institutions is another topic of Caring Communities (Wegleitner & Schuchter, 2021).

The handbook on Caring Communities (Wegleitner & Schuchter, 2021), which was created and published in Austria, gives guidelines for and of Caring Communities. Important keywords are trust, empowerment, enabling, offering and accepting help as well as multipliers in the community. First of all, it should be highlighted that trust is the basis for working together in a community and also for networking within the community. Without trust it is not possible to offer or to accept help. Furthermore, trust is linked to empowerment too: on the one hand oneself empowerment to have the ability for active acting, and on the other hand trust in the knowledge that a community or society is offering the frameworks for empowerment. This is not only relevant for the older generation but is an important part of intergenerational exchange and justice. Enabling means maintaining one's own capacity for action and using it in the community. Multipliers in the community offer peer-to-peer support, peer counseling and low-threshold opportunities for enabling a help and care culture in the community (Wegleitner & Schuchter, 2021).

Beside this, exchange dialogues and places of care are main keywords in the context of Caring Communities and basic principles for creating a help and care attitude. For multipliers, stakeholders as well as anybody within a community it is essential to know where the places of care are. Where to go and where to meet relevant people should be very easy and transparent when someone is facing a problem. Therefore, the highest possible diversity should be taken into account in a specific region; inclusive structures for all people in the community are needed for Caring Communities to work in everyday life. With people getting older, poverty and questions of welfare systems and political arrangements also become relevant. In this context, Caring Communities can prevent poverty and support a good life within society, even up to a very high age, using community capacities (Wegleitner & Schuchter, 2021).

When talking about the concept of Caring Communities in the context of dementia, it is essential to keep in mind that the concept and also the consequences of dementia should be seen on the individual level (micro), the institutional level (meso) as well as the societal and political level (macro). Without this it is not possible to discuss appropriate strategies for dealing with a rising number of dementia-related illnesses and their special consequences for the society as a whole. According to this, the next section will highlight some facts about dementia. After that, it will be discussed how Caring Communities can help in a society where the number of people with dementia is expected to increase in the next few years.

Approximately 55.2 million people all over the world were living with dementia in the year 2019. Most affected people live in the western pacific region, i.e., in Australia, New Zealand, Japan, China, Philippines and Mongolia. Europe follows in the second place with 14.1 million people affected by dementia. Dementia is not a specific disease, it is a group of symptoms which affect memory, behavior, thinking, social skills, a person's activities of daily life (ADLs) as well as their social autonomy. When talking about the concept of Caring Communities within a society, empowerment, participation and autonomy are important

factors when creating dementia-inclusive structures (BMASK, 2011; World Health Organization, 2021; Deutsche Alzheimer Gesellschaft e.V., 2022; Juraskovich & Ostermann, 2012; Nagl-Cupal et al., 2018; Robausch & Grün, 2015; Sütterlin et al., 2011; Wancata, 2015; Webster, 2021).

There are many different types of dementia. The most common types are Alzheimer's dementia, vascular dementia, Lewy body dementia, frontotemporal dementia and early-onset dementia. Alzheimer's dementia is the most common type and it affects people who are 65 years or older. No matter what type of dementia, this disease influences many areas of life, in personal and societal spaces not just of those who are affected but also of their relatives and (other) carers (BMASK, 2011; World Health Organization, 2021; Deutsche Alzheimer Gesellschaft e.V., 2022; Juraskovich & Ostermann, 2012; Nagl-Cupal et al., 2018; Robausch & Grün, 2015; Sütterlin et al., 2011; Wancata, 2015; Webster, 2021).

In order to be able to act appropriately, it is necessary to recognize dementia early enough so that needs-matching framework conditions, also within caring communities, can be set. Alzheimer's disease international recommends to pay attention to ten warning signs of dementia: The first warning sign is memory loss. Most people are familiar with this first sign, to forget daily life facts or appointments. The second sign is difficulty to performing familiar tasks, like preparing a meal or doing other activities in the household or garden. The third warning sign are problems with language, e.g. forgetting simple words. Fourthly, to face disorientation in time and place, is another warning sign: People with dementia can get lost in their own streets. Fifth, poor or decreased judgement is also a warning sign. For example, people are wearing heavy clothes even though it is very hot outside. Next, having problems with keeping track of things is another warning sign. For example, this could be official appointments, regular doctors' appointments or knowledge of important telephone numbers or addresses. Another sign is misplacing things, for example, putting the key in the fridge. Changes in mood and behavior are not very well known, but they are also very important when talking about dementia. People living with dementia also have big problems with coordinating visual and spatial information, e.g., when driving a car or using public transportation. The last warning sign is withdrawal from work and social activities, that means people become passive and disinterested in activities which they were used to do (Alzheimer's Disease International, 2017).

Within Caring Communities, these ten warning signs can be taken into account to create a dementia-inclusive society, and also serve to identify at an early stage which structures are required. Preparation in a community and the creation of appropriate structures for awareness raising and inclusion building are ongoing processes and should not be installed only when there are many cases of, e.g., dementia in a community. Connected to this, the next chapter will focus on a participatory approach based on a practical example, where this was the basis for installing a Caring Community.

### **Participatory Approaches: Practical Project Dementia-Friendly Municipality**

This chapter wants to introduce a research and development project based on the concept of Caring Communities with a special aim on the dimension of dementia-inclusive structures. The research and development project took place in a small town in the South of Austria, with the aim of fostering a Caring Community especially for people with dementia and their relatives. The participatory approach had the aim to create this together with the people in the community, so the project was designed and implemented together with the community. The

the jointly developed activities and methods were aimed to raise public awareness of dementia with the focus on supporting those affected and their family members. One form of a caring community is the dementia-friendly community where people with dementia and their families find the acceptance and support they need. These communities are characterized, among others, by efforts to enable social inclusion and overcome stigmatization as well as an open approach to dementia in general (Perchtaler et al., 2022).

The participation methods used during the project phase were an open citizen forum, stakeholder workshops, a future conference, events for the general public, such as a dementia march or lecture series, various training courses and the establishment of inclusive meeting spaces such as a dementia café. An intergenerational approach was in the focus of all these activities. (Perchtaler et al., 2022).

In the context of the scientific monitoring of the project, participants, actors and people living in the residential environment were also interviewed about their needs and the measures implemented. A small group of actors was also actively involved as co-researchers in a peer-to-peer survey in the residential environment. The results indicate positive developments towards a caring community primarily due to the positive acceptance and sustainable anchoring of the activities, the longterm commitment of stakeholders and the participation of affected families together with nonaffected families (Gruber & Hagendorfer-Jauk, 2020).

From our experience, several conditions need to be fulfilled for the subject of participatory approaches in the context of Caring Communities and dementia. Successful social participation of a disadvantaged group, like people with dementia, in a Caring Community is successful when communities develop a fundamental social attitude towards inclusion. This is the basis for all corresponding actions and behaviors. Key findings, which have been collected during the one-year period of preparation, the two-year project phase of conduction and now already 2.5 years post project collaboration, are defined and summarized as framework conditions for success. It needs newly established meeting spaces where people can meet each other within a community. Furthermore, it is also essential to actively engage people in their community, especially in times of crisis, like the COVID-19 pandemic. So, one of the basic elements is to develop a social attitude and dementia-inclusive attitude in the region (Perchtaler et al., 2022).

Social participation in the communal environment is a current and important issue in social coexistence. Particularly in the area of dementia, it is essential to involve those affected and their relatives in the community and to develop capacities in the sense of a shared culture of care in a community or neighborhood. Care networks in the municipal environment can be developed and strengthened through continuous initiatives that are linked to the current circumstances and challenges (capabilities). Participatory care networks should be promoted and professionally supported, the concept of Caring Communities with its framework can help to promote this (Perchtaler et al., 2022).

## **Conclusion**

Based on the underlying research question of this paper, the following conclusions can be drawn. Participatory approaches offer great opportunities in the context discussed above because they can improve community capacity building for the whole community as well as the neighborhood. These approaches access also the needs of those affected by dementia and their relatives. Individuum-oriented support solutions which are strongly needed for this

target group can be established with the help of transdisciplinary research and a development team which helps directly in the community. Co-work between science and practice could be engaged in this way. It is essential to have guiding principles: it is necessary to work and collaborate together in the community to establish a common working framework which is understood and supported by all the members who are participating. Then it is possible to establish diversity sensitive methods of participation and to indicate communication formats and the support needed for all stakeholders and target groups. With this, Caring Communities and participatory research can help to design a collaborative approach to dementia, which is rooted in and strongly connected to the needs of those affected as well as their caregivers and relatives.

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