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# Challenges in Transportation System to Support Independent Mobility of People with Dementia

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**Abstract.** The demographic change in view of the aging population leads to people suffering from dementia worldwide. In order to maintain the social participation of this group of persons and thus their mobility for as long as possible, it is important to deal with social aspects of dementia. In this context, the preservation of independent mobility of people with dementia is also important. The purpose of this paper is to present findings of a qualitative study, in which barriers for traffic participation have been identified from the perspectives of experts, caregivers, and patients. In order for dementia patients to have a sense of security and orientation, spaces should be constructed so that certain patterns can be aligned with dementia patient's cognitive capabilities. The paper distinguishes different forms of barriers, such as cognitive (e.g. information overload, spatial-visual impairment, situational complexity), social (e.g. stigmatization, cognitively or emotionally induced conflicts) and physical barriers which are specific for dementia.

## 1. Introduction

Dementia has become an increasing concern for an aging society. According to the World Health Organization [1] 35.56 million people worldwide suffer from a form of dementia; 2.3 million people worldwide have been diagnosed with dementia in 2010. The Austrian dementia report reflects a similar trend, indicating that in 2013 64.307 people suffered from dementia [2]. This trend challenges transportation systems of contemporary societies worldwide when the importance of inclusion is emphasized, which in turn allows for participation in traffic under conditions of disability and illness. A number of studies have addressed the issues of traffic participation of people with dementia. Psychological studies addressed the effects of driving with dementia as well as terminating driving for people with dementia, which can be a burden for families and caregivers. Furthermore, research also emphasizes the dangers of cognitive impairments, such as wandering behaviour.

However, the preservation of independent mobility regarding people with dementia is particularly important from a public health point of view. It is expected that the promotion of (active) mobility would have positive psychological [3] and positive medical effects (e.g. delay the course of the disease [4] [5]). The encouragement of mobility might positively influence the course of the disease and lead to an improvement in the quality of life, questions which are still in need of further exploration [6].



The mobility of dementia patients outside of their homes is often very limited. As a result of spatial disorientation, they have “voluntarily” been led to live an immobile lifestyle. This, however, leads to spatial and as a consequence to social isolation. The neglect of social activities degrades the quality of life of the dementia patient, which in turn has a negative impact on their perception skills, cardiovascular rhythm, brain plasticity and mood. [7]

The Austrian guideline “Better Living with Dementia” [4] and the German S3 guideline “Dementias” [5] recommend regular bodily activities and active intellectual exercises, as well as a social life for dementia to set in later.

A high quality of life - despite chronic disease and impairment - is defined as the "best" state of health that can be achieved, which encompasses all dimensions of physical, mental and social well-being [8] [9]. This is important not only for dementia patients, but also for their family members, friends and caregivers. Moreover, because of subjective perception and evaluations the individual health situation can be very versatile. This fact reflects the great importance of social capital, values and resources, as well as the potential for social participation [10] [9].

The remainder of this paper will present results of the research project “Dementia and Mobility” in which mobility barriers and facilitators for people suffering from early and medium stages of dementia and their caregivers have been identified.

## 2. Methodical Approach

A qualitative research design based on case studies was used to investigate the mobility behavior of people with dementia. Guided interviews with affected persons (N=10), caregivers and experts have been combined in order to understand the relationship between individual change (due to illness) and the situations of traffic participation. Interviews were often conducted together with relatives or caregivers which is also the situation in which affected people participate in road traffic. Moreover, experts and caregivers were interviewed to understand the problems of people suffering from dementia from different, but interrelated perspectives. Qualitative research design is especially useful to understand how people experience situations in everyday-life, how they develop coping strategies and also how agency is gained (or lost) under the conditions of dyadic units (patient-caregiver-dyad).

Experts were interviewed (1) about how dementia impinges on participating in social life and which care models and approaches are used by professionals in the field, (2) about mobility, changes of mobility patterns and mobility barriers, (3) about possible solutions for maintaining active mobility and to reduce mobility barriers, (4) finally, they were asked to assess specific barriers as well as existing tools and measures.

Caregivers (relatives) were asked to describe the problems and changes concerning mobility and adaption to traffic situation along the course of illness development. They were asked to talk about their experiences of travelling together and to articulate their needs and possible solutions to meet them. Like the experts, they were also asked to assess specific barriers and existing tools and measures.

Affected persons were interviewed (1) about their experiences with traffic participation alone and/or together with a caregiver and (2) about elements of and typical situations on the street (walking on narrow sidewalks, opportunities to sit down, snow and ice, availability of escalators, entries to busses and trams, traffic lights, the quality of the sidewalks, other road users, traffic signs and means of orientation, handrails along stairs) and barriers with which they are confronted.

Recommendations for ensuring an ethically correct approach for studying people affected by dementia can be given: It is important to always speak out clear instructions (simple, short sentences), keep calm and try to empathize with the patient, avoid taking corrective actions, avoid overstimulation during interview situations or on-trip investigations, give orientation, repeat and summarize information, verbalize emotions, recall memories from the past and being familiar with one's biography in advance of the investigation.

Caregivers and relatives indirectly influence mobility behavior of dementia patients. For instance, caregivers and relatives tend to control the general activities, social participation and the self-esteem of people with dementia, which tends to influence their psychological constitution. Relatives, private

caregivers, professional caregivers and experts were also interviewed in order to gain a broad overview of different mobility issues related to dementia patients.

### **3. Characteristics of people with dementia participating in traffic**

To a large extent, research on issues of transportation of dementia patients focuses on motorized transport, in which traffic safety in terms of danger of harming others and oneself is the key problem. However, in order to maintain the autonomous mobility of dementia patients for as long as possible, transport modes with lower thresholds of participation like walking or using public transportation become more important. In our sample, 3 persons were still able to travel alone and use walking and, to a much lesser degree, public transportation as the preferred transportation mode. In the other cases a relative or professional caregiver accompanied the person on their trips. One case used a bicycle (together with a caregiver) and switched to public transportation when cycling was no longer possible. From a short to a medium-term perspective, the supply of such means of transport will be limited to that of public transport and walking. Although, in the long term the development of autonomous vehicles could represent a great opportunity for the mobility options of dementia patients, as well as some other groups of people whose mobility is restricted.

For active and safe participation in traffic, depending on the means of transport used and the frequented public space, various physical cognitive abilities (for example concentration, decision-making and orientation) are required. The extent of limitation or rather the loss of these abilities can have many causes. It can also occur in a wide variety of groups of persons, including healthy people. However, from past experiences, it can be concluded that there could be more or less frequent impairments of one or more abilities, such as those mentioned above, in dementia patients. These impairments can also be described in terms of the inability to carry-out roles and to fulfill role-expectations. Roles are schemes of interaction which are institutionalized to different types of settings like social statuses, occupational positions or every-day life situations. Obstacles and barriers always occur whenever the required abilities to take a role in a traffic situation are no longer present. The reason why there is no requirement for a person involved in traffic to handle situations is that the conditions to master these situations were taken for granted and have not yet become a relevant theme of reflection. Concededly, first of all the knowledge about limitations or the loss of skills in different groups of people, and second of all the knowledge of the postulated requirements for situational management can either help to reduce the problems and barriers of this group of persons or compensate strategies.

### **4. Mobility types and degrees in the context of dementia**

Depending on the mobility behaviour, persons (groups) can be assigned different “mobility types.” Cerwenka et al. [11] differentiate two categories according to the individual decision of means of transport:

- Choice Drivers / Riders
- Captive Drivers / Riders

Choice Drivers may – provided that the access, the possibility or the qualification for usage is given, such as private car availability or a valid ticket for public transportation – use all available means of transport. Choice Drivers are, therefore, not limited to the use of individual means of transportation. Captive Drivers, on the other hand, are bound to the use of certain means of transport and cannot freely choose them due to, for example, external constraints or subjective reasons [11].

As the sociological concept of illness denotes loss of capacity to carry out role expectations, course of illness is very often characterized by the transformation of choice riders/drivers into captive drivers. This process is partly induced by dementia-specific processes of degeneration and partly by inscriptive processes in which other actors (caregivers, professionals) regard persons suffering from dementia unable to correctly carry out role expectations.

## 5. Dementia specific barriers

A mobility barrier is a physical, psychological or social barrier that prevents a person from participating in public or individual road transport. From the actor's point of view, a mobility barrier means that persons believe, according to their assessment and definition of the situation, that they cannot fully satisfy their (legitimate) mobility needs with the means at their disposal and under the given infrastructural and social conditions.

Dementia-specific barriers have a dynamic component, depending on the progress of illness. Various models have been developed which distinguish between different phases. Each phase is characterized by the loss of specific cognitive and/or manual abilities which are articulated with the ability of taking various kinds of situational roles. The barriers which we describe in this paper are related to earlier stages of dementia.

**Table 1.** Stage Names and Skill Levels.

Stage	Stage Name	Skill Level
1	Normal Aging	No difficulties, either subjectively or objectively.
2	Possible Mild Cognitive Impairment	Complains of forgetting location of objects. Subjective word finding difficulties.
3	Mild Cognitive Impairment	Decreased job function evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4	Mild Dementia	Decreased ability to perform complex tasks (e.g. planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.
5	Moderate Dementia	Requires assistance in choosing proper clothing to wear for day, season, and occasion.
6a	Moderately Severe Dementia	Difficulty putting clothing on properly without assistance.
6b		Unable to bathe properly (e.g. difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks.
6c		Inability to handle mechanics of toileting (e.g. forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.
6d		Urinary incontinence, occasional or more frequent over the past weeks.
6e		Fecal Incontinence, occasional or more frequently over the past weeks.
7a		Severe Dementia
7b		Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over).
7c		Ambulatory ability lost (cannot walk without personal assistance).
7d		Ability to sit up without assistance lost (e.g. the individual will fall over if there are no lateral rests on the chair).
7e		Loss of the ability to smile.
7f		Can no longer hold up head

A very useful process model which combines functional, cognitive, emotional, neurologic, neuropathologic, and biomolecular dimensions of AD is Reisberg's concept of retrogenesis [12]. Retrogenesis is defined as the process by which degenerative mechanisms reverse the order of acquisition in normal development. For the purposes of this paper, Reisberg's [13] Global Deterioration Scale (GDS) which describes seven clinically distinguishable global stages from normality to severe dementia of the Alzheimer (AD) type and which Reisberg further operationalized in the functional assessment

staging (FAST), is the most appropriate scale as it is closely related to role expectations in every-day life, including abilities needed for traffic participation.

For the purposes of traffic participation, however, the clinical items must be reframed and adapted to traffic situations. Arguably autonomous traffic participation is theoretically possible up to GDS stage four “in which deficits are readily manifest in a detailed clinical interview and in which individuals generally have a deficit in the management of instrumental activities of daily life” [14], and it ends with stage five “in which individuals can no longer survive if left on their own” (ibid.).

Especially in the early stages of dementia, affected persons have by and large the same problems concerning traffic participation as healthy persons of higher age. They also experience similar barriers. All of our interview partners describe an overall attitude of cautiousness, characterized by passivity and tendencies to withdraw from conflict. When asked: “What would you do at a narrow sidewalk when someone approaches you”, the answer usually was: “I step down and wait.”

With reference to traffic situations and situational roles we can distinguish three aspects: (1) the emotional aspect which is mainly about feelings of shame, stigmatization and uncertainty, (2) the behavioral aspect (inappropriate behaviour, reaction or interaction) and (3) the orientation aspect (finding one’s way, locating oneself in space and time).

### 5.1. *The emotional aspect*

*5.1.1. Stigmatizing oneself and others.* Shame and stigmatization (feeling of being deviant) rise in early stages of dementia and are one important reason why people shy away from participating in public life even though they still have the necessary competences. Stigma, therefore is closely related with lack of reciprocity as a way in which people with dementia are perceived within society [15]. The stigmatization can affect both dementia patients themselves (e.g. social malpractice, discrimination) as well as others (e.g. through lack of inhibition: there might be no threshold towards other transport users).

An important event which may have some stigmatizing effect is the loss of the driving licence or of access to one’s car. Experts and relatives unanimously found that at a certain stage of illness development, driving is a severe danger for the driver and for other road users. Very often they see a “white lie” as the best way to deal with the situation and find some excuse why the car cannot be used any more (e.g. it is damaged and must be repaired). Although this kind of deception has ethical implications, relatives feel that their decision is justified with reference to other goods and persons have to be protected, including the sick person.

Interestingly, this process can also be interpreted as an important step of forming a dyadic relationship in which the caregivers must take over responsibilities for the sick person. Decision making and action more and more become an issue of division of labour, based on a kind of “distributed cognition” [16].

One of our interview partners lost his driving license just some weeks before the date of the interview and we had the opportunity study the reaction formation to this event. He described the situation of psychological testing and that he failed to fulfil certain requirements regarding reaction and concentration. He also understood that some decisions concerning his driving abilities have been made, although in his account they haven’t been communicated openly and directly (“But, I must say, I recognized, that he [the psychologist], jotted down some notes: insufficient.” When the interviewer asked how he is without having a driving license, he responded: “I must adapt to the situation [...] You have to. There is no other way.” Trying to adapt to circumstances which must be taken as given, is, as we have seen, the typical attitude of participation in road traffic under the condition of high age, but it is also a constructive strategy to deal with feelings of frustration of anger which might be associated with such a loss. It is important, however, to offer some alternative which compensates the loss: “Well, I just walk, I walk every day one hour in the morning and half an hour in the afternoon.”

In this case, the stigmatizing event (I am unable to drive a car) is transformed into a condition of life to which new ways of adaption have to be developed. The consequence is not withdrawal, but a creative change of mobility patterns.

*5.1.2. Isolation through negative experiences.* Problems in action planning can have a serious adverse effect on the everyday life of dementia patients. The focus here is on understanding when to take which action (e.g. getting up, going to the door and getting off at a stop). If a person is missing this ability, it can lead to a great deal of uncertainty and thus he or she will become increasingly isolated. This problem can affect not only all means of transport, but it can also lead to the gradual avoidance of pathways. Moreover, the dementia patient might withdraw from his or hers once accustomed environment all together.

In one case in which a caregiver together with his wife used public transportation, some situations were described which induced stress because a bus was not well prepared to give enough time for entering or leaving. Other passengers did not realize that the couple needed more time and became angry and also the bus-driver got nervous in order to keep to the time schedule. While the situation is well defined for parents with small children in baby carriages or for persons using wheelchairs, this is not the case for persons suffering from dementia. Such examples show that malign social situations [17] are still the norm and there is still much need to transforming them into benign situations.

## *5.2. The behavioural aspect*

*5.2.1. Being oblivious about (informal) behavioural rules.* Dementia patients may forget about formal and informal behavioural patterns in the streets (e.g. “getting off or on” or “walking on the left or right side” on escalators, etc.). This can be perceived as disturbing or problematic. Reasons for non-adherence to such rules can be, for example, selective attention, problems in visual and spatial perception, or difficulties in consciously recognizing their own and other’s needs.

Depending the consequences of these lapses in terms of reactions of other road users, they can be interpreted in more benign or more malign ways by the affected persons [17]. An episode in which one interview partner in her role as a cyclist ignored a traffic control by the police nicely illustrates this issue. Confronted with the unexpected behaviour of the cyclist, the caregiver could explain the situation to the policemen who reacted politely and did not intervene immediately.

*5.2.2. Inappropriate reactions to incidents (e.g. when a traffic light turns to red or during a malfunction).* The impairment to make decisions with speed or the ability to anticipate and assess the development of situations can lead to inappropriate reactions to events. For example, dementia patients may be surprised when a traffic light turns to red and as a consequence they might not know how to react anymore. For other road users, this behaviour (e.g. sudden stops or backing up) can be unexpected and thus problematic.

*5.2.3. The purchase of a ticket or the procedure of purchasing a ticket may be forgotten.* As a result of difficulties in concentration, selective attention or problems with regard to the arrangement of chronologically successive sequences (perception of cause-effect contexts), dementia patients could forget the procedure of the ticket procurement or partial aspects thereof. Complications such as these solely occur in public transport. In light of this, it is essential how the dementia patient responds or reacts during for instance if a ticket control takes place. Seeing that dementia patients can often hide their illness, it is nearly impossible for outsiders – without such experience – to know whether or not they have encountered a person with dementia.

The abilities necessary to carry out these actions described as behavioural aspect get lost in rather early stages in the course of illness. The problem is that plans of action are complex schematizations of typical lines of conduct. The elements of the schematized behavioural chain are implicit and often carried out automatically. Sometimes the whole scheme is damaged if just one schematized motion gets lost. One caregiver made the experience that an ability which gets lost can be relearned if the specific element in a whole scheme of action that has been forgotten is identified. Abilities which are completely and irreversibly lost, must be compensated by caregivers. In other words, retrogenesis has to be

complemented by a new form of forward-oriented development in which a caregiver takes over the functions lost by the sick person. Together they become a new system of action which is more of the distributed cognition kind than a social system in which interaction between two persons is based on complementary roles. One interview partner (caregiver) described this process nicely as Janus-faced action in which the healthy part of the system is aware of the present and the future, while the sick part withdraws more and more into his or her own past. We might understand this Janus-faced system as a new and emerging form of personhood.

### 5.3. *The orientation aspect*

*5.3.1. Navigational problems (in known or unknown surrounding).* Dementia patients may have navigational problems not only in unknown (mostly related to stage 3), but also in known areas (stage 4). It may be that they no longer know where they want to go, how they reach a certain destination, or how they get home from their current location. This may be due to deficiencies in the concentration, orientation, or abstraction ability required for reading maps and symbols. Such problems may occur both on foot or in private transport (either motorized or non-motorized).

In our sample, one of the three persons who were still autonomously mobile was able to keep his orientation. He was able to choose between various routes which he knew very well. All of these routes, however, did not interfere much with road traffic. Another person used a path from the place she lived to the flat of an old friend which she knew for decades. In the third case, the person knew about orientation problems, but they were not ascribed to dementia-induced disorientation, but to a weak spatial orientation in general. This person was well aware that she should not leave the beaten tracks from which she can always return home. For all other ways she asks for company by relatives or caregivers.

Orientation by using technical means (e.g. smart phones) was no option for them as they were not familiar with the technology and its practical use. In one case, the interview partner didn't feel any necessity, in the second case the person felt overcharged by using smart phone technology or similar tools. The third case could even be described as a biography of avoiding technological change. She retired at the time when computers pervaded offices and workplaces and managed to avoid using computer technology during the last year of her occupational career. Her biography can be read as a paradigmatic case of an "avoidance biography" and this attitude can also be found in the ways she refuses technology today. It is quite probable that this type of technology avoidance biography is a widespread phenomenon among elderly women and men who retired in the early 1980s and the beginning of the 1990s.

*5.3.2. Orientation problems in a crowd, in high passenger or road traffic.* Quite often in our interviews, we learned that dementia patients feel strained and unable to cope with complex situations. Large crowds of people, for example, cause problems for dementia patients in regard to their concentration, their visual and spatial perception, their orientation, their ability to make decisions and the conscious recognition of their own and foreign needs. This fact is, to some extent, caused by the situationally induced stress.

*5.3.3. Time-related misjudgement (e.g. waiting time, business hours).* Selective attention (as a particular aspect of concentration) and problems with the estimation of the duration of time can lead to the fact that dementia patients misjudge waiting periods. Problems, such as these, mainly occur either on foot or in public transport. On the one hand, due to the lack of time reference, affected persons may leave the public transport stop immediately after their arrival. On the other hand, the temporal disorientation can lead to the fact that dementia patients visit the correct stop, but at the wrong time (for example at 3 o'clock in the morning).

## 6. Suggestions and conclusions

Dementia includes a broad variety of symptoms, which are mostly met through subjective perception. Studies must take into account the severity but also the individual form of these symptoms and adapt accordingly. A further element to be considered is co-morbidity: people who suffer from dementia are often not only afflicted by this disease alone, but are also affected by other age-related and/or mental impairments (e.g. depression as a consequence of dementia). Some patients must be excluded from the study due to more severe symptoms which did not allow for traffic participation any more. In these cases, it would be advisable to talk to relatives and caregivers about mobility barriers and the consequential problems before and after these trips.

In our case studies we could clearly identify the shift from choice to captive traffic participation in the course of the process of retrogenesis. On the one hand, abilities got lost, on the other hand, technical assistance which aligns with the biographical experience of the persons exist. One important and a little bit frustrating finding of the DeMo project seems to be that improving traffic participation by technological assistance is nearly impossible.

Two other aspects, however, are much more important: the design of dementia-friendly traffic situations in terms of giving these road users more space and time when they travel together with their caregivers. Persons with dementia, however, can participate in road traffic when they become caregiver-patient-dyads, a little social system which one of our interview partners (caregivers) described as Janus-faced action in which the healthy part of the system is aware of the present and the future, while the sick path withdraws more and more into his or her own past. These dyads also experience specific traffic barriers as the spaces and rhythms of modern traffic often are not apt to their needs. According to the theory of retrogenesis, persons with dementia need simplified environments of a similar kind than small children in which orientation and navigation is possible under the condition that complex plans of action cannot be conceived and carried in the same way, healthy adults can. These simplified environments have a physical (infrastructural), but also a social component; they are a kind of “*kosmion*” constituted by the dyadic relationship between the caregiver and the person living with dementia. The challenge is, how these environments can be built into the traffic system without disturbing its function for other participants

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