

Overlooked Transport Participants – Mentally Impaired but Still Mobile

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Abstract. Providing an inclusive transport system is a global ambition. Whereas, mobility needs and mobility barriers of people suffering from a physical impairment have already been observed frequently, people suffering from mental impairments (due to e.g. anxiety disorders, obsessive-compulsive disorders, dementia or other degenerative diseases) are often overlooked. Numerous studies already suggest that the number of people with mental impairment will significantly increase due to the demographic change and is also shown by the prevalence of mental diseases. Whereby, not even the data collected do necessarily give the full picture of the actual situation. Thus, the importance of mobility needs and mobility problems of people with mental impairments will gain dramatically. Participating in the transport system is a basic need that furthermore requires the ability of adopting different roles (e.g. driver, pedestrian). Due to explanatory studies of the authors, it could be shown what kind of problems people with mental impairment are faced with while participating in the transport system or interacting in public space. Thus, these studies represent the first step that is needed to consider the specific needs of people with mental impairments in future planning. The identified problems of people who are suffering from mental impairment are various. Thereby it can be distinguished between problems triggered by structural (e.g. absence of emergency buttons, spacious stations), organisational (e.g. absence of security stuff, lacking information according time table of transit) or social conditions (e.g. crowded places or vehicles, stigmatisation). This paper presents an overall view of specific requirements of people with mental impairment and suggests possible solutions for planning and designing an inclusive transport system.

1. Introduction

The aim of providing an overall inclusive transport system is stated in mobility-related action plans all around the world, including Austria. However, politics and planners in Austria hardly address people suffering from mental impairments (e.g. anxiety disorder, dementia) and therefore are not aware of certain needs regarding their mobility behaviour. Until now, these groups were overlooked in both transport-related research as well as planning activities. By conducting two exploratory studies (“PHOBILITY” and “DeMo”) and applying various methodologies for generating mobility-related



data, it is possible to study and rather understand the behaviour of people suffering from different mental impairments (anxiety disorders, obsessive-compulsive disorders, dementia or other degenerative diseases) and its effects on the usage of the transport system.

Several sources show estimations about the number of people with mental impairments which is supposed to significantly increase due to demographic change and other socio-economic developments. The amount of days of sickness leave at the workplace due to mental impairments has doubled from 2000 to 2013 [1].

The prevalence of people suffering from anxiety disorder was estimated to be 267 Mio in 2015 worldwide, whereas this number already increased by 14.9% from 2005 till 2015 [2].

Due to demographic change a growing prevalence of mental illnesses is predicted, especially considering dementia. E.g. it is expected that the prevalence of dementia will increase by 8-10% from 2015 until 2035 in European countries such as Italy, Germany, Spain, Finland, Portugal and Austria [3]. According to the Austrian report on dementia, 64.307 people were suffering of dementia in Austria in 2013 [4]. Other projections for the number of people being affected by dementia estimate a number of 174.600 people for 2030 [5]. Nevertheless, it is assumed that the actual number of people suffering from anxiety disorders and/or dementia is (much) higher.

By having those impressions, it seems to be evident to include the group of people suffering from mental impairments within transport- and spatial-planning-related research objectives and approaches as well as on-field measurements; especially in order to meet the challenge of providing an overall inclusive transport system.

2. Theoretical background and methodical approach

2.1. Theoretical background

Behavioural research in transport-related topics is based on quantitative indicators that describe and explain the mobility behaviour of people, e.g. distance travelled, travel time, trips per day or qualitative information such as travel motives and individual preferences. Of course, data has to be representative according to the different types of people (gender, lifestyles, roles, impairments etc.) of transport users. In general, data is used for forecasts and the allocation of various resources (e.g. financial, personnel, spatial, infrastructural) for designing and operating a transport system. In addition to that, a continuous analysis of the provided supply (e.g. means and modes of transport, other infrastructure, and information) enables the determination whether an equal access for different groups of people (social roles, lifestyles, impairments) is provided. Unless equal access to the transport system is provided, additional infrastructural, organisational, informative and design-related measures (e.g. new implementations, rearrangements) have to be reviewed and implemented. Along with that, various mobility barriers that complicate the participation in transport for certain people can be identified by matching concrete mobility needs with the provided supply. Mobility barriers can either be caused by infrastructural or organisational elements, but also by social conditions (e.g. masses of people in restricted spaces, lack of understanding) or certain symptoms of disease that are enhanced by the participation in transport. Until now, people suffering from mental impairments are overlooked and therefore hardly addressed in the designing and development process of transport systems. Furthermore, equal access and the possibility of being mobile (in any case) contributes to life quality and well-being within a society. E.g. in case of dementia patients, it was found that social activities are highly affected by spatial disorientation which crucially restricts mobility as well as social activities and therefore worsen the course of the dementia disease [6]. Same hypotheses are assumed for people suffering from (various types of) anxiety disorders.

In order to properly address mobility needs of people suffering from mental impairments (1) characteristics of the behaviour and (2) certain mobility barriers have to be identified and qualitatively described in order to achieve measures with a high accuracy and effectiveness. For associating mobility barriers with certain mental impairments, the concept of either describing a transport participant as captive or as choice rider can be used.

Captive riders are dependent to one single mode of transport, e.g. cycling, whereas choice riders are free to choose between ranges of modes of transport [7]. Being captive towards one single mode of transport is not necessarily caused by impairment but can also be due to a very limited supply of modes of transport in an area and/or within a certain time window. This distinction is relevant for determining whether a mental impairment or simply the provided supply is the reason for the usage of certain means/modes of transport. Furthermore, it is interesting to investigate the change of being either a choice or captive rider during the course of disease. E.g. it can be estimated whether affected people got stuck to certain modes of transport. Furthermore, it is assumed that the proportion of captive riders rises depending on the severity of disease, e.g. in general or at times.

Prior aim of this scientific discussion is to probe an approach for including people with mental impairments in transport-related research. The chosen approach was proven by applying it within an exploration study covering people with phobia, anxiety disorders, and obsessive-compulsive disorders and will also be discussed for its applicability of people suffering from dementia. The used methodologies were selected together with health experts and relatives of certain mentally impaired people. It can be guaranteed that ethical principles and data protection principles are entirely fulfilled throughout the studies. The participation in exploration studies always happens on a voluntary basis.

2.2. Methodical approach

For covering the relevant information of the characteristics of mobility behaviour and mobility barriers, different methods were selected for being applied. Of course, the methods that might be appropriate for the target group (people with mental impairments) were intensively discussed together with health experts. Eventually, face-to-face in-depth interviews, ‘walk-alongs’ and GPS-location-based survey technologies were used to collect qualitative and (a small amount of) quantitative information on the mobility behaviour of people suffering from mental impairments. An objective was also to differentiate between the mobility behaviour before, during and after the disease. In addition to that, mobility barriers as well as (personal) strategies for compensating certain barriers were determined. The following scheme (see figure 1) can be applied (1) in order to describe the characteristics of the mobility behaviour of people suffering from mental impairments and (2) for showing in which stage to identify mobility barriers, avoidance behaviour and coping strategies.

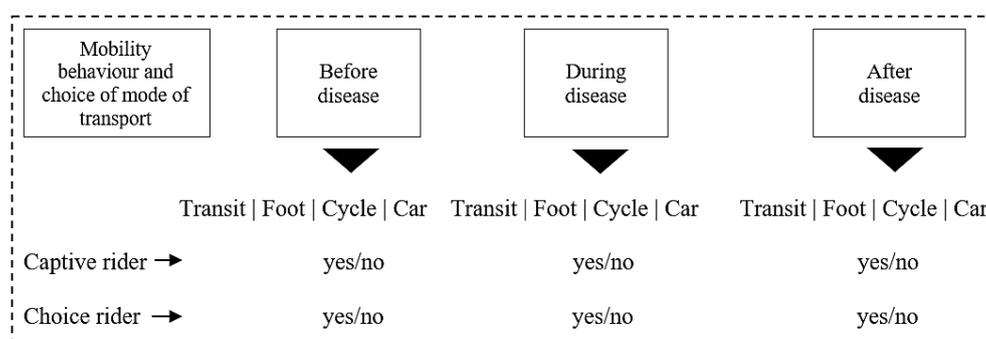


Figure 1: Exemplary characterisation of mobility behaviour

By conducting in-depth interviews, it is not just possible collecting information of the actual behaviour but also learning about the course of disease and dates when the mobility behaviour changed. It is possible to also question whether the changes are due to personal developments such as relocations, changes of employment or due to the disease. For verifying certain information on a random basis, study participants are asked to track their trips and on-trip mobility barriers via a GPS-tool. By doing so, valuable information can be collected. Often, exactly these valuable data cannot or is not remembered by study participants after a trip or journey is completed. Another method for experiencing the on-trip difficulties for people suffering from mental impairments are 'walk alongs', which can be assigned to mobile methods [8]. By choosing that method it is possible to generate ethnologic-sociological as well as mobility-related data. From a researchers' experience, this methodological approach provides an added-value which cannot be covered by conventional transport-related survey methods. By performing this personal and joint trip(-chain) and having conversations throughout the travel period, a basis of trust can be build and a higher amount of relevant information can be gathered.

3. Results and discussion

The study addresses transport providers, healthcare and researchers from various disciplines as well as transport users. Insights of the mobility behaviour and occurring mobility barriers of people suffering from mental impairments are given. Furthermore, different methodological approaches for investigating these high sensitive groups are discussed.

3.1. Characteristics of the mobility behaviour of people with mental impairments

The mobility behaviour of people suffering from mental impairments is characterized by (1) preventive and (2) steady decision making (either by the people themselves or by their caregivers) with regard to minimize or even avoid infrastructural, organisational or social implied barriers. This means effort in planning as well as doing a trip or journey is much higher compared to non-mentally-impaired people. However, even within this group of people, routines (in daily mobility) simplify mobility patterns and therefore trips or journeys do not differ, but rather are repeated on a regular basis (e.g. daily, weekly). It cannot be determined whether certain modes of transport are preferred or avoided by people suffering from mental impairments such as anxiety disorders. The decision for a preferred mode of transport is very individual and dependent on the particular situation. Although this might not differ from other transport participants, another and even more interesting finding is that there is a significant change of behaviour due to the occurrence of disease. As the course of disease changes, also the preferences for modes of transport change. People who were used to drive their car before the outbreak of their mental impairment might not be able to do so during a peak of disease or vice versa, caused e.g. by the fact that they are not able to properly assess a situation as harmless or less irritating.

It was found that people who are affected by anxiety disorders, obsessive-compulsive disorders or phobias either suffer from the loss of the ability to recognize a situation/or a minor irritation as harmless or aren't able to reclaim space in public areas [9]. Minor irritations could be for example other people (unintentionally) looking at them or certain furniture in vehicles (e.g. metal, padding). The problem of reclaiming space especially occurs within transit infrastructure or vehicles during rush hours or immense traffic loads (also meaning vehicles on a street).

Due to the fact that participating in transport is stated as very stressful, nerve-racking and (sometimes) hardly possible, people with (certain) mental impairments often require the help of other people such as relatives, friends or professional care givers, whereby the changes of behaviour due to disease multiply (e.g. mode choice, number of trips per day also change for the responsible caregivers). People get rides by their spouses or children, or are accompanied by them during certain journeys, especially those that are not familiar. Special reaction and further help is required in terms of short-term

appointments or detours (e.g. detour of a bus due to an unforeseen disruption). Reactions might vary from trip cancellations to a change of travel time or raise the amount of required resources (e.g. monetary, in case a cab is required or humanly, in case company is necessary).

Caused by a non-representative amount of quantitative data (just few study participants were willing to collect their on-trip data via technologies), no significant statements about the trips per day, travel time or distance travelled can be made at this time.

3.2. Mobility barriers and coping strategies of people with mental impairments

On a first stage, mobility barriers can be divided into two main groups. (1) A barrier can exist before leaving a place respective starting a journey. Therefore, it can be assumed that this barrier is already known and people strictly avoid being mobile/participate in transport caused by certain barriers or problematic situations. (2) However, barriers may also occur during a journey/trip and (a) either are known and can be handled (by accepting detours) or (b) suddenly occur during a journey/trip and result in an inability to act or can be handled by retrieving internalized strategies of action (see figure 2). Hereby, preventive and steady decision-making-processes while being mobile can be embedded within the personal development of people suffering from mental impairments. As long as coping strategies (e.g. for self-distraction from problematic situations) are available and internalised, affected people do not perceive potential mobility barriers at all or at least not as severe.

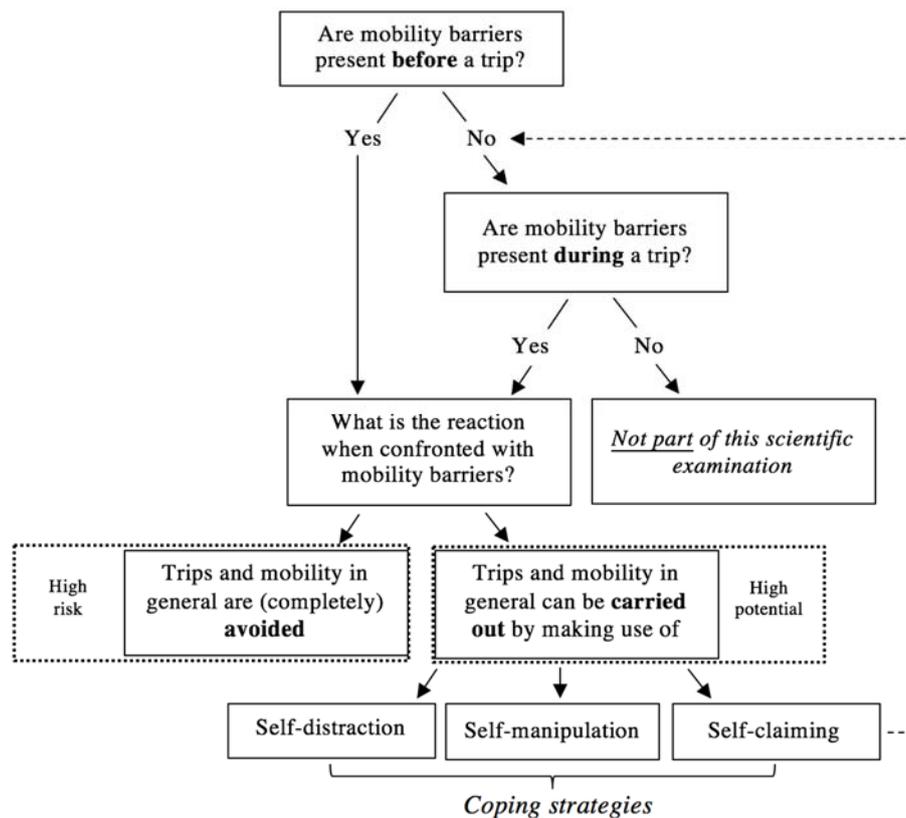


Figure 2: Identification chart for mobility barriers of people suffering from mental impairments

From the perspective of the public body (responsible for satisfying mobility needs within a society) it should not be acceptable that some people are not able to make trips and participate in social activities (which are strongly linked with being mobile). However, this is exactly what many people who are

suffering from mental impairments are confronted with. This group is marked with “high risk” in figure 2. People that struggle with such behavioural limitations and have not yet developed certain strategies for compensating it, might not be mobile at all. This, furthermore, might worsen the course of disease. In order to enable the participation in essential activities (e.g. social interactions, working, leisure, health care), the public body as well as spatial and transport planners are required to take action.

On the contrary, people who are aware and in use of coping strategies (see figure 2) are of high potential for making a transport system inclusive again.

Results from an exploratory study on which this paper is based on show that for many people of the investigated target group, transit is not always accessible or useable as it is not possible to leave public vehicles at all (required) times [9]. Further, tight and dark corridors or places, which make spatial orientation more difficult and the lack of a possibility to escape (e.g. in transit stations) can keep people with anxiety disorders, obsessive-compulsive disorders or phobias from using certain modes of transport or paths or areas of the (public) transport infrastructure [9].

However, the big advantage of people being aware of their struggles and (potential) barriers and are also able to overcome (potential or given) threads, make use of coping strategies for being mobile. Such coping strategies (as shown in figure 2) can be self-distracting, self-manipulating or self-claiming. Self-distracting means for example listening to music, reading the newspaper or wondering in one’s own mind. Self-manipulating and self-claiming refers to actions such as giving oneself (fictive) rewards for managing certain trips or journeys or re-claiming trips/space by identifying acceptable trip-chains or modes of transport for satisfying certain mobility needs.

3.3. Applicability of the approach for another type of mental impairment: dementia

Studying the mobility behaviour and mobility barriers of people suffering from mental impairments is hardly comparable to similar study designs covering other types of transport participants. Talking about sensitive information regarding the course of a disease (including triggers, symptoms, risks and doubts) can be challenging and (even more) threatening for the study participants. By applying the methodological mix (in-depth interviews, ‘walk alongs’, GPS-location-based technologies) for the group of people affected by phobia, anxiety disorder and compulsive-disruptive disorder, first impressions on how to associate mental impairment with mobility behaviour could be gained. Since the methodological approach was partly proven as suitable, it is also applied for people suffering from dementia in a modified version within an ongoing study.

Dementia patients differ from the people suffering from phobia, anxiety disorder and compulsive-disruptive disorder inasmuch as it is already evident, that the symptoms strongly vary from the degree of severity of the disease, wherefore the study design has to be adapted significantly. People suffering from dementia are not only affected by this mental impairment but in most cases, also by age-related or other mental (e.g. depression as a consequence of dementia) impairments. Also, some people who are affected by dementia, for example those that are affected by a high degree of severity of disease are excluded from the study design due to lack of sense addressing these people with adequate solutions. People who are affected by a lower degree of severity struggle with forgetfulness and spatial as well as timely sense of orientation [4], which means that interviews about their past trips and description of their chosen modes of transport, travel time or distance travelled might not be appropriate. Furthermore, people who suffer from dementia tend to deny personal deficits [4]. Therefore, they might not be willing to talk about mobility barriers or problematic pre- or on-trip situations. In this case, relatives and caregivers seem to be a more appropriate contact person.

After having conducted first expert interviews, recommendations for ensuring an ethical 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.

4. Suggestions and possible solutions for an overall inclusive transport system

It is suggested to start with the enhancement of mobility choices for people suffering from mental impairments by focusing on the de-stigmatisation as well as setting activities on awareness raising of the situation, especially in transport-related fields. By conducting studies with a significantly higher number of participants, quantitative data can be collected and representative statements can be made. For now, qualitative exploratory studies provide the backbone for transport-research-related study designs and identified needs for action and further research. A higher amount of data can furthermore be applied for transport modelling as well as simulation. Suppliers, operators and planners would get a broader view of the problem and may address measures more efficiently. However, the development and implementation of isolated solutions or recommendations have to be avoided.

More research activities on group-specific tools or strategies that serve self-distraction, self-calming and self-manipulation or communication- and information-needs are recommended. Strategies might be realized in form of technological or conventional non-technological tools as well as communication and information measurements. Furthermore, simple and guided ways throughout the transport system as well as trained staff (e.g. of transit operators) or easily detectable exit areas would simplify the participation in transport for people with mental impairments. However, it is important to not intensify stigmatisation of affected people by providing exclusively spaces such as separated train sections or areas within a transport system. It is highly recommended to always develop solutions and concrete measures in accordance with the health sector in order to maintain health promoting activities and actions. Overall, awareness has to be established especially in order to eliminate stigmatisation. This would comply with the needs of people with mental impairments and their trust in their own ability as well as trust in the provided system. Moreover, it would also comply with the claim of providing customer service on an appropriate level.

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References

- [1] Statistik Austria, „Definition of city regions 2011 – Assignment of Municipalities.“ („Stadtregionen Abgrenzung 2011 - Zuordnung der Gemeinden“), 2013.
- [2] T. Vos et al., “Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015,” *Lancet* 2016, 388, p. 1545-602, 2016.
- [3] OECD/EU, “Health at a Glance: Europe 2016 – State of Health in the EU Cycle,” OECD Publishing, Paris, 2016. <http://dx.doi.org/10.1787/9789264265592-en>
- [4] S. Höfler et al., “Austrian Dementia Report 2014,” (“Österreichischer Demenzbericht 2014“) Federal Ministry of Health, Vienna, 2015.
- [5] J. Wancata et al., „Updated forecasts on people suffering from dementia in Europe“ („Aktualisierte Prognosen Demenzerkrankter in Europa“), *unpublished*, Vienna, 2011. In: Höfler et al. „Austrian Dementia Report 2014,“ („Österreichischer Demenzbericht 2014“) Federal Ministry of Health, Vienna, 2015.
- [6] S. Teipel et al., “Information and communication technology solutions for outdoor navigation in dementia,” *Alzheimer's & Dementia* 12, p. 695-707, 2016.
- [7] P. Cerwenka, G. Hauger, B. Hörl, and M. Klamer, „Handbook for Transportation System

- Planning,“ (“Handbuch der Verkehrssystemplanung“) Österreichischer Kunst- und Kulturverlag, Vienna, 2007.
- [8] N.J. Ross, E. Renold, S. Holland and A. Hillman, “Moving stories: using mobile methods to explore the everyday lives of young people in public care,” *Qualitative Research Vol 9*, p. 605–623, 2009.
- [9] G. Hauger (Ed.), “PHOBILITY-Handbook, Transport participation of people suffering from mental disorders, especially phobia, anxiety disorder and obsessive-compulsive disorder,” (PHOBILITY-Handbuch, Verkehrsteilnahme von Menschen mit psychischen Erkrankungen – insbesondere Phobien, Angst- und Zwangsstörungen“) *IVS-Schriften*, No 39, Vienna, 2016.