

Proceedings of 7th Transport Research Arena TRA 2018, April 16-19, 2018, Vienna, Austria

Dementia on the move: Preliminary results based on a participative qualitative research project focusing on the daily mobility patterns of people with dementia

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Abstract

Around 130,000 people with dementia are currently living in Austria. Most of them continue living at home as long as possible after being diagnosed. People with dementia and their relatives undergo a progressive process of withdrawing from various social activities, which is accompanied by a reduction of their mobility in public space. However, mobility is a major factor that influences the degree of social participation of people with dementia. Up to now, knowledge on how people with dementia experience accessibility in public spaces within metropolitan areas of Austria has been very limited. Based on a qualitative case study approach, this research project carried out narrative interviews with people with dementia, assembled focus groups with relatives and associates, and used participant observations i.e. organised walks undertaken by the researchers as well as usability studies of transport information systems together with people with dementia. These studies were then analysed in-depth and compared to the daily mobility patterns in public spaces of people with dementia living in Vienna.

Keywords: mobility research; gender; dementia; cognitive disorder; diversity; mobility patterns; spatial planning; inclusion.

1. Introduction

Around 130,000 people with dementia are currently living in Austria. Most of them continue living at home as long as possible after being diagnosed. People with dementia and their relatives undergo a progressive process of withdrawing from various social activities, which is accompanied by a reduction of their mobility in public space. However, mobility is a major factor that influences social participation of people with dementia. Up to now, knowledge on how people with dementia experience accessibility in public space within metropolitan areas of Austria has been very limited. In collaboration between Institute for Palliative Care und Organisational Ethics, Faculty for Interdisciplinary Studies, Alpen-Adria University of Klagenfurt, Vienna, Graz (palliative and dementia care research, participatory qualitative approach, gender and ethical expertise), B-NK GmbH Consultancy for Sustainable Competence, Vienna (landscape and transport planning, management consultancy, gender and diversity expertise), CS Caritas Socialis GmbH (day centre and special-care home for the elderly in Vienna), and Wiener Linien (Vienna's public transport operator) the interdisciplinary research team pursued the following aims and issues:

- Everyday life experiences of mobility in public space of people with early and mid-stage dementia were studied to find out what promotes or hinders their mobility in public areas with a focus on the social environment and public transport.
- Client-centred usability studies that employed existing technical support systems for using public transport have been conducted in collaboration with people with dementia and their relatives in order to find out the usability requirements of this equipment.

Based on a qualitative case study approach, this research carried out narrative interviews with people with dementia, assembled focus groups with relatives and associates, and used participant observations i.e. organised walks undertaken by the researchers and carried out usability studies of transport information systems together with people with dementia. With the help of these methodical approaches, the everyday experiences of people with dementia living in Vienna concerning their mobility in public space were explored. Existing technical support systems and transport information systems were included as part of a "usability study" for people with dementia. Based on these insights, this research makes recommendations for more dementia-friendly transport system as well as for spatial and town planning practices that will be formulated for relevant stakeholders that include:

- social environmental groups and organisations (e.g. clubs, shops, etc.),
- town and urban planning focused equipment and orientation within the public sphere
- transport planning systems (esp. public transport).

This paper provides an insight of the project "Demenz in Bewegung" (which, in German, is roughly translated as: "Dementia on the move"), its approach and the first preliminary results. Some of the results have been published in German language. (Knoll et al. 2017)

- In-depth insight on the mobility patterns of people with dementia, the success and hindering factors when walking and/or travelling with the public transport system.
- People with dementia and their coping strategies when orientating themselves in the public sphere.
- Reflection on the up-to-date participatory approach when carrying out research not only about but also together WITH people with dementia.

2. Understanding the 'State of the Matter' concerning Dementia

2.1. People with dementia in Austria

In the year 2014, approximately 130,000 people with dementia were living in Austria. This number will likely experience a significantly increase until the year 2050 as a consequence of an aging domestic population structure of Austrian society. Two-thirds of the people with dementia in Austria are women. This can partly be ascribed to the longer life expectancy of women and the accompanying higher risk for illness among the elderly (Höfler, Sabine et al.: 2015). About 80 percent of all the people with dementia in Austria currently reside at home. The most common form of dementia is Alzheimer's disease. Even though scientific researchers as well as experts talk more and more about "cognitive disorders", individual progressions and "phases" (Fercher, Petra & Sramek, Gunvor: 2013) and less about the "stages" of dementia, in the clinical practise dementia is mostly divided in three different degrees of severity – based on the "mini-mental-state examination" (MMSE). In the "early stages" of dementia or "mild dementia", the symptoms include orientation problems regarding time and space, forgetfulness, problems with more complex tasks and a frequent denial of their own deficits. In the "middle stages" of dementia

the concerned persons are disoriented in time and space, they have problems with performing their daily routines such as personal hygiene, long-time memory and symptoms such as fear, anxiety and apathy can arise. The “late stages” of dementia or “severe dementia” is characterised with fragmentary memory, changes in personality, not recognising related persons or loved ones, loss of speaking abilities as well as advancing immobility. (Sepandj, Asita: 2015, 4ff)

Another classification of the dementia progress was developed by American social workers Naomi Feil and Vicki de Klerk-Rubin, who are specialised in working with the elderly (2013). They define four phases of dementia: “phase I” describes a beginning dementia and is characterised through deficient orientation, dissatisfaction as well as impatience, the people are mostly aware that they are becoming forgetful, but they deny it and blame others for it, additionally they are most likely not able to talk about their emotions. “Phase II”, also called the “middle stage” of dementia is characterised through confusions regarding time and include travels to the past, the short-term memory is fading more and more. In “phase III”, advanced dementia, individual movements are being repeated and are partly replacing the spoken language, the people are hardly able to follow and understand contexts of longer sentences. “Phase IV” or “severe dementia” stands for self-seclusion and withdrawal of the people concerned and an increasing limitation of motions and movement.

2.2. Day-to-day mobility of people with dementia

Achieving independent mobility is the key for social cohesiveness and for maintaining a self-reliant and independent lifestyle – especially in the case of people with dementia and their caretakers and/or loved ones. However, the effect on people with dementia and their relatives is often withdrawal from various social interactions proportional to the severity of the dementia process. Contingent to this withdrawal, day-to-day mobility in public spaces is strongly reduced, which leads to an isolation of those people. Anja Rutenkröger (2014, 4ff) summarised current research and provides the following conclusions: the ability to achieve movement and physical interaction reduce the risk for dementia up to 30 to 50 percent. Movements can improve the cognitive functions of already affected individuals (Rutenkröger, Anja: 2014, 7).

To make independent and self-reliant mobility for people with dementia and their loved ones possible and to reduce the risks for dementia through encouraging mobility and movement, it is necessary and a very important societal task to shape the environment in a way that people with dementia are not injuring themselves or getting stigmatised via society. (Heimerl, Katharina: 2015, 268f)

2.3. Enhanced understanding of dementia

In the past few years, studies on the societal participation of people with dementia and its enabling factors were pursued. A change in perspective was affected by the conception of dementia as a disability: Not the deficits of the people implicated are no longer in focus, but rather the interactions between the individual competences and the environmental conditions are reflected. For that reason, the structural conditions that are impeding people with dementia have come into focus. (Gronemeyer, Reimer: 2013) This point of view was also adopted by the Austrian dementia strategy „Demenzstrategie. Gut leben mit Demenz“, which was commissioned and prepared by the Austrian Government and refers to the UN-Convention on the Rights of Disabled People. An objective of the dementia strategy is the removal of those barriers, caused by attitude and environment, which hinder people with dementia to become an integrated part of society. (Juraszovich, Brigitte et al.: 2015)

3. Specific arrangements and built environment focussing the needs of people with dementia

Studies regarding the arrangement, built environment and furniture of spaces for people with dementia deal mostly with the shaping of interior spaces and therefore focus only on indoor situations of equipment and living arrangements. The interior design includes the following aspects: tips for contrasting materials, lightening, safety in bathroom and kitchen to minimise the risk for injuries (Bowes, Alison et al.: 2014), tips for preventing overstimulation caused by overfilled rooms and the creation of memory-spaces with well-known furnishings and decorations (Leuthold, Urs: 2009). Maria Maier et al. (2014) have examined whether the arrangements for certain hospitals are adequate enough for people with dementia and as a result they summarised a general set of recommendations for interior design. A few studies deal with the usage of gardens, which can be encouraged by circular paths for wandering around (Radzey, Beate: 2014). Sonia Teimann (2015) recommends private garden for nursing homes, which is situated as near as possible to the living area of the residents and offers a lot of seating accommodations. It is important that a garden has no direct gateway to the street (Tyll, Susanne: 2012). To

stimulate the senses, it would be beneficial to place objects in the garden such as water flows or raised vegetable- and flowerbeds for gardening (Teimann, Sonia: 2015) as well as fragrant plants (Tyll, Susanne; Bank Petra: 2012). Especially the usage of well-known plants, which reflect clearly the seasonal processes are recommended in this research. According to Felix Bohn (2014) entrance areas of nursing and caring homes should be clearly visible and identifiable.

Also in the technical sector, some products and specific applications have been developed for people with dementia. Among the various applications for mobile phones and tablet-computers in German language, there exists e.g. the following functions: self-tests (z. B. iMMST, BrainCheck, Dementia Test – Dr. Jey), memory games (Sea Hero Quest, Sprichwortquiz, Memory Check), memory functions (CareZone, MindMate), furnishing-planner (Dementia-Friendly Home App), information apps (Alzheimer Demenz Pocketcards, Fakten Demenz, DemenzProfi), help and notifications for emergencies (B-cared), care organisation and information (Pflege.kompakt Demenz/Schmerz) and applications for locating persons or with geofencing function (Hol mich App, Demenz-App, Walk Navi) (status: March 2017).

Special devices with locating functions, such as GPS or GMS, are available in various implementations. With the help of these systems, carers always know where the persons with dementia are located. Most devices also offer a geofencing function, which allow a user to mark a certain area as “secure”, for example, 500 metres around the residence of a person with dementia. In case that a person leaves that certain area, one or more relatives will be informed. Furthermore, almost all devices are equipped with an emergency button so that, in cases of an emergency, the carrier of the device is able to contact pre-defined persons, such as relatives, at all times. Devices with these functions are either tracker, bracelets, mobile phones for seniors, wristwatches or mobile phones.



Fig. 1: Overview on existing devices for people with dementia; diagram: B-NK GmbH

However, there are open research questions remaining regarding the utilization of public space by people with dementia. There are no research papers regarding this topic, which requires investigations into the orientation of people with dementia or necessary arrangements in outside areas, on the street or in one's home district.

4. The research project: “Dementia on the move”

4.1. Methodology

In the **narrative interviews**, people with dementia talk about their daily life, compare their mobility patterns from the past with mobility patterns they currently make today and articulate problems that they are currently facing in public spaces. In **walks**, the researchers accompany people with dementia by foot or on public transportation along their daily routes and trips. Within that process one researcher is documenting occurring barriers and problems while walking or using public transport by participatory observation, whilst the other researcher surveys, via a structured interview, the experiences, barriers, orientation points and supporting factors of either the individual or individuals in focus. During the accompanied trips, orientation characteristics, strategies, special needs and barriers were detected, which were helpful or obstructive for people with dementia. Significant findings about orientation in public space were additionally collected in the **usability study**. In that study, people with dementia had to solve small orientation tasks with help of the city and district maps of the City of Vienna as well as schedules of the “Wiener Linien”. The individuals being interviewed talked about how they are planning their routes at home and which aids they used for preparation of their trips. The usability study also evaluates which technical devices available on the market which support people with dementia. The study clearly reveals the attitudes people with dementia have towards those technologies, devices and aids.



Fig. 2 to 5: Impressions from the walks and the usability studies; photo credit: B-NK GmbH

4.2. Preliminary ethical considerations and selection of participants

Correspondent with the ethical principles of the Scottish Dementia Workshop Group (2014), the project team does not just carry out the research about people with dementia but actually together **with the individuals under study**. Throughout the study, people with dementia get a chance to speak about their situation as they were being questioned and accompanied by members of the research team. People with dementia were hence treated as experts of their own life circumstances and their day-to-day mobility in public spaces on their daily trips. Nevertheless, due to the fact that people with dementia belong to a vulnerable group, ethical considerations are crucial and of fundamental importance when setting up the research process. (Hopf, Christel: 2000; Alzheimer Europe: 2001). It is for this reason that ethical considerations were already made in the preliminary stage of this empirical study and an ethical application was submitted to and approved by the ethical commission of the Austrian Federal State of Carinthia. After the positive notification of the commission in December 2016, the first contact to people with dementia was established with the help of so called gatekeepers. The criteria for inclusion and exclusion in the empirical study simplified the selection of potential interviewees. These criteria were established on basis of the validation concept developed by Naomi Feil (Feil, Naomi; de Klerk-Rubin, Vicki: 2013) in which the four “phases” of dementia are characterised. Participants of the study should belong to the phase I and therefore are likely to show the following behaviour: deficient orientation, forgetfulness, problems with understanding complex tasks, denial of being dement, impatience and reservedness. The mini-mental-state examination (MMSE) was also used for the pre-selection of potential participants. A MMSE-figure of 20 to 26 was considered as optimal for the participation, meaning these people are still able to evaluate and communicate decisions, which is necessary for signing the participation agreement.

This approach helped to include a broad variety of participants. After a detailed information about the project, a declaration of consent was presented to the participants. With their signature, the persons confirmed that they were taking part in the study voluntarily and that they could stop their participation at any stage of the research process. Furthermore, the persons were asked for their permission on the use of photographs and if they agreed to the usage of a recording device. Only after obtaining the interviewees signature and an explanation about the planned activities of the empirical investigations were made in detail could the interviewers use their recording devices.

In most cases, the preparation time used for getting to know each other, during which casual talks about daily activities took place between interviewers and interviewees before the questioning relevant for the study had started, had a positive effect on this study. Based on the gained trust and the validation towards the participants, the persons were able to talk more casually and more open about their experience and their misadventures, told stories about their disorientation and their problems.

Prior to the study, the researchers themselves participated in a validation training with the validation expert Petra Fercher, in order to familiarize themselves with the specifics for taking up contact as well as with the person-centred communication principles for interacting with people with dementia. In this training, the characteristics of people with starting dementia were discussed as well as tips for a respectful and pleasant interaction with the participants were provided. These inputs and knowledge transfer were supported by roleplays together with the expert. To accommodate people with dementia as best as possible, the interviews, the accompanied walks and the usability studies were adapted to their daily routines of the interviewees and the duration of the investigations was individually adjusted to the particular daily conditions of the people with dementia.

5. Preliminary results

5.1. Participants

Overall, 27 people with dementia were involved in the empirical research, among them 15 women and 12 men. Of these, 23 participants took part in the narrative interviews, 15 took part at the usability study and 14 were involved in the accompanied walks. The age of the participants ranged from 48 to 92 years. The living and care situation was divided into persons living in nursing and caring homes, visitors of specific day care centres, and persons living at home with and without external care. It was therefore important to consider that the knowledge of the surrounding areas of the persons in the different living situations was very different. This was especially recognisable in the accompanied walks and had an impact on the choice of destination and the radius of the walk. Overall, the empathic listening and consideration of the needs and emotions of the persons was essential through the whole study in order to avoid any uncomfortable situations or exposing of any participants. This also included the usage of the term “dementia” in a wording adjusted to the participating persons (i.e. forgetfulness). In respective all participants were happy about being seen as experts and to talk about their lives, their routines, and their observations in public spaces.

5.2. Wishes for public spaces

Besides the wish for an individual human guide for their routes, the participants wished for seating possibilities and quiet green places. Seating possibilities within the city were especially a form of relief for elderly people along the way, since they were, in such cases, able to rest occasionally. On the other hand, the absence of seating possibilities leads to the fact that older people cannot interrupt their ways for a short break and this restricts their being on the road dramatically. Seating possibilities were also actively sought in order for the interviewees to be part of public life and to be among people.

A wish that was mentioned very often concerns the quality of staying in open spaces. The persons wished for a quiet space in which there was no car traffic, and in which they could enjoy the green vegetation and rest comfy on a bench.



Fig. 6: Woman lifting her walking frame; photo credit: B-NK GmbH

Another wish of the questioned research participants is concerning the floor coverings. These are an important aspect for the participation of persons who have shortcomings in walking or are dependent on rollators, wheel-chairs or walking sticks. Those persons need plane and seamless floor coverings for a barrier free use of public space. Paved paths are difficult to use for aids with wheels since the wheels strongly vibrate during which it is then necessary to put pressure on the aid to drive calm and peacefully. Furthermore, persons with wheelchairs or rollators are especially sensitive to the cross slopes of sidewalks, because the wheeled aid devices tend to drift strongly in one direction. A feat of strength is already required just to walk or drive with those aids.

The high curb stones of sideways present another barrier for wheelchairs and rollators that also demand an additional effort in strength. It was observed that persons with rollators had to pick up and carry their devices in order to lift them up onto the sidewalks.

5.3. Technical Aids

For orientation, several persons were using maps. Technical devices and applications on mobile phones and tablet-computers were not used at all to plan routes or finding ways being disoriented by people with dementia. The evaluation shows that most people refuse to use technical devices and the possession of mobile phones by seniors is very rare. If the seniors had one, most of the time it was forgotten at home or not taken along on the walks. In daily life, the mobile phone was mainly used for making phone calls.

The reasons for the non-existing or rare use of technical aids are various: fear towards technical devices, lacking information, concerns for wrong handling or additional costs. In addition to that, most of the participants were mainly living in a time in which technical devices did not exist in the way they do today and they were never used for daily work or only in the end of their careers.

6. Outlook

Based on the results of the empirical study, applying a qualitative methodology mix that consisted of narrative interviews, accompanied walks and usability tests, basic experience and knowledge was obtained on the one hand, while on the other hand, concrete action-orientated recommendations are currently in the process of being developed. These recommendations will then be directed at different stakeholder groups:

- Professional town and transport planners as well as decision makers in the field of public transportation, transport infrastructure and planning
- Staff members of public transportation companies, such as coach, tram and underground drivers as well as underground security and supervision personnel.
- Representatives of the research community and developing community in the interface transportation, mobility issues and the Ambient Assisted Living (AAL) sector, who develop technological and/or communication-based products and services in the areas of transport information, telematics etc. targeting people with dementia

In the year 2018, these recommendations will be further developed in a participatory approach with the help of round-tables and stakeholder dialogues and will be published at the end of the research project „Dementia on the move”.

Acknowledgements

The project is financed by the Austrian Federal Ministry of Transport, Innovation and Technology (BMVIT) within the funding programme "Mobilität der Zukunft" ("mobility for tomorrow") and has a duration of 28 months starting in September 2016. The funding programme is managed by the Austrian Research Promotion Agency (FFG) and the project number is 855001.

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