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DOCTORAL DISSERTATION

Explaining activity-related travel behaviour in persons with disabilities by means of health condition and contextual factors

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An Neven

Promoter: Prof. Dr Geert Wets
Co-promoters: Prof. Dr Peter Feys
Prof. Dr Davy Janssens

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Members of the jury

Prof. dr. Jean-Michel Rigo, Hasselt University, chair

Prof. dr. Geert Wets, Hasselt University, promoter

Prof. dr. Peter Feys, Hasselt University, co-promoter

Prof. dr. Davy Janssens, Hasselt University, co-promoter

Prof. dr. Tom Bellemans, Hasselt University

Prof. dr. Robert Motl, University of Illinois at Urbana-Champaign, Department of Kinesiology and Community Health, College of Applied Health Sciences

Prof. dr. Antonio Páez, McMaster University, School of Geography & Earth sciences

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List of abbreviations

ADL	Activities of Daily Living
ANOVA	Analysis of Variance
ATS	Adapted Transport Services
DARP	Dial-A-Ride Problem
DRT	Demand Responsive Transport
DS	Disease Steps
EDSS	Expanded Disability Status Scale
FA	Fysieke Activiteit
FAI	Frenchay Activities Index
GPS	Global Positioning System
HADS	Hospital Anxiety & Depression Scale
ICF	International Classification of Functioning, Disability and Health
IPF	Iterative Proportional Fitting
IQR	InterQuartile Range
LMS	Less Mobile Services
MD-H-DARP	Multi-Depot Heterogeneous Dial-A-Ride Problem
MFIS	Modified Fatigue Impact Scale
MS	Multiple Sclerosis
MSFC	Multiple Sclerosis Functional Composite
MSWS-12	Multiple Sclerosis Walking Scale 12
OV	Openbaar Vervoer
PA	Physical Activity
PASAT	Paced Auditory Serial Addition Test
PMB	Personen met Beperkingen
PmMS	Personen met Multiple Sclerose
PT	Public Transport
PVSAT	Paced Visual Serial Addition Test
PWD	Persons with Disabilities
PwMS	Persons with Multiple Sclerosis
QoL	Quality of Life
RBANS	Repeatable Battery for Assessment of Neuro-psychological Status
SAM	StepWatch Activity Monitor
SD	Standard Deviation
SF-36	36-Item Short Form Healthy Survey
T25FW	Timed 25-Foot Walk Test
TAZ	Transportation Analysis Zone
TMT	Trail Making Test
VAV	VraagAfhankelijk Vervoer
VRP	Vehicle Routing Problem
VRPPD	Vehicle Routing Problem with Pickup and Delivery

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Executive summary

Mobility, or the making of (physical) trips from one place to another, is one of the basic conditions to participate in professional, social and economic life. Individuals have a personal need to perform various activities, and for this reason they have to travel to the destination where this specific activity takes place. Persons with disabilities (PWD) may experience multiple functional disorders, which can have an influence on their functioning and by which their participation in society can be limited, leading to a decline in independence and autonomy; as well as to societal and economic consequences for the wider society.

According to the *International Classification of Functioning, Disability and Health* (ICF) of the World Health Organization, disability is described as the interaction between features of the person (functioning), and the overall context in which the person lives (contextual factors). Hence, participation restrictions are not inferred from disease-related dysfunctions alone, but are a dynamic interaction between the health condition of an individual, and contextual (personal and environmental) factors: a person may become disabled or enabled within a particular mobility context, rather than focusing on specific impairments in isolation. The distinction between an urban or rural environment, the support of a social network, the supply of (adapted) transport, the distance to provisions or the availability of mobility devices, among others, may play an important role in the activity-related travel behaviour of an individual, and his/her participation in society.

In order to enable PWD to fully participate in society, disabling situations (e.g. in the living space of individuals, or in the mobility system) should be limited as much as possible. Because of budget constraints, it is important to establish which investments, e.g. in attributes of the mobility system, would have the greatest impact for the participation enhancement and quality of life of PWD. While there is growing attention to the out-of-home mobility of elderly and PWD, knowledge about underlying disabling mechanisms or determinants causing changes (or decreases) in activity-related travel behaviour is sparse. However, knowledge about key factors influencing changes in activity-related travel behaviour is necessary in rehabilitation, in order to define guidelines for interventions to optimize their travel possibilities, with social participation enhancement of PWD in daily life as ultimate goal.

This doctoral thesis aims to provide more insights into the activity-related travel behaviour of PWD. In a first track, we aim to document on a detailed level the activity-related travel behaviour in PWD with different disability level (*Mapping mobility*). In a second track, we investigate the impact of both health condition, measured on different levels of the ICF framework, and contextual personal and environmental factors, on this activity-related travel behaviour (*Explaining*

mobility). In a third track, we determine which policy decisions regarding adapted transport services can be made to make the mobility system more inclusive, while guaranteeing its financial sustainability (*Supporting mobility*).

Part of the work in this doctoral thesis, i.e. the first 2 tracks about mapping and explaining mobility, is specifically performed in persons with Multiple Sclerosis (PwMS). Choosing a well-defined patient group as research population enables us to investigate their behaviour in depth (e.g. by looking at the impact of specific symptoms), as it would be too heterogeneous to include all persons with all kinds of different impairments in these tracks. Multiple sclerosis (MS) is a progressive inflammatory and neurodegenerative chronic disease of the central nervous system, with a life-long progression of the disease which can be very unpredictable and various between and within PwMS. The patient group MS is chosen because of the occurrence of multi-dimensional symptoms of various severities, involving both young and older persons (as MS occurs during the complete life span), and (work) active and less active persons.

In the track of supporting mobility, the results will be generalized to the larger population of all PWD, with different types and disability severities. While the travel patterns and/or experienced problems may be different between different patient groups (and are thus investigated in detail only in MS as research population), supporting measures to optimize their travel behaviour should be developed for the full population of PWD, as the majority of supporting measures are beneficial for different groups of PWD, leading to a higher cost-efficiency because of economies of scale.

In **chapter 1**, an exploratory pilot study was performed to get more insights into the activity-related travel behaviour in MS. The activity-related travel behaviour of 36 PwMS with different overall disability level and 24 age-/sex-matched healthy controls was measured, by using a combination of subjective self-report activity-related travel diaries and objective GPS tracking devices. In the diaries, persons had to indicate all information about their outdoor activities (e.g. activity type, start time and location) and resulting trips (e.g. travel mode and company). By use of the GPS loggers, more accurate information was obtained about traveled routes, and forgotten trips could be detected, as PwMS may forgot to fill out all their trips in the travel diaries because of possible cognitive problems. Participants were required to fill out the travel diary and wear the GPS logger during the data collection period of seven consecutive days. Besides, information about overall disability characteristics was gained by standard clinical tests and questionnaires. PwMS were divided in three subgroups based on the EDSS (Expanded Disability Status Scale) describing overall disability while taking important ambulatory dysfunction into account.

It was shown that persons with mild MS (EDSS 1.5-4.0, n=17) showed similar travel characteristics as healthy controls regarding their number of trips (4.2 daily

trips on average), travel mode (most trips as car driver, 15% of trips by non-motorized travel modes) and company (most trips performed alone). However persons with mild MS are still physical active and able to walk and/or drive independently, they self-limited their trips as car driver, as they appealed to others for trips with longer distances and drove less in bad weather conditions or on unfamiliar roads. Statistically significant changes in activity-related travel behaviour were detected in the moderate (EDSS 4.5-6.5, n=8) and severe MS subgroups (EDSS 6.5-8.0, n=11) compared with healthy controls: driving independently became less frequent, significant more trips were made with company and the duration of performed activities had increased.

In **chapter 2**, the specific impact of health condition (physical, cognitive and psychosocial functioning) as well as contextual (personal and environmental) factors on the activity-related travel behaviour in MS was assessed. 108 PwMS with various disability, in line with the disease severity of Flanders, and living in both residential and community settings, in both rural and urban areas in various provinces, participated. PwMS were divided in three subgroups, according to their Disease Steps (DS) describing ambulatory dysfunction (mild MS: DS ≤ 2 , n=51; moderate MS: DS 3-4, n=27; severe MS: DS 5-6, n=30). Health condition was assessed by standardized clinical tests on different levels of the ICF-framework: measures were conducted on the level of the body (body functions/structures level), the level of the individual (activity level) and the level of the individual as a member of society (participation level). Contextual factors (personal and environmental) were collected by means of a questionnaire. A combination of activity-related travel diaries and objective GPS tracking devices was used to investigate the activity-related travel behaviour during seven consecutive days.

The results showed that the activity-related travel behaviour in MS decreased significantly in persons with higher disability severity, confirming previous results of the pilot study. The overall significant associations with physical functioning measures indicated that the number of trips decreased with increasing ambulatory dysfunction, while the relation between cognitive function was less obvious. Personal factors like the household size, educational level and age, among others, correlated (poor to low) with the number of trips; of which similar results were found previously in studies with healthy persons. Our study showed that environmental factors may influence the activity-related travel behaviour as well, as in the mild MS subgroup the total number of trips was dependent on the distance to friends or the nearest shops, while in the severe MS subgroup persons living farther away from rehabilitation services had a lower probability of going to these services. Multiple regression analyses confirmed that, to measure or predict activity-related travel behaviour in MS, it is important to take into account not only health condition (mostly physical functioning), but as well contextual factors.

In **chapter 3**, it was analyzed in detail whether disease-related physical, cognitive or psychosocial impairments contributed to the reporting rate of data collection

methods in travel behaviour studies (subjective self-report travel diaries and objective GPS tracking devices), besides socio-demographic and trip-related characteristics. The same PwMS as in the previous chapter were included. After implementing the data of the travel diaries in a database, all individual trips were manually compared by viewing the GPS traces in a geographic information system software package and visually comparing them with the information from the travel diary, and complementing the database with the trips detected by the GPS data. The final database consisted of all trips made during the data collection period, by which every trip was labelled as registered in the diary alone, by means of the GPS tracking device alone, or by both data collection instruments.

The study demonstrated that there was only limited influence of disease-related impairments on the reporting rate (and associating data quality) of subjective travel diaries and objective GPS tracking devices, as well as only limited significant differences between subgroups with various disability severity. 66% of the trips were reported in both data collection methods, while overall more than one fifth of all trips were forgotten to be registered by GPS (and even 29% by persons with severe disability), and 11% were forgotten to be reported in the diary. It was shown that self-report travel diaries seemed to be better suitable for persons with a higher disability severity, as they had to think about a number of organizational issues when making a trip and hereby forgot to take their GPS more often.

In **chapter 4**, more insights into the walking activity in MS are provided. Physical activity (PA) is most commonly measured as number of steps, while also walking intensity and walking activity duration are keys for a healthy lifestyle. Therefore, we investigated the number of steps PwMS take, the number of steps and minutes they walk at low and moderate intensity, and their walking activity duration for 2, 3, 6, 10, 12 and 14 uninterrupted minutes; all related to degree of disability. Step data from the StepWatch Activity Monitor (SAM) were collected for seven consecutive days in a subset of 64 PwMS, distinguished in a mild (DS ≤ 2 , n=31) and moderate MS subgroup (DS 3-5, n=34). Standardized clinical tests were performed.

It was shown that step count in MS was lower than PA recommendations, and negatively influenced by a higher disability degree. PwMS are 77% of the day inactive, and making steps for 22% at low (1-80 steps/min) and only 1% at moderate (≥ 82 steps/min) intensity. Both MS subgroups rarely walked for more than 6 uninterrupted minutes, especially not at moderate intensity level, albeit capable. The results showed that PwMS need to be motivated to make steps at moderate intensity, but as well to make steps for longer periods of time (minimal 10 uninterrupted minutes) at moderate intensity level in their community setting, in order to comply with PA guidelines.

After these four in depth studies in PwMS, supporting measures for the larger population of PWD (with all types and severities of disability) are developed.

In **chapter 5**, an optimization methodology is described, to analyze the minimal resource requirements of a Demand Responsive Transport (DRT) system to offer round the clock DRT by individual service providers for a case study in Flanders. A microscopic simulation of the demand of PWD for transportation, spatial and temporal effects taken into account, was applied over the whole service area, in order to obtain a detailed overview of all transportation requests that need to be processed by each individual service provider. Specific travel data of PWD (with specific disability-related attributes) were collected by means of a survey that was distributed among 344 PWD. Next, a separate vehicle routing plan was created for each service provider for both a weekday and weekend day, taking into account heterogeneous users (persons with different severity and type of disabilities), heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots (locations where vehicles are stored). The implementation of a geographically covered DRT system for the transportation of PWD in Flanders in the prediction years 2015, 2020 and 2030, was applied. The results of the Flemish application, in terms of the required number of vehicles and drivers, and vehicle kilometers, showed that the new DRT system seemed unaffordable for the society, despite the applied optimization methodology.

In **chapter 6**, the impact of different policy decisions on the resource requirements of this DRT system in Flanders, were determined: a base scenario assuming a geographically covering subsidized DRT system; a more economical scenario limiting the subsidized DRT services; a more accessible public transport (PT); more flexibility of the users of the DRT system; an increase in the service area of the DRT service providers; and a doubling of the current supply of transport by volunteers. The resource requirements were calculated for each of the considered scenarios and for the prediction years 2015, 2020 and 2030.

The results showed that changing the modal split (the mix between the different DRT providers), the realization of adequate PT and an improved flexibility, seem to be key elements in Flanders to minimize the resource requirements for this DRT system. Our applied methodology can easily be transferred to other regions or areas, or used for other DRT applications, as the flexibility of the model allows to easily modify the input criteria based on the specific context. This information can be used by governments for the optimization of their DRT system.

Based on the knowledge obtained by the performed studies in this doctoral thesis, a number of clinical and policy implications are defined:

- Behavioral strategies should be developed in order to encourage PwMS to make more trips and participate (more) in society. Behavioural therapy could help to develop better coping and problem-solving skills to overcome anxiety in the making of trips by PwMS with mild ambulatory dysfunction, especially in the making of trips as car driver. Besides, motivational and educational strategies may encourage PwMS to make

steps at higher intensity levels and for longer uninterrupted time intervals, in order to improve their PA behaviour. Self-management interventions are recommended to adapt their lifestyle incorporating a high level of PA, and educational programs are recommended to make patients exercise-ready and enable the belief that an active lifestyle can be achieved.

- Because of the importance of environmental factors in the activity-related travel behaviour in MS, multi-disciplinary teams should include counselling on living situation and on advice regarding environmental factors, for example advising patients to consider moving to a housing location closer to medical and rehabilitation services for optimal use. Policy makers should be recommended to integrate medical and other services in community, instead of locate them remotely and relatively isolated from other social services. Enhancing community environments could serve as a promising approach to increase the outdoor participation of persons with (more severe) impairments.
- Current innovations in GPS technology and mobile positioning data may lower respondent burden in activity-related travel behaviour studies, but self-report travel diaries seemed to be better suitable for persons with a higher disability severity. In order to make a substantiated choice of data collection instrument in studies in PWD, disease-related capabilities of participants should be taken into account, and the selected method should be targeted towards the (disability level) of the target group.
- If (policy) measures or decisions are taken to make the mobility system more inclusive for all PWD, it is recommended to perform a sensitivity analysis on beforehand, to establish which investments in (attributes of) the mobility system would have the greatest impact. This analysis should take into account the various social advantages and disadvantages of the service attributes changes, not only in monetary terms, but also in terms of participation enhancement and quality of life of PWD.

There are some methodological considerations related to the measurements and technologies used: the lack of a longitudinal study to be able to identify possible influencing factors causing changes in activity-related travel behaviour over time; possible functioning problems in other neurological domains or other contextual factors leading to changes in activity-related travel behaviour; exclusion of home-bound PwMS who could provide useful information about why they were not making trips (anymore); the extensive combination of self-report travel diaries and GPS tracking devices which may lead to respondent burden; and the relatively small and unequal sample size in the different subgroups. As well, the used time interval of 1 minute may cause an overestimation of walking activity at low intensity, and results should be interpreted with caution as there is large variability in intensity thresholds between studies. In the last 2 studies about supporting

mobility, using travel diaries would give exact information of individual activity patterns of PWD, and the attractiveness of specific care related facilities may be included in future studies.

MS served as a useful model to investigate possible effects of different symptoms on activity-related travel behaviour, by which the methodology and results can therefore likely be transferred to persons with other diseases with (partly) similar personal characteristics or life categories. Future research in this field could focus on the impact of environmental factors on the walking activity in MS, and walking activity across the time of the day, related to their performed activities and trips.

Concluded, activity-related travel behaviour may serve as an ecological valid measurement of a person's functioning in daily life within the community. While rehabilitation strategies are mostly performed on the body functions/structures or activity level of the ICF framework, their ultimate goal is to enhance societal participation, so it is important to understand the full impact of the intervention by obtaining data in real-life conditions. Activity-related travel behaviour may be more sensitive to detect dysfunction or unfavorable changes at functioning level due to deterioration. Measures of activity-related travel behaviour may also be used as benchmarks in patients with different type and severity of disability, to detect whether patients are approximately making trips as expected; or as a direct self-management information tool for patients themselves. In rehabilitation strategies focusing on environmental modification, it is important to have knowledge about the contextual key factors influencing changes in activity-related travel behaviour, in order to make the social and built environment, or mobility system, more accessible for all persons, those with and without disabilities.

Nevertheless, activity-related travel behaviour covers an entire range of different transport-related dimensions (frequency of trips, distances traveled, modal split, health-related active transport measures, among others). Selecting appropriate outcome measures of activity-related travel behaviour in the field of rehabilitation should therefore be based on the expected, or desirable, outcomes of the specific intervention at participation level; targeted towards the specific patient group and towards the needs or expectations of the patients themselves. A complex interaction of factors may contribute if the experience of mobility loss by PWD results in dissatisfaction with their participation frequency, and in turn, in social exclusion.

Nederlandstalige samenvatting

Mobiliteit, of het maken van (fysieke) verplaatsingen van de ene locatie naar de andere, is één van de basisvoorwaarden om deel te nemen aan het professionele, sociale en economische leven. Mensen hebben een persoonlijke nood om verschillende activiteiten uit te voeren, en moeten zich daarom verplaatsen naar de locatie waar de specifieke activiteit plaatsvindt. Personen met een beperking (PMB) kunnen verschillende meervoudige functionele problemen ervaren, die mogelijk een invloed hebben op hun functioneren en hun deelname in de maatschappij beperkt, leidend tot een verminderde onafhankelijkheid en autonomie; en met sociale en economische gevolgen voor de samenleving.

Volgens de *Internationale classificatie van het menselijk functioneren* (ICF) van de Wereldgezondheidsorganisatie wordt een beperking, of de mate van beperkt zijn, beschouwd als de wisselwerking tussen eigenschappen van de persoon (het menselijk functioneren) en de bredere context waarin deze persoon leeft (contextuele factoren). Participatieproblemen zijn dus niet te wijten aan ziekte-gerelateerde stoornissen alleen, maar zijn een dynamische interactie tussen de gezondheidstoestand van een persoon en contextuele (persoonlijke en externe) factoren: in plaats van enkel te focussen op geïsoleerde specifieke stoornissen, kan een persoon immers beperkt of ondersteund worden door een specifieke mobiliteitscontext. Het onderscheid tussen een stedelijke of landelijke omgeving, de ondersteuning door een sociaal netwerk, het aanbod aan (aangepast) vervoer, de afstand tot voorzieningen of de aanwezigheid van mobiliteitshulpmiddelen, onder andere, kan een belangrijke rol spelen in het activiteiten-gebaseerde verplaatsingsgedrag van een persoon, en zijn/haar deelname aan de samenleving.

Om PMB te ondersteunen om volwaardig deel te nemen aan de samenleving, zouden beperkende situaties (bv. in de leefomgeving van de PMB, of in het mobiliteitssysteem) zoveel als mogelijk beperkt moeten worden. Omwille van budgettaire beperkingen is het belangrijk om te bepalen welke investeringen, o.a. in (eigenschappen van) het mobiliteitssysteem, de grootste impact hebben op het verhogen van de deelname van PMB aan de samenleving en op hun levenskwaliteit. Ondanks toenemende aandacht voor het buitenshuis verplaatsingsgedrag van ouderen en PMB, is er slechts weinig kennis over onderliggende beperkende factoren die ervoor zorgen dat het activiteiten-gebaseerde verplaatsingsgedrag van PMB wijzigt (of afneemt). Kennis over de belangrijkste factoren die ervoor zorgen dat veranderingen in het activiteiten-gebaseerde verplaatsingsgedrag optreden, is echter noodzakelijk in het kader van revalidatie. Op basis van deze kennis kunnen immers richtlijnen voor interventies uitgewerkt worden om de verplaatsingsmogelijkheden van PMB te optimaliseren, met als ultieme doel het verhogen van de deelname aan de samenleving in het dagelijkse leven.

Dit doctoraatswerk tracht om meer inzicht te bieden in het activiteiten-gebaseerde verplaatsingsgedrag van PMB. In een eerste spoor trachten we het activiteiten-gebaseerde verplaatsingsgedrag van PMB met verschillende beperkingsgraad op een gedetailleerd niveau te documenteren (*Mobiliteit in kaart brengen*). In een tweede spoor onderzoeken we de impact van de gezondheidstoestand, gemeten op verschillende niveaus van het ICF-kader, en contextuele persoonlijke en externe factoren, op dit activiteiten-gerelateerde verplaatsingsgedrag (*Mobiliteit verklaren*). In een derde spoor analyseren we welke beleidsbeslissingen omtrent aangepaste vervoersdiensten kunnen gemaakt worden om het mobiliteitssysteem meer inclusief te maken, terwijl de financiële haalbaarheid ervan gewaarborgd blijft (*Mobiliteit ondersteunen*).

Een gedeelte van dit doctoraatswerk, namelijk de eerste 2 sporen over het in kaart brengen en verklaren van mobiliteit, is uitgevoerd bij personen met Multiple Sclerose (PmMS). Door een welbepaalde patiëntengroep als onderzoekspopulatie te gebruiken, kan het activiteiten-gebaseerde verplaatsingsgedrag in de diepte onderzocht worden (bv. bepalen van de invloed van verschillende symptomen), aangezien het immers te heterogeen zou zijn om hierbij alle personen met alle mogelijke soorten van beperkingen mee op te nemen. Multiple Sclerose (MS) is een progressieve en neurodegeneratieve chronische ontstekingsziekte van het centrale zenuwstelsel, met een levenslang progressief verloop van de ziekte dat heel onvoorspelbaar en verschillend kan zijn. MS is als onderzoekspopulatie gekozen omwille van multidimensionale symptomen van verschillende ernst, bij zowel jonge als oudere personen (aangezien MS zich voordoet tijdens het volledige levensloop), en bij zowel (werk)actieve als minder actieve personen.

In het spoor over het ondersteunen van mobiliteit, veralgemenen we de resultaten naar alle PMB, met verschillende typen en ernst van beperking. Hoewel de verplaatsingspatronen en/of ervaren problemen verschillend kunnen zijn tussen diverse patiëntengroepen (en dus enkel in MS als onderzoekspopulatie in detail worden onderzocht), worden maatregelen om het verplaatsingsgedrag te optimaliseren best uitgewerkt voor de volledige populatie van PMB. Een aantal ondersteunende maatregelen zullen immers positief zijn voor verschillende groepen van PMB, wat leidt tot meer kostenefficiëntie omdat op deze manier schaalvoordelen kunnen behaald worden.

In **hoofdstuk 1** werd een verkennende pilootstudie uitgevoerd om meer inzicht te krijgen in het activiteiten-gebaseerde verplaatsingsgedrag van PmMS. 36 PmMS met verschillende ernst van beperking en 24 gezonde controlepersonen, overeenkomend qua leeftijd en geslacht, werden onderzocht door gebruik te maken van een combinatie van subjectieve zelf-gerapporteerde activiteiten-gebaseerde verplaatsingsdagboekjes en objectieve GPS tracking loggers. In de dagboekjes moesten personen alle informatie over hun buitenshuis uitgevoerde activiteiten (bv. activiteitstype, starttijdstip, locatie) en bijhorende verplaatsingen (bv. vervoerswijze en gezelschap) invullen. De GPS loggers gaven nauwkeurige

informatie over afgelegde routes, en vergeten verplaatsingen – aangezien PwMS mogelijk vergaten om alle verplaatsingen in het dagboekje in te vullen omwille van cognitieve problemen - konden hierdoor achterhaald worden. Deelnemers werden gevraagd om de dagboekjes in te vullen en de GPS loggers met zich mee te dragen tijdens elke buitenshuis uitgevoerde verplaatsing, gedurende een onderzoeksperiode van 7 opeenvolgende dagen. Daarnaast werd informatie over de gezondheidstoestand verzameld door middel van gestandaardiseerde klinische testen en vragenlijsten. PmMS werden opgedeeld in drie subgroepen, gebaseerd op de EDSS (Expanded Disability Status Scale), die de algemene beperkingsgraad aangeeft, rekening houdend met belangrijke ambulante (wandel) beperkingen.

Personen met milde MS (EDSS 1.5-4.0, n=17 personen in subgroep) hadden vergelijkbare verplaatsingskenmerken als gezonde controlepersonen wat betreft aantal verplaatsingen (gemiddeld 4.2/dag), vervoerswijze (meeste verplaatsingen als autobestuurder, 15% van verplaatsingen uitgevoerd door niet-gemotoriseerde vervoerswijzen) en gezelschap (meeste verplaatsingen alleen). Hoewel personen met milde MS nog fysiek actief waren en in staat om zelfstandig te wandelen en/of auto te rijden, beperkten ze zelf hun verplaatsingen als autobestuurder, aangezien ze beroep deden op anderen voor verdere verplaatsingen en minder vaak reden tijdens slechte weersomstandigheden of op onbekende wegen. Het activiteiten-gebaseerde verplaatsingsgedrag wijzigde significant in de gematigde (EDSS 4.5-6.5, n=8) en ernstige MS subgroep (EDSS 6.5-8.0, n=11), vergeleken met de gezonde controlepersonen: zelfstandig rijden kwam minder vaak voor, opvallend meer verplaatsingen werden uitgevoerd met gezelschap, en de duurtijd van hun uitgevoerde activiteiten was langer.

In **hoofdstuk 2** werd de specifieke impact van de gezondheidstoestand (fysieke, cognitieve en psychosociale functioneren), en van de contextuele (persoonlijke en externe) factoren onderzocht op het activiteiten-gebaseerde verplaatsingsgedrag bij MS. 108 PmMS met verschillende beperkingsgraad namen deel, in lijn met de prevalentie volgens beperkingsgraad in Vlaanderen, en zowel wonend in een residentiële als in een gemeenschapsomgeving, in zowel landelijke en stedelijke gebieden in verschillende provincies. PmMS werden opgedeeld in drie subgroepen gebaseerd op de DS (Disease Steps), die de mate van ambulante (wandel) beperkingen beschrijft (milde MS: DS ≤ 2 , n=51; gematigde MS: DS 3-4, n=27; ernstige MS: DS 5-6, n=30). De gezondheidstoestand werd onderzocht door gestandaardiseerde klinische testen op verschillende niveaus van het ICF-kader: testen werden uitgevoerd op het niveau van het lichaam (functies en anatomische eigenschappen), op het niveau van de persoon (activiteitsniveau) en op het niveau van de persoon als lid van de samenleving (participatieniveau). Contextuele (persoonlijke en externe) factoren werden in kaart gebracht d.m.v. een vragenlijst. Activiteiten-gebaseerde verplaatsingsdagboekjes en objectieve GPS loggers werden gebruikt om het activiteiten-gebaseerde verplaatsingsgedrag gedurende 7 opeenvolgende dagen te onderzoeken.

De resultaten toonden aan dat het activiteiten-gebaseerde verplaatsingsgedrag bij MS significant verminderde bij personen met een hogere beperkingsgraad, wat de vorige resultaten van de literatuurstudie bevestigde. De significante relatie met uitkomstmaten van fysieke functioneren toonde aan dat het aantal verplaatsingen afnam bij toenemende ambulante (wandel) beperking, terwijl de relatie met het cognitieve functioneren minder duidelijk was. Persoonlijke factoren, zoals o.a. huishoudgrootte, opleidingsniveau en leeftijd, correleerden (beperkt) met het aantal verplaatsingen, vergelijkbaar met vorige studies bij gezonde personen. Onze studie toonde aan dat externe (omgevings-)factoren het activiteiten-gebaseerde verplaatsingsgedrag bij MS ook beïnvloedden, aangezien in de milde MS subgroep het totale aantal verplaatsingen afhankelijk was van de afstand naar vrienden en dichtstbijzijnde winkels, terwijl in de ernstige MS subgroep personen die verderaf woonden van revalidatievoorzieningen, deze minder vaak bezochten. Meervoudige regressieanalyses bevestigden dat het belangrijk is om niet enkel te focussen op de gezondheidstoestand (vooral in termen van fysieke functioneren) om het activiteiten-gebaseerde verplaatsingsgedrag te meten of te voorspellen, maar ook rekening te houden met contextuele factoren.

In **hoofdstuk 3** werd onderzocht of ziekte-gerelateerde fysieke, cognitieve of psychosociale beperkingen invloed hadden op de rapporteringsgraad van zelf-gerapporteerde verplaatsingsdagboekjes en objectieve GPS loggers, naast socio-demografische en verplaatsingsgerelateerde kenmerken. De onderzoekspopulatie bestond uit dezelfde PmMS als in het vorige hoofdstuk. Nadat de gegevens van de dagboekjes werden ingegeven in een databank, werden alle individuele verplaatsingen manueel vergeleken door de GPS-gegevens te bekijken in een geografisch informatiesysteem programma en deze visueel te vergelijken met de informatie van de verplaatsingsdagboekjes, en de databank aan te vullen met de verplaatsingen die achterhaald waren door de GPS gegevens (maar niet ingevuld werden in de dagboekjes). De finale databank bestond uit alle verplaatsingen die gemaakt waren tijdens de dataverzamelingsperiode, waarbij elke verplaatsing werd gelabeld: enkel gerapporteerd in het dagboekje, enkel geregistreerd door de GPS logger, of geregistreerd door beide dataverzamelingsinstrumenten.

De studie toonde aan dat er slechts beperkte invloed was van ziekte-gerelateerde beperkingen op de rapporteringsgraad (en dus datakwaliteit) van de subjectieve verplaatsingsdagboekjes en objectieve GPS loggers, alsook dat er slechts weinig significante verschillen waren tussen de subgroepen met verschillende ernst van beperking. In totaal werd 66% van alle verplaatsingen geregistreerd in beide dataverzamelingsmethoden, terwijl meer dan één vijfde niet geregistreerd werd door de GPS (tot zelfs 29% in de ernstige MS subgroep), en 11% niet werd gerapporteerd in de dagboekjes. Zelf-gerapporteerde verplaatsingsdagboekjes bleken beter geschikt voor personen met een hogere beperkingsgraad, aangezien deze personen aan een heleboel organisatorische zaken moesten denken wanneer ze een verplaatsing maakten, en hierdoor vaker vergaten om de GPS logger met zich mee te dragen.

In **hoofdstuk 4** werd meer inzicht geboden in wandelactiviteit bij MS. Fysieke activiteit (FA) wordt meestal gemeten als het aantal stappen, terwijl ook wandelintensiteit en duurtijd van wandelen van belang zijn voor een gezonde levensstijl. Daarom onderzochten we het aantal stappen dat PmMS afleggen, het aantal stappen en minuten dat ze afleggen aan lage en middelmatige intensiteit, en de duurtijd van wandelen gedurende 2, 3, 6, 8, 10, 12 en 14 onafgebroken minuten; telkens gerelateerd aan hun beperkingsgraad. Stappendata van de StepWatch Activity Monitor (SAM) werden verzameld voor 7 opeenvolgende dagen in een deelgroep van 64 PmMS, opgedeeld in een milde ($DS \leq 2$, $n=31$) en gematigde MS subgroep ($DS 3-5$, $n=34$). Gestandaardiseerde klinische testen werden afgenomen bij de deelnemers.

Het aantal stappen bij MS was lager dan FA aanbevelingen, en werd negatief beïnvloed door een hogere beperkingsgraad. PmMS zijn 77% van de dag inactief, en maken stappen voor 22% aan lage (1-80 stappen/min) en slechts 1% aan middelmatige (≥ 82 stappen/min) intensiteit. Beide MS subgroepen wandelden amper voor meer dan 6 onafgebroken minuten, en zeker niet aan middelmatige intensiteit, ondanks dat ze daar wel toe in staat waren. De resultaten tonen aan dat PmMS gemotiveerd moeten worden om te wandelen aan middelmatige intensiteit, maar ook dat ze moeten wandelen gedurende langere tijdperioden (minimaal 10 ononderbroken minuten) aan middelmatig intensiteitsniveau in hun leefomgeving, om FA richtlijnen te behalen.

Na deze vier studies over PmMS, werden ondersteunende maatregelen uitgewerkt voor de grotere populatie van PMB (met diverse typen en ernst van beperking).

In **hoofdstuk 5** werd een optimalisatie methodologie beschreven om de minimale benodigde middelen van een vraagafhankelijk vervoerssysteem (VAV) te bepalen. Als gevalstudie werd verondersteld dat in Vlaanderen gedurende de volledige dag VAV werd voorzien door individuele vervoersaanbieders. De vervoersvraag van PMB werd microscopisch gesimuleerd over het gehele werkingsgebied, rekening houdend met ruimtelijke en tijdsaspecten, om zo een gedetailleerd overzicht te krijgen van alle ritten die per vervoersaanbieder moesten uitgevoerd worden. Verplaatsingsgegevens en informatie over de beperkingsstatus (bv. type en ernst van beperking, gebruik hulpmiddel, assistentie) van PMB werden verzameld door een vragenlijst die werd ingevuld door 344 PMB. Een rittenplanningsmodel werd doorgevoerd voor elke vervoersaanbieder afzonderlijk, voor zowel een week- als een weekenddag, hierbij rekening houdend met heterogene gebruikers (personen met verschillende typen en ernst van beperking), heterogene voertuigen (gewone en rolstoeltoegankelijke voertuigen) en meervoudige geografisch gelegen depots (locaties waar voertuigen worden gestockeerd). De implementatie van een gebiedsdekkend VAV systeem voor het vervoer van PMB in Vlaanderen werd doorgerekend voor de toekomstjaren 2015, 2020 en 2030. De resultaten van de Vlaamse gevalstudie, in termen van het aantal benodigde aantal voertuigen en

chauffeurs, en voertuigkilometers, toonden aan dat het nieuwe VAV systeem onhaalbaar bleek voor de samenleving, ondanks de toegepaste optimalisatie.

In **hoofdstuk 6** werd de impact van verschillende beleidsbeslissingen op de minimale benodigde middelen van dit VAV systeem in Vlaanderen onderzocht: een basisscenario dat een gebiedsdekkend gesubsidieerd VAV veronderstelt; een meer economisch scenario waarbij het VAV slechts gedeeltelijk gesubsidieerd wordt; een toegankelijker openbaar vervoer (OV); meer flexibiliteit van de gebruikers van het VAV systeem; een groter werkingsgebied van de VAV vervoersaanbieders; en een verdubbeling van het huidige vervoersaanbod door vrijwilligers. De benodigde middelen werden berekend voor elk van de veronderstelde scenario's en voor de toekomstjaren 2015, 2020 en 2030.

De resultaten toonden aan dat het wijzigen van de modale verdeling (de keuze tussen de verschillende VAV aanbieders), het realiseren van meer toegankelijk OV en een verhoogde flexibiliteit, de belangrijkste factoren zijn in Vlaanderen om de benodigde middelen van dit VAV systeem te minimaliseren. De toegepaste methodologie kan gemakkelijk getransfereerd worden naar andere regio's of gebieden, of gebruikt worden voor andere VAV toepassingen, aangezien de flexibiliteit van het model toelaat om eenvoudig de invoergegevens te wijzigen op basis van de specifieke context. Deze informatie kan gebruikt worden door overheden om hun VAV systeem te optimaliseren.

Op basis van de verworven kennis in de uitgevoerde studies in dit doctoraatswerk, zijn een aantal klinische en beleidsaanbevelingen opgesteld:

- Gedragsinterventies zouden ontwikkeld moeten worden om PmMS aan te moedigen om meer verplaatsingen te maken en (meer) deel te nemen aan de samenleving. Gedragstherapieën kunnen helpen bij personen met milde MS om betere probleemoplossende vaardigheden te ontwikkelen, om zo angstgevoelens tijdens het maken van verplaatsingen te overwinnen, voornamelijk tijdens verplaatsingen als autobestuurder. Motiverende en educatieve interventies kunnen PmMS overtuigen om meer stappen te zetten aan hogere intensiteitsniveaus en voor een langere ononderbroken tijdsduur, om zo hun FA niveau te verbeteren. Zelfmanagement interventies worden aanbevolen om hun levensstijl om te vormen naar een hoog niveau van FA, en educatieve programma's worden aangeraden om patiënten 'trainingsklaar' te maken en het besef te ondersteunen dat een actieve levensstijl kan bereikt worden.
- Omwille van het belang van externe (omgevings-)factoren in het activiteiten-gebaseerde verplaatsingsgedrag, zouden multidisciplinaire teams bij MS advies moeten geven over de leefomgeving en andere externe factoren, bv. door patiënten aan te raden om dichterbij medische en revalidatievoorzieningen te gaan wonen. Verder worden beleidsmakers

aangeraden om medische en andere voorzieningen te integreren in de samenleving, in plaats van deze ergens afgelegen te lokaliseren, relatief geïsoleerd van andere sociale voorzieningen. Het verbeteren van de leefomgeving lijkt een veelbelovende aanpak om de deelname aan de samenleving door personen met (ernstige) beperkingen te verhogen.

- Huidige ontwikkelingen in GPS technologie en mobiele positioneringsdata kunnen de last (burden) van respondenten in activiteiten-gebaseerde verplaatsingsstudies verminderen, maar zelf-gerapporteerde dagboekjes bleken meer geschikt voor personen met een ernstigere beperkingsgraad. Om een geschikte keuze van dataverzamelingsinstrument te maken bij studies met PMB, moeten de ziekte-gerelateerde vaardigheden van deelnemers mee in rekening genomen worden, en de geselecteerde methode moet gericht zijn op (de beperkingsgraad van) de doelgroep zelf.
- Indien (beleids-)maatregelen of beslissingen worden genomen om het mobiliteitssysteem meer inclusief te maken voor PMB, is het aanbevolen om vooraf een sensitiviteitsanalyse uit te voeren, om te bepalen welke investeringen in (eigenschappen van) het mobiliteitssysteem de grootste impact zouden hebben. Deze analyse zou diverse sociale voor- en nadelen van de scenario's moeten omvatten, niet alleen in monetaire termen maar ook in termen van participatieverbetering en levenskwaliteit van PMB.

Er zijn een aantal methodologische bedenkingen, gerelateerd aan de gebruikte uitkomstmaten en technologieën: het gebrek aan een longitudinale studie om beïnvloedende factoren in het activiteiten-gebaseerde verplaatsingsgedrag doorheen de tijd te kunnen identificeren; mogelijke functioneringsproblemen in andere neurologische domeinen of mogelijke andere contextuele factoren die leiden tot wijzigingen in het activiteiten-gebaseerde verplaatsingsgedrag; een exclusie van thuisgebonden PmMS die nuttige informatie kunnen geven waarom ze geen verplaatsingen maken; de omvangrijke combinatie van zelf-gerapporteerde verplaatsingsdagboekjes en GPS loggers die tot respondentenlast kon leiden; en de relatief kleine en ongelijke groottes van de verschillende subgroepen. Verder kan het gebruikte tijdsinterval van 1 minuut leiden tot een overschatting van de wandelactiviteit aan lage intensiteit, en worden de resultaten omtrent intensiteit best voorzichtig geïnterpreteerd omwille van de verschillende grenswaarden voor intensiteitsniveaus tussen verschillende studies. In de laatste 2 studies zou exacte informatie omtrent individuele activiteitenpatronen van PMB mogelijk zijn geweest door verplaatsingsdagboekjes te gebruiken, en kan de attractiviteit van specifieke zorggerelateerde voorzieningen best opgenomen worden in toekomstige studies.

MS diende als een geschikt onderzoeksmodel om de mogelijke effecten van verschillende symptomen op het activiteiten-gebaseerde verplaatsingsgedrag te onderzoeken, waardoor de methodologie en resultaten vermoedelijk ook kunnen

gebruikt worden bij andere ziekten met (deels) vergelijkbare persoonlijke kenmerken of levenscategorieën. Verder onderzoek in dit domein kan zich richten op de invloed van externe factoren op wandelactiviteit in MS, en wandelactiviteit doorheen de dag in relatie met de uitgevoerde activiteiten en verplaatsingen.

Er kan gesteld worden dat het activiteiten-gebaseerde verplaatsingsgedrag kan dienen als een ecologisch geldige uitkomstmaat van het menselijk functioneren in het dagelijkse leven binnen de samenleving. Revalidatiestrategieën worden meestal uitgevoerd op het niveau van het lichaam of op het activiteitsniveau van het ICF-kader, maar hun uiteindelijke doel is de maatschappelijke participatie te verbeteren. Het is dus belangrijk om de volledige impact van de interventie te begrijpen door gegevens in real-life omstandigheden te verzamelen. Het activiteiten-gebaseerd verplaatsingsgedrag kan meer gevoelig zijn om ongunstige veranderingen op vlak van menselijk functioneren, ten gevolge van achteruitgang, te detecteren. Uitkomstmaten van het activiteiten-gebaseerd verplaatsingsgedrag kunnen ook gebruikt worden als benchmarks, om te kijken of PMB met een verschillend type en ernst van beperking ongeveer evenveel verplaatsingen maken zoals verwacht (namelijk of ze een verwacht verplaatsingsgedrag vertonen); of als directe zelfmanagement tool voor patiënten zelf. Bij revalidatiestrategieën die focussen op de wijziging van externe factoren, is het belangrijk om kennis te hebben over de contextuele factoren die het activiteiten-gebaseerde verplaatsingsgedrag het sterkst beïnvloeden. Hierdoor kan de sociale en bebouwde omgeving, of het mobiliteitssysteem, beter toegankelijk gemaakt worden voor alle personen, zowel deze met als zonder beperkingen.

Het activiteiten-gebaseerde verplaatsingsgedrag omvat weliswaar een hele waaier aan verschillende verplaatsingsdimensies (zoals frequentie van verplaatsingen, afgelegde afstanden, modale verdeling met inbegrip van gezondheidsgerelateerde actieve vervoerswijzen, etc.). Het selecteren van geschikte uitkomstmaten van activiteiten-gerelateerd verplaatsingsgedrag in het domein van revalidatie zou dan ook gebaseerd moeten zijn op de verwachte, of gewenste, uitkomsten van de specifieke interventie op participatieniveau van het ICF-kader, gericht op de specifieke patiëntengroep en op de noden of verwachtingen van de patiënten zelf. Het hangt van een complexe interactie van factoren af of het verlies van mobiliteit bij PMB er toe leidt dat ze ontevreden zijn met hun deelname in de maatschappij, of op zijn beurt leidt tot sociale exclusie.

GENERAL INTRODUCTION

1. ABOUT THIS DOCTORAL THESIS

Mobility, or the making of (physical) trips from one place to another, is one of the basic conditions to participate in professional, social and economic life. Individuals have a personal need to perform various activities, and for this reason they have to travel to the destination where this specific activity takes place. Persons with disabilities (PWD) may experience multiple functional disorders, which can have an influence on their functioning and by which their participation in society can be limited, leading to a decline in independence and autonomy; as well as to societal and economic consequences for the wider society.

Participation restrictions are not inferred from disease-related dysfunctions alone, but are a dynamic interaction between the health condition of an individual, and contextual (personal and environmental) factors: a person may, among others, become disabled or enabled within a particular mobility context. In order to enable PWD to fully participate in society, disabling situations (e.g. in the living space of individuals, or in the mobility system) should be limited as much as possible.

While there is growing attention to the out-of-home mobility of elderly and PWD, knowledge about the underlying disabling mechanisms or determinants causing changes (or decreases) in travel behaviour is sparse. However, knowledge about key factors influencing changes in activity-related travel behaviour is necessary in rehabilitation, in order to define guidelines for interventions to improve the possibilities for social participation of PWD to a desired level in daily life as ultimate goal. Measures of the activity-related travel behaviour may also be used as benchmarks in patients with different type and severity of disability, to detect whether patients are approximately making trips as expected, and can serve as a baseline of information to proceed with subsequent planning and decision making.

This doctoral thesis aims to provide more insights into the activity-related travel behaviour of PWD, by documenting their activity-related travel behaviour in detail, by investigating the specific impact of health condition (measured on different levels of the International Classification of Functioning, Disability and Health (ICF)) and contextual personal and environmental factors, and by determining which policy decisions regarding adapted transport services can be made to make the mobility system more inclusive while guaranteeing its financial sustainability.

This general introduction provides background information on the main topics of this doctoral thesis. In the first part, the relevance of mobility as one of the basic conditions for activity participation is motivated. Secondly, the ICF-framework of the WHO is explained. The next part describes why it is important to measure the travel behaviour of PWD and how it can be measured, while the fourth part gives more information about the research populations used in this work. The general introduction ends with a short presentation of the thesis outline and the performed studies.

2. MOBILITY AS ONE OF THE BASIC CONDITIONS FOR PARTICIPATION

2.1. Mobility as a derived demand

The time-geography theory of Hägerstrand (Hägerstrand, 1970), one of the basic theories about the movement of people in time and space, describes that different individuals are in touch with each other and stay at a geographical place over time (performing activities), and leave each other and the place afterwards. Indeed, individuals have a personal need to perform various activities, and for this reason they have to travel to the destination where this specific activity takes place, because of economic, social, recreational and other personal objectives. Among others, individuals may have a need to go to work, to go shopping (daily groceries or fun shopping), to visit family or friends, to perform leisure activities, to follow educational courses, to go to see a doctor, or to perform other activities. Mobility, or the making of (physical) trips from one place to another, can be considered as a *derived demand*: the demand of transportation occurs as a result of the fact that individuals want to participate in activities at various locations. Recent developments in digital technologies allow individuals to project (virtual) presence beyond physical location in space and time, so without the need for physical travel (e.g. teleshopping or teleworking) as well. Both mobility, or the actual travel behaviour of individuals through movement, and extensibility, i.e. the ability to project virtual presence in space and time, are preconditions to participate in professional, social and economic life (Miller, 2006).

In this doctoral thesis we will only focus on the mobility, or the actual out-of-home travel behaviour (and thus not the extensibility), of individuals.

The travel behaviour of persons is a product of the activities they wish or have to perform in order to achieve particular goals or objectives; within the situational, household, spatial, temporal, spatial-temporal and institutional constraints set by the environment that limit the number of feasible activities (Janssens, Wets, Brijs, Vanhoof, & Timmermans, 2003) (Arentze & Timmermans, 2004). For example, a person cannot be at different locations at the same time (situational constraints); bringing children to school by the only car in the household may impose that other particular activities by car cannot be performed by household members (household constraints); particular activities cannot be performed at particular locations (spatial constraints); some activities require a minimum amount of time (temporal constraints); a person has to travel between different locations which requires some time (spatial-temporal constraints); and particular activities can only be performed at specific time frames, e.g. opening hours of shops (institutional constraints) (Arentze & Timmermans, 2004). However, a number of factors may cause that some individuals experience more, or more serious, limitations than others in performing their trips.

2.2. Transport disadvantage & impact for individual and society

If the travel possibilities of someone don't allow to participate in the society in an adequate manner, and therefore this individual can make fewer trips than she/he finds desirable, this person suffers from 'transport disadvantage' (Meert, Bourgeois, van Hoof, & Asperges, 2003)(Meert, 2003). Hereby, the person may suffer from a decreased participation, an inadequate integration on the labour market and financial impact, a loss of independence, a feeling of isolation and a lack of social interactions leading to reduced quality of life, and others.

Previous studies identified various factors contributing to transport disadvantage: socio-economic position, ethnic minorities, geographical (rural) location, non-licensed drivers, financial constraints, psychological aspects such as fear, age or physical barriers, as well as a combination of different of these factors, among others (Hine & Mitchell, 2003) (Engels & Liu, 2011) (Bastiaanssen, 2012). In this doctoral thesis we will focus on transport disadvantage because of **disability**.

Improving the travel possibilities to a level as desired by persons with disabilities (PWD) is not only beneficial for the individuals themselves, but also for the wider society. If PWD are not reducing their travel behaviour, and/or are able to continue travel (longer) in their disease progression, hereby prolonging their societal participation, the need for residential care is eliminated. Active persons will stay healthy for a longer time period, in comparison with persons who no longer perform outdoor activities in society. More independence in society leads to more home or ambulant care, instead of staying in a hospital, or other nursing or rehabilitation center. An increased degree of participation offers social benefits, since people will stay longer involved in diverse activities. If PWD can be supported in maintaining their safe out-of-home mobility longer, this is expected to have an overall positive effect not only on their (and their caregivers' or family) wellbeing and quality of life, but also on society in general.

From an economics point of view, there is also a financial cost of the fact that a growing number of elderly and PWD cannot participate in professional, social and/or economic life because their mobility needs are not met. A longer mobility behaviour provides PWD to stay longer active in society by working longer (both paid work as voluntary work – limiting indirect production losses related to early retirement or sick leaves), participating longer as a consumer, and staying longer social active. An increased degree of participation and independent behaviour in diverse activities, like shopping or leisure activities, will offer economical profits.

2.3. Mobility in relation to activity participation

Transport disadvantage may disable the (activity) participation in the society, and lead to social exclusion: the lack of resources and/or inability to participate in the activities and relationships that a majority of people in a society would consider normal (Levitas, 2000). Transportation is increasingly considered as facilitating (if

available) or hindering (if not) inclusion in all the normal aspects of society, given the fact that a vast majority of activities are spatially dispersed (Paéz, Mercado, Farber, Morency, & Roorda, 2009).

Transportation-related social exclusion has been discussed previously in literature, by which a conceptual framework was developed for the analysis of (the relation between) mobility and social exclusion (Paéz & Farber, 2012). It was shown that personal, living space and economic attributes – generally associated with the demographic, economic and environmental variables describing the individual and the surrounding environment – influence both the mobility and extensibility of an individual. On a higher level, activity participation is the realization of one or more opportunities available either because they are accessible (they can be reached by the individual, given a mobility situation) or because the individual can project herself without having to physically move (extensibility) (Paéz & Farber, 2012). In turn, it was shown that activity participation impacts the well-being of an individual, and the composition of social networks.

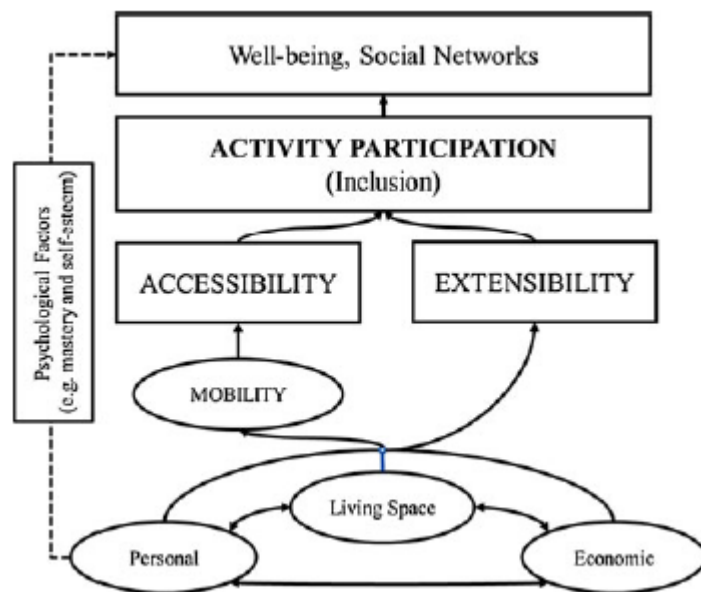


Figure 1: Mobility and social exclusion (Paéz & Farber, 2012)

While mobility or transport (disadvantage) is an important factor in the degree of activity participation (or social exclusion on the contrary) (Paéz, Mercado, Farber, Morency, & Roorda, 2009); other personal or contextual factors may give rise to disabling situations as well. For example, disability may happen already at the doorstep of an individual because of personal factors (e.g. having an impairment), economic factors (e.g. costs of modifications) or living space (lack of a ramp or other needed home modifications) – even before mobility systems are involved. Besides, as well temporal, societal or political components, and others, can influence the activity participation of an individual (Paéz & Farber, 2012).

2.4. Scope of this doctoral thesis

In this doctoral thesis, we will focus on the mobility, or travel behaviour, of PWD in relation to the health condition (i.e., the complete physical, mental and social functioning), and personal (e.g. demographic characteristics) and environmental contextual factors, facilitating or hindering the person’s functioning. Knowledge about key factors influencing changes in activity-related travel behaviour will enable us to define guidelines for interventions to optimize their travel possibilities, with social participation enhancement of PWD in daily life as ultimate goal. Compared to the conceptual framework in Figure 1, this doctoral thesis thus examines only part of the activity participation components, i.e., only the mobility component and its influencing factors. Figure 2 gives an overview of the scope of this doctoral thesis, in the context of activity participation.

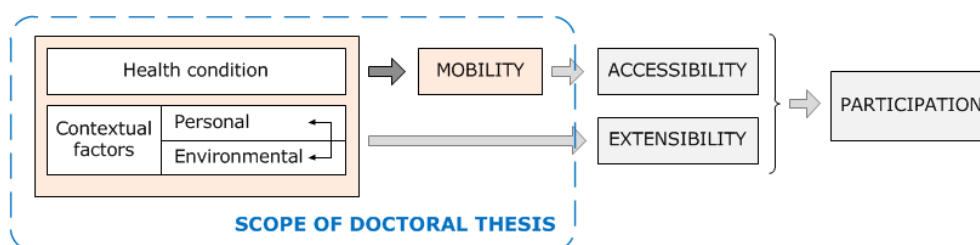


Figure 2: Scope of doctoral thesis - focus on mobility

2.5. ‘Average’ person may experience limitations as well

Not only persons who are born or have acquired an impairment may experience participation restrictions, but almost everyone tends to lose ability as they age or at various times during the course of their life. For example, most persons, at some point in their life, need to use crutches or some other aid because of an accident or illness, hindering their walking ability. As the average person as well may have (temporary) non-average needs or limitations at some moments, a large proportion of the population is sooner or later confronted with participation restrictions because of the mismatch between the environment we live or travel in, and the (changing) capabilities of the individual.

In particular, the population's ageing and de-greening presents society with major challenges regarding maintaining its social participation (WHO, 2014), as the gradual accumulation of multiple minor impairments impacts the ability to maintain an active and independent lifestyle for a growing proportion of the population. Most recent Eurostat population projections, shown in Figure 3, demonstrate that the EU28-population is projected to continue to age (with associated potential to develop physical limitations in large numbers), while the share of those aged 80 years or above is projected to even more than double between 2013 and 2080 (Eurostat, 2015). The share of individuals in the society who are experiencing participation restrictions, should therefore not be underestimated.

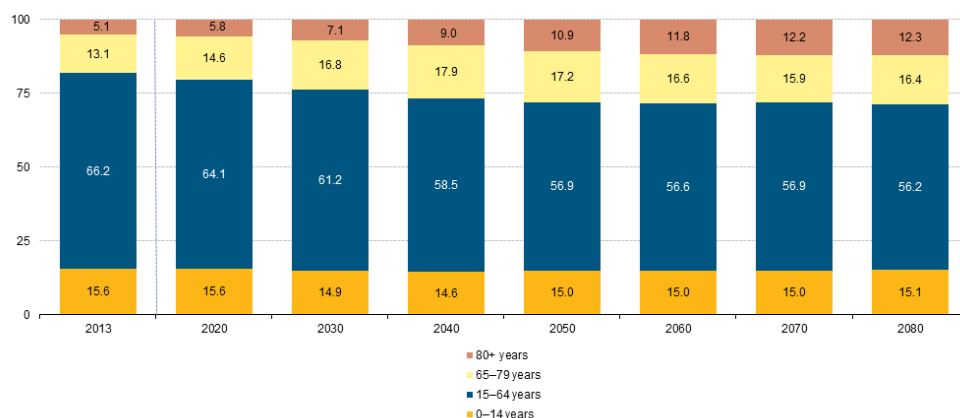


Figure 3: Population structure by major age groups in 2013-2080 (projections EUROPOP2013 for 2020-2080), in EU-28, in % of the total population

3. INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (WHO)

3.1. Description of the ICF framework

According to the *International Classification of Functioning, Disability and Health* (ICF) of the World Health Organization, disability is described as the interaction between features of the person (functioning), and the overall context in which the person lives (contextual factors). The ICF is an international framework for describing and measuring health and disability in all its dimensions, and can be used in clinical settings as a framework for rehabilitation programming. The ICF provides a scientific basis for understanding and studying health and health-related states, outcomes, determinants, and changes in health and functioning (WHO, 2001). An overview of the ICF framework is shown in Figure 4.

In the ICF framework, health is defined as the complete physical, mental and social functioning of a person. This functioning is a multi-dimensional umbrella term and refers to various levels:

- **Body functions and structures:** functioning at the level of the body (e.g. physiological functions and anatomical parts of body systems);
- **Activities:** functioning at the level of the individual (e.g. the execution of a specific task or action, like walking 200 meters);
- **Participation:** functioning of a person as a member of society (e.g. the involvement in a life situation). Participation restrictions, on the other hand, refer to problems individuals may experience in involvement in life situations.

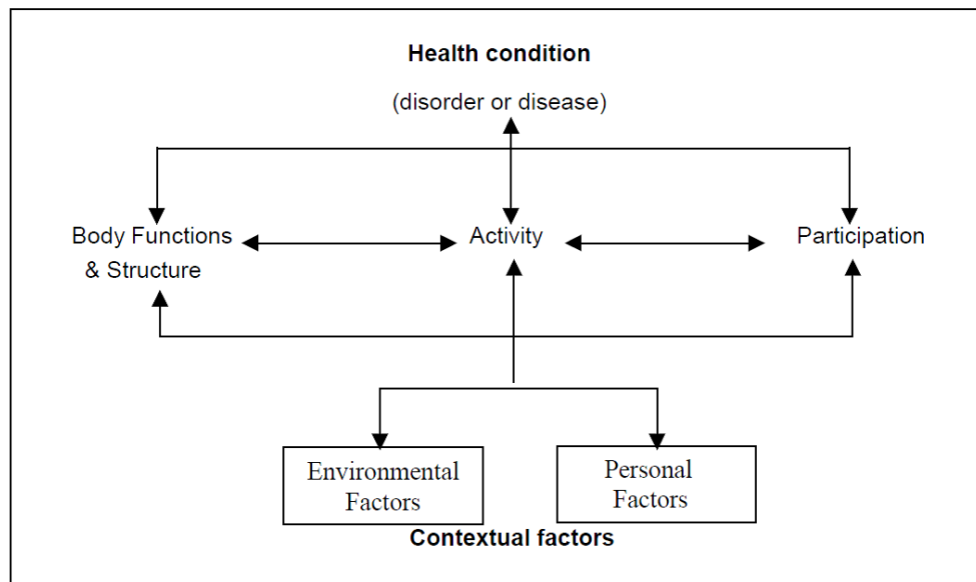


Figure 4: International Classification of Functioning, Disability and Health

The ICF looks beyond the idea of a purely medical conceptualization of dysfunction and clarifies that we cannot infer participation (restriction) in everyday life from diagnosis alone. Indeed, this framework also takes into account other critical aspects of disability, i.e., **contextual factors** that have an important role on the functioning of an individual. Contextual factors include both **personal factors** (e.g. gender, age, educational level) and **environmental factors** (which are not within the person's control, e.g. degree or urbanization, government and laws); and represent the physical, social and attitudinal environment in which people live and conduct their lives. These factors can be considered as either facilitators or barriers of the person's functioning. For example, what an individual can do in a standard environment (capacity - e.g. some kind of clinical assessment, like a standard walking test providing more insights into the walking speed) may differ

from what the person actually does in his current usual environment (performance – e.g. a lower walking speed while travelling) due to an inaccessible environment.

A person's level of functioning is therefore conceptualized as a dynamic interaction between his health condition, and contextual (personal/environmental) factors. A person may become disabled or enabled within a particular mobility context, rather than focusing on specific impairments in isolation. The distinction between an urban or rural environment, the support of a social network, the supply of (adapted) transport, the distance to provisions or the availability of mobility devices, among others, may play an important role in the participation in society.

In order to enable PWD to fully participate in society, limiting disabling situations or contexts should be limited as much as possible. Because of budget constraints, it is important to establish which investments, e.g. in attributes of the mobility system, would have the greatest impact for the participation enhancement and quality of life of PWD.

3.2. Influence of contextual factors on mobility

In healthy persons, previous studies already showed the specific relation between personal and environmental factors, and their activity-related travel behaviour (Contrino & McGuckin, 2009) (Rosenbloom, 2004) (Syam, Khan, & Reeves, 2012) (van Wee, Holwerda, & van Baren, 2002). External (environmental) factors like the region's structure, the topography, the mobility supply and infrastructure, distribution of workplaces or social institutions, were shown to impact the travel behaviour as they determine behavioral options. Socio-demographic (personal) factors like income level, age, household structure, employment status and gender, determine individual options and necessities for mobility activities, while attitudinal (personal) factors like values, norms and attitudes affect preferences for specific destinations, routes and transport modes. It is shown that travel behaviour changes throughout the life course, with females and older people generally being less mobile. Figure 5 shows an overview of factors that may influence individual mobility behaviour (ADD HOME, 2007).

Some results of the most recent Travel Behaviour Research Flanders (Declercq, Janssens, & Wets, 2014) are shown in Table 1, to illustrate the impact of personal factors (gender and age category) on the travel behaviour in terms of number of trips, performed distances, travel mode and type of activities. It is demonstrated that women on average make less trips, travel more as a car passenger and make fewer work-related trips than men. Significant differences could also be detected between different age categories, with older people generally being less mobile.

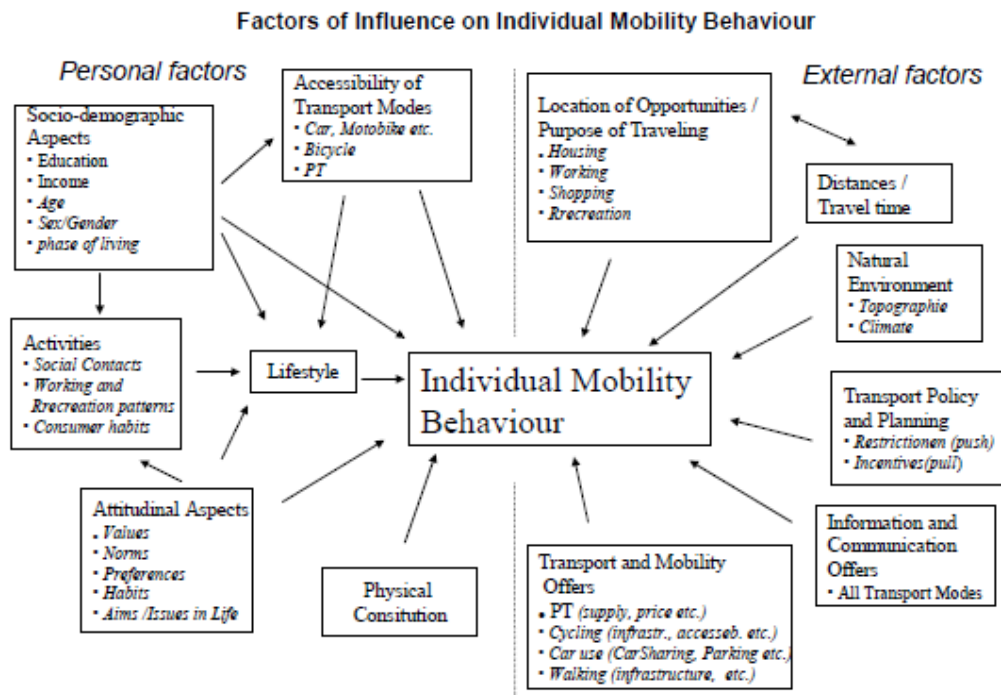


Figure 5: Contextual factors that may influence mobility behaviour (ADD HOME, 2007)

Table 1: Selection of results, Travel Behaviour Research Flanders: impact of gender & age

GENDER	Male	Female							
Number of trips per day	2.9	2.6							
Distance per day (km)	44.1	35.2							
% of trips as car driver	57.3	45.8							
% trips as car passenger	11.0	23.3							
% trips by foot	9.6	12.2							
% work trips	24.6	16.7							
% trips for shopping	19.5	25.0							
AGE CATEGORY	6-12	13-17	18-24	25-34	35-44	45-54	55-64	65+	
Number of trips per day	2.7	2.4	2.7	3.0	3.5	2.9	3.1	2.00	
Distance per day	27.3	38.0	43.2	54.1	50.2	43.9	46.1	16.57	
% of trips as car driver	/	/	31.8	63.9	73.7	64.9	65.5	47.91	
% trips as car passenger	56.3	45.3	16.4	13.3	4.9	9.8	13.6	16.58	
% trips by foot	15.2	12.4	15.1	10.0	8.6	6.6	11.3	14.16	
% work trips	/	/	13.3	33.4	34.3	32.2	18.1	1.92	
% trips for shopping	11.9	14.6	14.7	20.9	15.6	24.4	28.3	35.58	

4. TRAVEL BEHAVIOUR OF PERSONS WITH DISABILITIES

4.1. Importance of measuring travel behaviour of PWD

As modelling travel demand has always been a major area of concern in transportation research, the travel behaviour of 'ordinary' populations, without a disease, is already examined on a large scale. This is not the case in many patient groups with disabilities. The target group of PWD is difficult to describe within a general population, as the population of PWD is often delineated based on various diagnostic criteria and definitions, used by different actors (e.g. doctors, social workers, psychologists) in different social contexts (benefit schemes, agencies for disabled persons, among others). In general, PWD can be defined as persons who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various personal and environmental barriers, hinders their full and effective participation in society on an equal basis with others. PWD may experience one or multiple functional disorders (e.g. physical, cognitive, psychosocial), which can have an influence on their functioning and participation in society, leading to a decline in independence and autonomy.

Among others, PWD may experience problems with driving a car independently, because this requires to handle a complicated set of skills and interaction with the environment. For example, driving ability can be influenced by problems with visibility (detection of road signs, judging distances), concentration (resistant to distraction by other cars or radio), memory (proper route from point A to B), coordination between both legs (braking, accelerating), coordination between arms and legs, fatigue (worsening all symptoms), and others. As well, PWD may experience problems using public transport (PT), as they may not be able to walk or travel to the PT stop, or because the vehicles are not (fully) accessible in relation to their needs. The accessibility status of the public domain can also create mobility problems, as inaccessible surfaces may hinder PWD to make trips by foot or with a mobility aid (e.g. crutches, rollator or wheelchair), or make trips alone. Besides changes in travel mode, mobility problems may also lead PWD to limit trips to familiar environments, to not travel long distances (anymore), to limit their unaccompanied trips, or to make fewer trips than they really want to make. This may not only have an influence on the quality of life of PWD themselves, but also on their relatives and friends, who may give up certain activities to transport the PWD to his/her work or other locations.

There is growing attention to the out-of-home mobility of older persons from various disciplines including gerontology, transport studies, health research and urban studies; by which their travel behaviour was often represented in terms of trips made, traveled distances and transport mode used. Conventionally used indicators of accessibility have been trip generation (providing an indication of out-of-home activity engagement) or the distance traveled during the course of the day (as proxy for the range of opportunities potentially available to individuals) (Páez, Mercado, Farber, Morency, & Roorda, 2009); while most research however

tended to concentrate on their mobility by motorized modes, instead of addressing the multi-modal travel behaviour of seniors (Moniruzzaman, Páez, Habib, & Morency, 2013). As well, first studies in PWD have been conducted, for example about the relation of transport use and supply and the occurrence of obesity (Samimi, Mohammadian, & Madanizadeh, 2009) (Parra, et al., 2009), changes in use of transport after stroke (Wendel, Stahl, Risberg, Pessah-Rasmussen, & Iwarsson, 2010) (Risser, Iwarsson, & Stahl, 2012) (Logan & Dyas, 2004), challenges using public transport by persons with cognitive limitations (Rosenkvist, Risser, Iwarsson, Wendel, & Stahl, 2009), driving performance in persons with MS (Devos, Brijs, Alders, Wets, & Feys, 2013) (Schultheis, Garay, & DeLuca, 2001), among others. However, the *multimodal activity-related travel behaviour in PWD in general*, including all trips they make, the use of travel modes (including trips by foot, bicycle, specialized transport, assistive device, among others), traveled distances, among others, has only rarely been examined.

Moreover, most travel behaviour studies in PWD are descriptive, but failed to decipher the **underlying mechanisms or determinants causing the changes in travel behaviour**, although this knowledge is important to develop tailored interventions and mobility measures. Knowledge about the key factors influencing changes in activity-related travel behaviour in PWD is sparse, but necessary in rehabilitation, **in order to define guidelines for interventions to optimize their travel possibilities, with social participation enhancement in daily life as ultimate goal**. Collecting and analyzing of activity-related travel data in PWD (which trips are performed and how often) is necessary, as alleviating the challenges faced by PWD is important towards building more inclusive societies (Farber & Páez, 2010).

Measures of the activity-related travel behaviour may also be used as benchmarks in patients with different type and severity of disability, to detect whether patients are approximately making trips as expected. Hereby, the existing activity-related travel behaviour of PWD would provide a baseline of information to proceed with subsequent planning and decision making.

4.2. Measuring activity-related travel behaviour

Travel demand is mostly derived from the activities individuals and households need or wish to perform (Mokhtarian & Salomon, 2001). While traditional 4-step transport models were trip-based and considered trips as isolated events with ignoring the reason (i.e., the activity type) why people were travelling, activity-based transport models focus on activities, assuming that most travel is a means to bridge activities that are separated in time and space. The aim of activity-based transport models is to estimate which activities are conducted where, when, for how long, with whom, the transport mode involved, and preferably also the route; which makes them better able to capture behavioral realism of individuals (Arentze & Timmermans, 2004). Activity-based transport models can be

characterized as follows: travel is derived from demand for activity participation; sequences or patterns of behaviour (and not individual trips) are the relevant unit of analysis; household and other social structures influence travel and activity behaviour; spatial, temporal, transportation and interdependencies constrain both activity and travel behaviour; and activity-based approaches reflect the scheduling of activities in time and space (McNally & Rindt, 2007).

Traditionally, activity-related travel behaviour studies are investigated by means of **paper and pencil self-report activity-related 'travel diaries'**, which typically require participants to provide information about the activity purpose, travel mode, start and end time, location of the trip origin and destination, and company of the trip (Axhausen, Zimmerman, Schönfelder, Rindsfuser, & Haupt, 2002). While these travel behaviour data may suffer from incompleteness or inaccuracies because of the detailed required trip-level information (Bricka, Sen, Paleti, & Bhat, 2012) (Shoval, et al., 2010), they are an important source of information for understanding why and how people make their trips; and have the advantage that diaries can be filled in at any time and at any place.

Over the past decade, recent advances in Global Positioning System (GPS) technology and mobile positioning data have resulted in supplementing (and sometimes replacing) of conventional paper self-report travel diaries as a collection method with **GPS tracking devices to record travel behaviour** (Bellemans, Kochan, Janssens, Wets, & Timmermans, 2007) (Cich, Knapen, Bellemans, Janssens, & Wets, 2015) (Raza, Knapen, Declercq, Bellemans, & Janssens, 2015). GPS devices offer researchers the opportunity for continuous and intensive high-resolution data collection in time and space for long periods of time (Shoval, et al., 2010), with a lower burden for the respondent.

Until recently, the assessment of outdoor activity-related travel behaviour in PWD relied mainly on self-report travel diaries or reports of family caregivers or institutional staff, using behavioral checklists, observational approaches or activity monitoring, while GPS tracking technology has only rarely applied in PWD (Shoval, et al., 2008). Travel behaviour studies in persons with cognitive impairments may create methodological challenges, as commonly used self-report diaries rely on recall and honest reporting, and require individuals to have no or limited cognitive deficits to reduce potential bias in reporting results (Hale, et al., 2007). While previous studies about walking and physical activity already showed only limited reliability and validity regarding the frequency of different activity types (Dewulf, Neutens, Van Dyck, de Bourdeaudhuij, & Van de Weghe, 2012)(Helmerhorst, Brage, Warren, Besson, & Ekelund, 2012), there is relatively little research available about the reliability of travel behaviour studies in PWD in general. It may be expected that the accuracy of self-report surveys or diaries may be influenced by disease-related cognitive dysfunctions, while persons suffering from physical problems like fine hand motor skills, may not be able to fill in diaries.

4.3. Measuring walking activity

As walking is a key component for physical functioning and independence during activities of daily life (ADL) (Goldman, et al., 2013), it has an important influence on societal participation of PWD as well. While the majority of the work in this doctoral thesis is performed about the activity-related travel behaviour in general (including all travel modes), part of the work is performed specifically about the walking behaviour of PWD in community setting. Hereby, the frequency, intensity and uninterrupted duration of walking activity are considered as outcome measures for participation in society.

Walking activity is an important part of physical activity (PA), which can be defined as any bodily movement produced by skeletal muscles that requires energy expenditure. Persons with physical limitations, like persons with Multiple Sclerosis, are showing decreased walking mobility and PA in a daily life community setting, which however cannot all be explained by their physical limitations alone (Motl, McAuley, & Snook, 2005).

In order to measure walking activity, traditionally, standardized walking tests are being applied, by which individuals have to execute a single activity (e.g. walk a certain distance) within a limited time frame in an artificial setting. While these tests sample capacity, which is the highest probable level of functioning within a standardized environment (WHO, 2001), they may however be influenced by factors like fatigue or day variability, and might be more reflective of *best possible* walking performance instead of habitual walking performance (Gijbels, et al., 2010).

In recent years, accelerometer-based technology (like pedometers or walking activity monitors) enabled reliable and valid data recording of both frequency and intensity of walking activity (Motl, McAuley, Snook, & Scott, 2006) (Mudge, Stott, & Walt, 2007), and is therefore an objective way to quantify habitual walking performance. As habitual walking performance is performed in a proper ecological setting, i.e. in a customary living environment, it can be considered as the gold standard for measuring walking mobility (Pearson, Busse, van Deursen, & Wiles, 2004). The number of steps taken per day is shown to provide a reliable and valid outcome of free-living walking behaviour (Motl, Pilutti, Learmonth, Goldman, & Brown, 2013).

5. RESEARCH POPULATION

Part of the work in this doctoral thesis is performed in persons with Multiple Sclerosis (PwMS), in order to investigate the activity-related travel behaviour of this specific patient group in depth. In the other part of this thesis, it is determined which measures can be made to make to mobility system more inclusive, both for PwMS as for PWD in general, with different types and disability severities.

5.1. Persons with Multiple Sclerosis

5.1.1. Definition and prevalence

Multiple sclerosis (MS) is a progressive inflammatory and neurodegenerative chronic disease of the central nervous system, and one of the most common causes of neurological disability in young adults (Turpin, Carroll, Cassidy, & Hader, 2007). The disease onset starts mainly at young adult age (with an initial active life and travel pattern), while the progression of the disease is life-long and can be very unpredictable and various between and within PwMS. In most patients, MS is characterized initially by episodes of reversible neurological deficits, which is often followed by progressive neurological deterioration over time. The cause of MS is still unknown, but appears to involve a combination of genetic susceptibility and a non-genetic trigger (like a virus, metabolism or environmental factors), together resulting in a self-sustaining autoimmune disease that leads to recurrent immune attacks on the central nervous system. In MS, the myelinated axons in the central nervous system are attacked, destroying the myelin and the axons to varying degrees (Goldenberg, 2012) (Weinshenker, 1996) (Cree, 2007), leading to a slowed nerve signal transmission speed.

PwMS may be grouped into four major categories based on the course of the disease. *Relapsing-remitting MS* is the most common form, affecting about 85% of the MS population, and characterized by relapses or exacerbations of symptoms followed by periods of remission, when symptoms improve or (fully or partially) disappear. Relapsing-remitting MS may evolve to *secondary progressive MS*, by which the disease course continues to worsen with or without occasional relapses, minor remissions and plateaus. *Primary progressive MS* affects approximately 10% of PwMS, and is characterized by a gradual increase of symptoms from the onset of the disease, without relapses or remissions. *Progressive-relapsing MS* affects fewer than 5% of PwMS, and is progressive from disease onset, with intermittent relapses of worsening symptoms along the way, without remission (Lublin & Reingold, 1996) (Goldenberg, 2012).

The estimated prevalence rate of MS is 83 per 100 000 in Europe for the past three decades, with higher rates in northern countries and for women (ratio of two females for one male), and with the highest rates for the age group 35-64 years (Pugliatti, et al., 2006). The prevalence in Flanders, Belgium is estimated on 74 per 100 000 (Van Ooteghem, De Hooghe, Vlietnick, & Carton, 1994).

5.1.2. Symptoms and activity limitations

Because of the location and extent of nerve demyelination lesions in the central nervous system differ across PwMS, a variety of clinical symptoms may occur. MS is characterized by multiple symptoms in different neurological systems, of which commonly affected domains in MS include mobility, hand function, vision, fatigue, cognition, bowel and bladder function, sensory, spasticity, pain, depression, tremor and coordination. The majority of PwMS perceive at least some degree of

impairment in most domains immediately after disease onset, while the severity of impairment increases with disease duration across all domains. Within the first year after onset, already 81% of PwMS reported symptoms of unexplained fatigue, while 50% reported symptoms of affected mobility (Kister, et al., 2013).

Research into the body functions/structures and activity level (ICF framework) of PwMS is well elaborated. Regarding outcome measures on participation level, specific difficulties with activities related to all aspects of daily life in MS (Lexell, Iwarsson, & Lexell, 2006) (Einarsson, Gottberg, Fredrikson, Koch, & Widén Holmqvist, 2006) (Salter, Cutter, Tyry, Marrie, & Vollmer, 2010), including its social and employment impact (Hakim, et al., 2000) (Phillips & Stuifbergen, 2006), were previously described by using self-report methods. Community walking and PA was measured by questionnaires and accelerometry (Motl, McAuley, Snook, & Scott, 2006) (Gijbels, et al., 2010); while driving ability was investigated by computerized driving tests (Schultheis, Garay, & DeLuca, 2001). However, activity-related travel behaviour in MS in general has rarely been examined before, while it may serve as an ecological valid measurement of a person's functioning in daily life within the community, likely influencing quality of life.

The patient group MS is chosen because of the occurrence of multi-dimensional symptoms of various severities, involving both young and older persons (as MS occurs during the complete life span), and (work) active and less active persons. In this way, MS may serve as a useful model to investigate the possible effects of different symptoms on activity-related travel behaviour, and might have a useful application in other neurological diseases with (partly) similar symptoms (e.g. brain injury and stroke).

5.1.3. Disease severity

The Expanded Disability Status Scale (EDSS) is one of the most widely utilized assessment instruments (in clinical studies) to describe and evaluate disability in MS, and is based on a standard neurological examination of different functional systems (Kurtzke, 1983). The score ranges from 0 (normal neurological exam) to 10 (death due to MS), with a higher score indicating a higher disability level. The lower end of the range refers to PwMS who are fully ambulatory, while the middle and higher end (moderate to severe disability) are defined by the impairment to ambulation.

The Disease Steps (DS) describes and evaluates ambulatory dysfunction in MS, and is based on a simple general physical examination and the assistive devices needed to walk 25 feet (7.62 meters) (Hohol, Orav, & Weiner, 1995). The score ranges from 0 (normal) to 6 (essentially confined to a wheelchair), with a higher score indicating a higher disability level. The DS has high associations with the

EDSS (Hohol, Oray, & Weiner, 1999), with more consistent intervals regarding the ambulatory dysfunction represented by the different grades.

The EDSS and DS are shown in Figure 6.

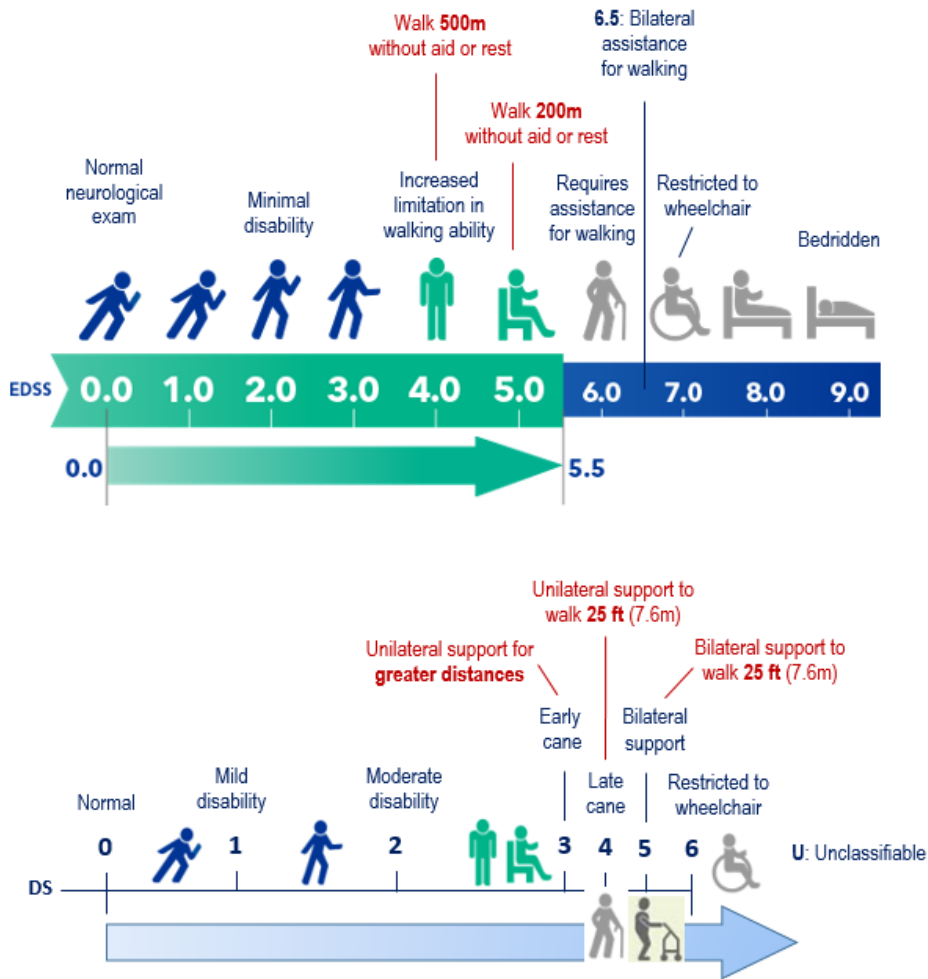


Figure 6: Classification of (ambulatory) dysfunction by Expanded Disability Status Scale (EDSS) and Disease Steps (DS)

5.2. Persons with disabilities

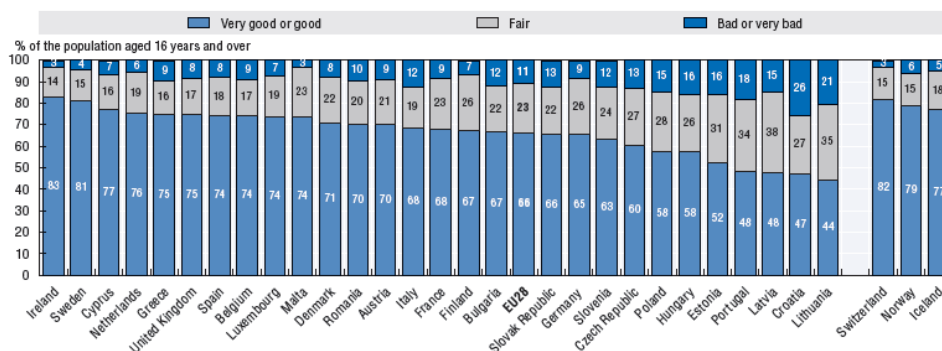
The target group of PWD is difficult to describe within a general population. The population of PWD is often delineated based on various diagnostic criteria and definitions, used by different actors (e.g. doctors, social workers, psychologists) in very different social contexts (benefit schemes, agencies for disabled persons, among others). The use of various instruments causes that diverse results about

the number of PWD may be obtained, which cannot be compared between regions. A classification of PWD based on diagnostic criteria must therefore be seen as a flexible outcome, resulting from time and culture bound assessment processes (Stone, 1984). Another way to estimate the number of PWD is based on the number of benefits or allowances that are provided to persons based on the basis of disability. However, this method is somewhat inaccurate as well, since not all PWD receive allowances, and some PWD receive different allowances. In general, PWD are defined as persons who have long-term physical, mental, intellectual or sensory impairments which, in interaction with personal and environmental barriers, hinders their full and effective participation in society on an equal basis with others.

Generally, it is stated that in modern Western societies about one third (33%) of the entire population suffers from a health disorder, that one third of persons with a disorder has an activity limitation (11%), and that again one third of them experiences serious participation restrictions (3-4%) by which their normal role fulfillment in the society (given age, gender and socio-cultural background) is limited (Wood & Badley, 1984).

Population surveys sometimes include questions about perceived general health status of respondents, whether they have a chronic illness and/or whether they are limited in usual activities because of their health problems – which have found to be a good predictor of people's future health care use (Bond, Dickinson, Matthews, Jagger, & Brayne, 2006). As responses may be affected by social and cultural factors, or differ between answer categories, cross-regional or -country differences in perceived health status can however be difficult to interpret. On average, 11% of adults in the European Union recently reported to be in bad or very bad health (OECD, 2014), as shown in Table 2 and corresponding to the one third rule of persons experiencing activity limitations.

Table 2: Self-reported health status, 2012



Source: EU-Statistics on Income and Living Conditions survey

Some results from the BELDAM (BELgian DAily Mobility) study (Cornelis, et al., 2012), the Belgian travel behaviour study, are shown in Table 3. In average, 11% of the Belgian population experiences some difficulties with using specific travel modes like walking, cycling, driving a car or getting in or out a PT vehicle.

Table 3: Selection of results, BELDAM: difficulties with using specific travel modes

TRAVEL MODE/TASK	No problem	Possible, but difficult	Possible with assistance	Impossible
Walking	89%	9%	1%	1%
Cycling	86%	6%	1%	8%
Get in/out a car	93%	6%	1%	1%
Driving a car	84%	2%	0%	14%
Get in/out a PT vehicle	91%	7%	1%	2%

Because of the described uncertainties and lack of accurate figures regarding the number of PWD, in this doctoral thesis a synthetic population of PWD for the region of Flanders (Belgium) was built.

5.3. DRT service providers in the region of Flanders

In order to enable PWD to fully participate in society, disabling situations or contexts should be limited as much as possible. Recently, increasing attention is being paid to the inclusivity of the mobility system, in terms of e.g. more accessible PT vehicles and stations and more accessible design of public space, but there is still considerable room for improvement. As several countries started to develop disability discrimination legislation for transport authorities to provide transport to PWD in the 1970s-1980s (Nelson, Wright, Masson, Ambrosino, &

Naniopoulos, 2010), many Demand Responsive Transport (DRT) services were being developed to meet this transport challenge. DRT services may be considered as transport on demand from passengers, using fleets of vehicles scheduled to pick up and drop off people in accordance with their needs (Grosso, Higgins, Mageean, & Nelson, 2002), and are frequently offered in the context of door-to-door transportation of elderly and PWD.

As DRT services are expensive to provide and thus costly for individual consumers or for society (in case of subsidized transport by the government), it is imperative to maximize its efficiency, given its increasing importance with social participation enhancement of PWD as ultimate goal.

In the last two studies of this doctoral work, a case study of DRT service providers in the region of Flanders (Belgium) was applied. The research population of DRT service providers in Flanders consisted on the one hand of 'Less Mobile Services' (LMS), voluntary organizations relying on a limited number of volunteers who use their own passenger car to offer transportation services to PWD in their neighborhood. On the other hand, the research population consisted of geographically dispersed 'Adapted Transport Services' (ATS), service providers subsidized by the Flemish government and using a heterogeneous fleet of vehicles with at least one adapted vehicle, also suitable for transporting persons in a wheelchair.

6. THESIS OUTLINE

6.1. Overview of aims and studies in doctoral thesis

The aim of this doctoral thesis is to provide more insights into the activity-related travel behaviour of PWD. In a first track, we aim to document on a detailed level the activity-related travel behaviour in PWD with different disability level (*Mapping mobility*). In a second track, we investigate the impact of both health condition, measured on different levels of the ICF framework, and contextual personal and environmental factors, on this travel behaviour (*Explaining mobility*). In a third track, we determine which policy decisions regarding adapted transport services can be made to make the mobility system more inclusive, while guaranteeing its financial sustainability (*Supporting mobility*).

In the tracks about mapping and explaining mobility, we will look more in detail to the activity-related travel behaviour, and influencing factors, of one specific patient group, i.e. persons with Multiple Sclerosis. Choosing a well-defined patient group as research population enables us to investigate their behaviour in depth (e.g. by looking at the impact of specific symptoms), as it would be too broad to include all persons with all kinds of different impairments in these tracks. For example, the approach for measuring activity-related travel behaviour in persons with severe intellectual problems would be different from persons with physical

problems, making a comparison between both types of disability impossible. As the patient group MS involves persons with possible multi-dimensional symptoms of various severities, and various life characteristics, it can serve as a useful model to investigate the activity-related travel behaviour in depth.

In the track of supporting mobility, the results will be generalized to the larger population of all PWD (with all types and severities of disability, e.g. including sensory and intellectual impairments, among others). Although the travel patterns and/or experienced problems may be different between different patient groups (and are thus investigated in detail in MS as research population), it is important to develop measures to support their travel behaviour for the full population of PWD, as the majority of supporting measures are beneficial for different groups of PWD. In this way, the measures will probably be more cost-efficient as economies of scale can be achieved (e.g. by combing trips of several PWD).

The outline of this doctoral thesis is shown in Figure 7.

Firstly, the activity-related travel behaviour is mapped and explained in detail in the patient group of PwMS.

In **chapter 1**, an exploratory pilot study was performed to get more insights into the activity-related travel behaviour in MS, and in the appropriateness of the used outcome measures and study design. The activity-related travel behaviour of 36 PwMS with different overall disability level and 24 age-/sex-matched healthy controls was documented by using a combination of subjective self-report activity-related travel diaries and objective GPS tracking devices. *The present methodology offered detailed information about their actual outdoor travel behaviour, which was significantly changed in PwMs with moderate to severe disability.*

Chapter 2 describes the results of a large-scale study of 108 PwMS with various disability severity, in line with the disease severity of Flanders, and living in both residential and community settings, in both rural and urban areas in various provinces. The study assessed the specific impact of health condition (physical, cognitive and psychosocial functioning) as well as contextual (personal and environmental) factors on the activity-related travel behaviour in MS. *The results showed that enhancing community environments could be considered as approach to increase social participation in MS, as besides (physical functioning components of the) health condition, contextual personal and environmental factors as well seemed to be predictive for the activity-related travel behaviour in MS.*

In **chapter 3**, it is analyzed whether disease-related impairments contribute to the reporting rate of data collection methods in travel behaviour studies (subjective self-report travel diaries and objective GPS tracking devices), besides socio-demographic and trip-related characteristics. The reporting rate of both data

collection methods was analyzed in 108 PwMS with various disability severities during a seven days data collection period. *The results demonstrated that there was only limited influence of disease-related dysfunctions, and that self-report travel diaries seemed to be better suitable for persons with a higher disability severity.*

Chapter 4 provides more insights into the physical (walking) activity in MS by investigating the number of steps PwMS take, the number of steps they take at low and moderate intensity, and their walking activity duration for 2, 3, 6, 10, 12 and 14 uninterrupted minutes; all related to the degree of disability. Step data from the StepWatch Activity Monitor were collected for seven consecutive days in a subset of 64 PwMS, distinguished in a mild and moderate MS subgroup. *It was shown that PwMS need to be motivated to make steps for longer periods of time (minimal 10 uninterrupted minutes) at moderate intensity in their community setting, in order to comply with physical activity guidelines.*

Next, results of the activity-related travel behaviour are generalized to the larger population of PWD in a case study of Flanders, in order to support this behaviour.

In **chapter 5**, an optimization methodology is described, to analyze the minimal resource requirements of a Demand Responsive Transport (DRT) system in terms of vehicles and drivers required and total distance traveled, by means of a vehicle routing plan - taking into account heterogeneous users, heterogeneous vehicles and multiple geographically distributed depots. A microscopic simulation of the demand of PWD for transportation was applied over the whole service area. Specific travel data of PWD were collected by means of a survey that was distributed among 344 PWD. *The results of the Flemish case study showed that the new DRT system seemed unaffordable for the society, despite the applied optimization methodology.*

Chapter 6 aims to determine the impact of different policy decisions on the resource requirements of this DRT system: a more economical scenario, a more accessible public transport, more flexibility of the users, among others. The resource requirements were calculated for each of the considered scenarios and for the prediction years 2015, 2020 and 2030. *The results showed that changing the modal split, the realization of adequate public transport and an improved flexibility, seem to be key elements in Flanders to minimize the resource requirements.*

Based on the knowledge obtained by the previous chapters, the last chapter of this doctoral thesis discusses the main findings and (both policy and clinical) implications of the different studies. The chapter concludes with some recommendations for future research possibilities.

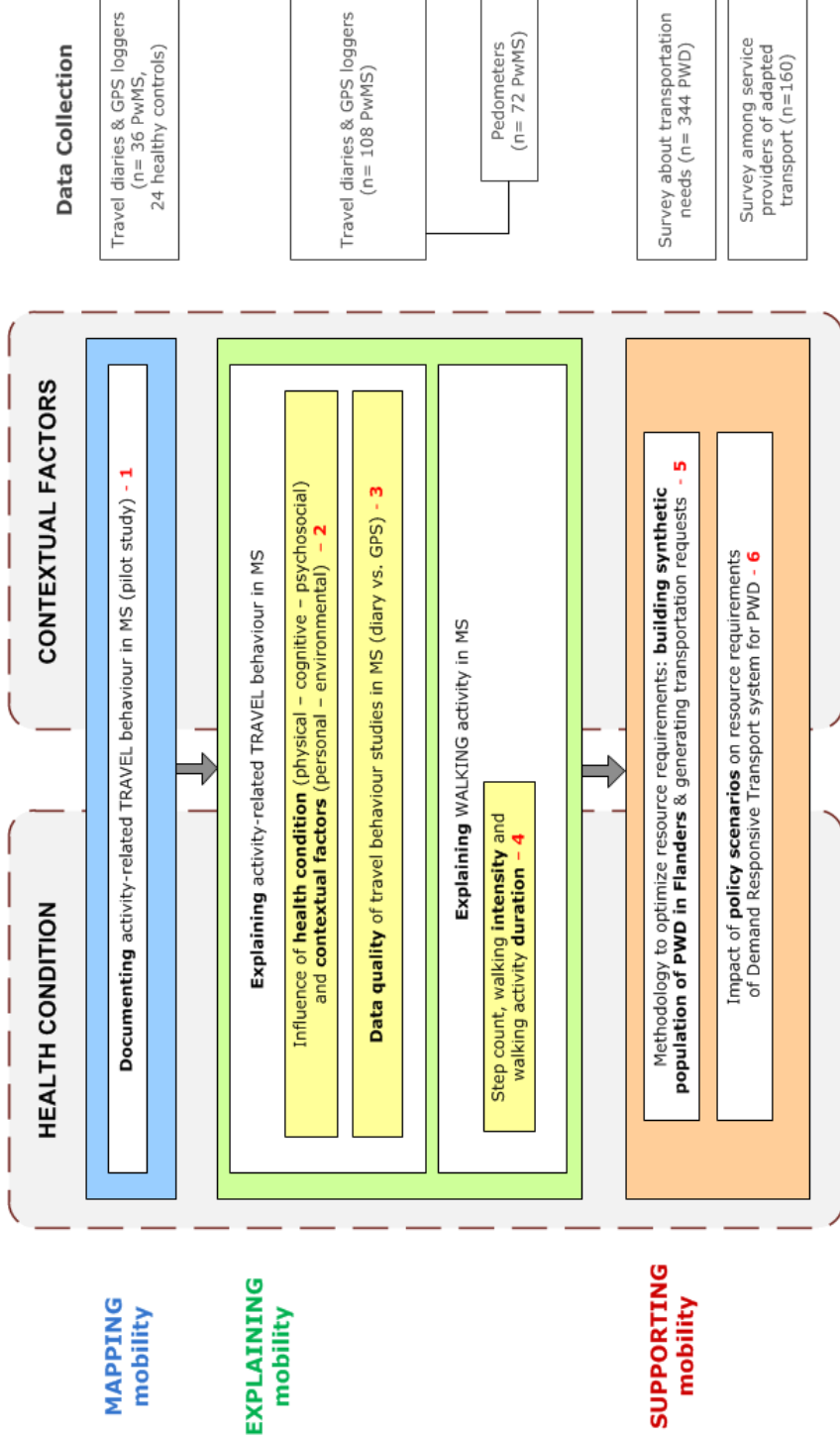


Figure 7: Outline of the doctoral thesis

6.2. Study designs, participants and outcome measures

An overview of the study designs and included (type and characteristics of) participants of each chapter is shown in Table 4.

An overview of the outcome measures used in the cross-sectional studies (chapter 1-4), according to the ICF framework, is shown in Table 5.

In order to get a complete overview of the health condition of participants, some measures were conducted on the body functions and structures level; some on the activity level (in a standard environment); and others between the activity and participation level (what a person actually does in his usual environment). In order to better understand the main focus of these health-related outcome measures, we have labeled the outcome measures as being physical, cognitive, or psychosocial. As well, we have indicated whether the outcome measures were performance-based (by objective observation of functional capacity by the researcher) or self-reported (reported by the participants themselves). Besides, a number of contextual personal and environmental factors were applied in the different studies.

Table 4: Overview of the study designs and participants characteristics of the different studies

Study design	Participants				
	Type	n	Inclusion criteria	Exclusion criteria	Disability severity
1	Cross-sectional	PwMS 36 HC 24	Diagnosis of MS Minimal one outdoor trip/week Age-/sex-matched	Corticosteroid 1 month before Additional non-MS related health problems	Mild: EDSS 1.5 - 4 (n=17) Mod: EDSS: 4.5 - 6.5 (n=8) Severe: EDSS > 6.5 (n=11)
2	Cross-sectional	PwMS *	Diagnosis of MS Minimal one outdoor trip/week	Corticosteroid 1 month before Additional non-MS related health problems	Mild: DS ≤ 2 (n=51) Mod: DS 3-4 (n=27) Severe: DS 5-6 (n=30)
3	Cross-sectional				
4	Cross-sectional	PwMS ‡ 72	Diagnosis of MS Minimal one outdoor trip/week	Corticosteroid 1 month before Use of wheelchair for all outdoor trips	Mild: DS ≤ 2 (n=31) Mod: DS 3-5 (n=33)
5	Methodological	PWD ** 344 Providers 160	Having a disability Providing adapted transport in Flanders	/	Range of different severities
6	Impact analysis				

PwMS: Persons with Multiple Sclerosis, HC: Healthy Controls, PWD: Persons with Disabilities, EDSS: Expanded Disability Status Scale, DS: Disease Steps. * The same subjects were included in chapter 2 and 3. ‡ Part of the subjects of chapter 2/3 were included in chapter 4. ** The same subjects were included in chapter 5 and 6.

Table 5: Overview of the outcome measures, according to the ICF framework, performed in the cross-sectional studies

Outcome measures used in cross-sectional studies	Level of ICF framework			Type of measure		Chapter			
	Body functions & structures	Activities	Activities & Participation	Performance-based	Self-report	1	2	3	4
TRAVEL BEHAVIOUR									
Activity-related travel behaviour (trips)			X	X	X	X	X	X	X
Walking activity			X	X					X
HEALTH CONDITION									
Type of MS					X	X			X
Disease duration					X	X	X	X	X
Expanded Disability Status Scale (EDSS)	X	X		X					X
Disease Steps (DS)	X	X		X				X	X
Multiple Sclerosis Functional Composite (MSFC)	X	X		X				X	X
Physical functioning									
Timed 25-Foot Walk Test (T25FW)		X		X		X	X	X	X
Nine Hole Peg Test (9HPT)		X		X		X	X	X	X
MS Walking Scale 12 (MSWS12)		X	X	X	X			X	X
36-Item Short Form Health Survey (SF-36)			X	X				X	X
Cognitive functioning									
Repeatable Battery for Assessment of Neuro-psychological Status (RBANS)		X		X		X			X

Outcome measures used in cross-sectional studies	Level of ICF framework			Type of measure		Chapter			
	Body functions & structures	Activities	Activities & Participation	Performance-based	Self-report	1	2	3	4
Dot Cancellation Test		X		X		X			
Trail Making Test (TMT)		X		X		X	X	X	
Paced Visual Serial Attention Test (PVSAT)		X		X		X	X	X	X
Psychosocial functioning									
Modified Fatigue Impact Scale (MFIS)	X	X			X	X	X	X	X
Hospital Anxiety & Depression Scale (HADS)	X				X	X	X	X	
Frenchay Activities Index (FAI)			X		X		X	X	
36-Item Short Form Health Survey (SF-36)			X		X		X	X	X
CONTEXTUAL FACTORS									
Personal									
Age, education, work					X	X	X	X	
Driving ability					X	X	X	X	
Household characteristics					X	X	X	X	
Environmental									
Degree of urbanization					X				X
Distance to bus stop					X				X
Distance to family, friends, rehabilitation and shops					X				X

MS: Multiple Sclerosis. ICF: International Classification of Functioning, Disability and Health.

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CHAPTER 1

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Documenting outdoor activity and travel behaviour in persons with neurological conditions using travel diaries and GPS tracking technology: a pilot study in multiple sclerosis.

An Neven¹
Davy Janssens¹
Geert Alders²
Geert Wets¹
Bart van Wijmeersch^{3,4}
Peter Feys³

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² REVAL - Rehabilitation Research Institute, Hasselt University, Diepenbeek, Belgium. Present address: Agoko nv, Neerpelt, Belgium.

³ REVAL - Rehabilitation Research Institute, BIOMED - Biomedical Research Institute, Faculty of Medicine and Life Sciences, Hasselt University, Diepenbeek, Belgium.

⁴ Rehabilitation & MS Center, Overpelt, Belgium.

ABSTRACT

Objective: Persons with Multiple Sclerosis (PwMS) experience several physical and cognitive problems which can influence their travel behaviour. This study aimed to document the number of activities, the activity type and the transport mode of the related trips that are daily made by PwMS. Their outdoor activity and travel behaviour was studied in relation to disease-related disability.

Methods: Thirty six PwMS (Expanded Disability Status Scale, EDSS, 1.5-8.0, age 27-63) and 24 healthy controls (age 25-62) were studied, using activity-related travel diaries and GPS tracking devices. Information about overall disability characteristics was gained by standard clinical tests and questionnaires. PwMS were further divided in three subgroups based on EDSS cut-off scores 4.5 and 6.5.

Results: Persons with mild ambulatory dysfunction (EDSS 1.5-4.0, n=17) showed similar travel characteristics to healthy controls, with few restrictions during travelling. Statistically significant changes in activity and travel behaviour were detected in the moderate (EDSS 4.5-6.5, n=8) and severe MS subgroups (EDSS >6.5-8.0, n=11) compared with healthy controls: driving independently became less frequent, significant more trips were made with company and the duration of performed activities had increased.

Conclusion: The combination of self-reported travel diaries and objective GPS loggers offered detailed information about the actual outdoor travel behaviour of PwMS, which was significantly changed in persons with Multiple Sclerosis with EDSS greater than 4.

Key words

GPS tracking technologies, Multiple Sclerosis, Travel.

1. INTRODUCTION

Multiple Sclerosis is a progressive inflammatory and neurodegenerative chronic disease of the central nervous system, and one of the most common causes of neurological disability in young adults (Turpin, Carroll, Cassidy, & Hader, 2007). MS is characterized by a combination of symptoms such as fatigue, memory and/or concentration problems, visual acuity, difficulties with movement execution because of muscular weakness, increased muscular tension and coordination problems, disorders of bladder and bowel functions, among others. Because of these physical and cognitive disorders, persons with MS (PwMS) may suffer progressively from walking difficulties (Vaney, Blaurock, Gattlen, & Meisels, 1996), a decreased driving ability (Schultheis, Garay, & DeLuca, 2001) and more dependence on the social environment for travelling (Einarsson, Gottberg, Frederikson, & von Koch, 2006). These consequences are thought to contribute to severe limitations in participating in daily life by means of social contacts, employment and leisure activities, which are all being reported to be decreased in MS (Lexell, Iwarsson, & Lexell, 2006). Specific difficulties with daily occupations in MS, like cleaning indoors, outdoors transportation, or social activities, were described formerly by using self-report methods. Finlayson et al. (n=430) indicated that the prevalence of activity limitations of PwMS varied by specific activity, by area of occupational performance and by type of MS (Finlayson, Impey, Nicolle, & Edwards, 1998). Lexell et al. (n=47) demonstrated that PwMS perceived difficulties with occupations related to all aspects of daily life (Lexell, Iwarsson, & Lexell, 2006), while the most frequently affected activities of daily living (ADL) could be classified as mobility-related and physically demanding according to Einarsson et al. (n=166) (Einarsson, Gottberg, Frederikson, & von Koch, 2006). Although 52% of the participants in this latter study were independent in personal ADL (self-care tasks, e.g. toileting, dressing, eating), only 30% were independent in instrumental ADL (more complex tasks such as communication, shopping, transportation) and 35% had a normal frequency of social or lifestyle activities. Hakim et al. (n=305) showed that MS had a profound impact on the social roles of PwMS and their relatives' well-being (Hakim, et al., 2000). In a study by Khan and Pallant (n=101), the majority of PwMS perceived a severe to extremely severe impact in moving outside home within the community and using transportation (Khan & Pallant, 2007). Because of these functional limitations, high rates of unemployment were frequently shown, e.g. Roessler et al., Philips et al., Paltamaa et al. (Roessler, Rumrill, & Fitzgerald, 2004) (Phillips & Stuijbergen, 2006) (Paltamaa, Sarasoja, Wikström, & Mälkiä, 2006).

Mobility, defined by the International Classification of Functioning (ICF) as *an individual's ability to move effectively in their own environment* (WHO, 2001), is clearly affected during the course of MS. If the travel possibilities of someone limit his/her participating in social life in an adequate manner (e.g. because of socio-economic position, age or physical/cognitive condition), this person suffers from decreased participation, inadequate integration on the labour market and financial impact, a loss of independence, a feeling of isolation and a lack of social interactions leading to reduced quality of life, and others (Finlayson & Denend, 2003) (Meert, 2003). Physical activity levels (Motl, McAuley, & Snook, 2005) and community walking (Gijbels, et al., 2010) of PwMS have increasingly being documented by means of questionnaires and accelerometry, of which the latter study was related to different MS disability levels, based on the Expanded Disability Status Scale (Gijbels, et al., 2010). However, as neither travel behaviour and mode, nor the influence of disease-related disability on travel in PwMS been documented, we could conclude that few data are available about their participation (restrictions) in daily outdoor activities (Wallace & Franc, 1999). Since MS predominantly starts at adult age and occurs during the complete life span, its population is characterized by a combination of young and older persons, (work) active and less active persons. As well, multi-dimensional symptoms of various severity occur so that MS may serve as a useful model to investigate the possible effects of different symptoms on travel behaviour. This model might have a useful application in other neurological diseases with (partly) similar symptoms (e.g. brain injury, stroke).

Overall, physical activity questionnaires show limited reliability and validity regarding the frequency of different activity types (e.g. respondents tend to indicate their highest recent, or their desired, rather than their true average frequency of participation) and the duration and amount of physical activity (problems of overestimates) (Shephard, 2003). As well, the measurement method may have a significant impact on the observed levels of physical activity, as self-report measures of physical activity generally differ with direct measures of physical activity (Prince, et al., 2008). Indeed, the accuracy of self-report surveys for measuring (physical) activity can be influenced by cognitive dysfunctions caused by MS like memory or emotional problems, e.g. depression (Gosney, Scott, Snook, & Motl, 2007). Commonly used activity questionnaires and diaries rely on recall and honest reporting, and require persons to have no or limited cognitive deficits to reduce potential bias in reporting results (Hale, et al., 2007). Depressed PwMS were three times more likely to perceive their disability as being greater than the measurement of physical instruments demonstrated

(Smith & Young, 2000). In the present study, a combination of subjective and objective measures was used for documenting outdoor activity and travel behaviour of PwMS. Mobility measures consisted of self-reported travel diaries to gain information about activities and trips made, and GPS loggers to obtain objective information about traveled routes and as a control instrument. In Israel and Germany, GPS tracking technologies have been used to analyse the mobility of persons with Alzheimer or related cognitive diseases (Shoval, et al., 2008), but similar instruments (to gather information on the spatial activity of persons) are currently only rarely applied.

Several papers have already been published about the challenges and changes in use of transport after a stroke, mostly focusing on public transport - by which a number of barriers were identified to have the potential to restrict autonomous outdoor mobility (e.g. infrastructure problems, lack of information, lack of self-confidence) (Wendel, Stahl, Risberg, Pessah-Rasmussen, & Iwarsson, 2010) (Risser, Iwarsson, & Stahl, 2012) (Logan & Dyas, 2004). To our knowledge, this is the first study documenting all aspects of outdoor travel behaviour in persons with neurological conditions like MS or stroke by use of as well self-reported travel diaries as well as objective GPS loggers. The objective of this study was to identify the activity and related travel behaviour of PwMS with different levels of severity, in terms of the number of activities, the activity type and the transport mode of the related trips that are daily made by PwMS. Their outdoor activity and travel behaviour was studied in relation to disease-related disability.

2. METHODS

2.1. Participants

36 persons with clinical definite MS (McDonald, et al., 2001), 14 men and 22 women, and 24 healthy age- and sex-matched control persons (average age of 47.62, SD 10.37, range 25-62), participated. PwMS with various degree of disability were included with criterion being the presence of at least minimal signs in functional systems (EDSS \geq 1.5) but still out of bed most of the day, and still making trips with a minimum of one trip each week. Exclusion criteria were a relapse or related corticosteroid treatment within one month before the study and/or additional non MS-related health problems restricting outdoor travel behaviour. PwMS were recruited in the existing network of PwMS of previous studies via researchers of the REVAL Rehabilitation Research Institute (PHL, UHasselt) and via care givers of the Rehabilitation and MS Centre Overpelt (Belgium), while control persons were recruited via students of Hasselt University. Candidates were carefully

informed about the study procedure and participated voluntarily. The study was approved by the Hasselt University Human Ethics Committee and conducted in accordance with the ethical standards from the Declaration of Helsinki (World Medical Association, 2008).

A research neurologist assessed the overall disability level of the PwMS, using the EDSS ranging from 0 (normal) to 10 (death), and determined the type of MS and potential other serious co-morbidities. PwMS were divided in three subgroups based on the EDSS describing overall disability while taking important ambulation dysfunction into account (Gijbels, et al., 2010). In the 'mild' subgroup, persons (n=17) with EDSS score of 1.5 to 4.0 were able to walk at least 500 meters without aid or some rest, in the 'moderate' subgroup PwMS (n=8) with EDSS score of 4.5 to 6.5 varied between requiring (unilateral or bilateral) assistance to ambulate 20 meters and being able to walk at least 300 meters without aid or some rest, while in the 'severe' subgroup persons (n=11) with EDSS score higher than 6.5 were unable to walk 5 meters or restricted to a wheelchair. Socio-demographic characteristics of healthy controls and PwMS by subgroup are summarized in Table 1, of which the division in usually used ambulatory devices was made according to the Hauser Ambulation Index (i.e. unilateral = cane or single crutch; bilateral = canes, crutches or walker) (Hauser, et al., 1983).

2.2. Experimental design and outcome measures

Both physical and cognitive function were assessed in order to investigate their relation to the number of daily activities and trips made, as well the transport modes used (in)dependently. Control data of healthy persons without physical or cognitive limitations were recorded for comparison.

In this observational study, there were 2 individual contact moments with the PwMS in the research centers or at the persons' home locations: during the first contact, clinical tests for physical, cognitive and psychosocial functioning were taken and activity and travel measures were thoroughly explained. PwMS then completed the travel diary and wore the GPS logger during the data collection period of 7 consecutive days. These mobility devices (travel diary and GPS logger) were additionally explained in a self-written manual and a permanent helpline was available. In the second meeting, the self-report indices and the GPS logger were returned. Control persons were asked to complete the travel diary and to wear the GPS logger for 7 consecutive days to gain similar information about their travel behaviour. Table 2 shows the clinical characteristics of PwMS by subgroup.

Table 1: Socio-demographic characteristics of persons with MS by subgroup and healthy controls.

Variable	Controls (n=24)	Mild (n=17)	Moderate (n=8)	Severe (n=11)
Gender (M/F)	8/16	5/12	5/3	4/7
Age (25-34/35-44/45-54/55-64)	4/5/7/8	2/6/6/3	1/3/1/3	0/2/5/4
Education (primary/ secondary/higher)	0/15/11	0/11/6	0/6/2	1/8/2
Work (full-time/half-time/ not working)	15/5/4	1/2/14	0/1/7	0/1/10
Living arrangements (alone/ with others)	1/23	1/16	0/8	3/8
Home (non-adapted/adapted/ ADL-houses)	24/0/0	17/0/0	5/3/0	6/1/4
Cars in household (0/1/≥2)	1/8/15	1/9/7	0/5/3	1/7/3
Driving ability (no/adapted/independent)	0/0/24	0/0/17	2/4/2	9/2/0
Ambulatory device (none/ unilateral/ bilateral/wheelchair)	24/0/0/0	17/0/0/0	3/3/0/2	0/0/0/11

2.2.1. Clinical outcome measures

The Multiple Sclerosis Functional Composite (MSFC) measured the ambulation/leg function, arm/hand function, and cognition (National Multiple Sclerosis Society, 2001). During the Timed 25-Foot Walk Test (T25FW) PwMS were instructed to walk 25 feet as quickly as possible, using their usual assistive devices. The 9 Hole Peg Test (9HPT), as test for manual dexterity, measured the time needed to put nine pegs in holes in a plastic board, and remove them again. The Paced Visual Serial Addition Test (PVSAT, maximal score of 60) measured working memory, attention and arithmetic capabilities. Persons were shown a number every 3 seconds and asked to say aloud the sum of the second last numbers. Additional information was obtained in some sub-domains using neurocognitive tests and psychosocial questionnaires. The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) measured cognitive decline in adults with a neurological disease (Duff, et al., 2008). In the Dot Cancellation Test persons had to cross out all groups of 4 dots on an A4 paper to measure their attention and concentration level. The Trail Making Test, measuring visual attention and task switching, recorded the time persons needed to connect 25 consecutive dots on a sheet of paper (numbers in Part A, numbers and letters in Part B). The impact of fatigue on daily functioning on the cognitive, physical and psychosocial level was measured by the Modified Fatigue Impact Scale (MFIS) (Kos, Nagels, D'Hooghe, Duportail, & Kerckhofs, 2006). The Hospital Anxiety and Depression Scale (HADS) questionnaire was used to assess the level of

depression and anxiety (Bambauer, Locke, Aupont, Mullan, & McLaughlin, 2005).

2.2.2. Mobility measures

To perform activities in society, it is imperative to travel to the destinations where activities take place, so both information about their trips and activities is required. A trip means an outdoor displacement which is identified by a clear activity motive (e.g. working, shopping), and can consist of one or several travel modes. A combination of self-reported travel diaries (Bellemans, Kochan, Janssens, Wets, & Timmermans, 2008) and objective GPS loggers was used to obtain a comprehensive understanding of the activity and travel behaviour of PwMS. In the diaries, persons had to indicate all information about their outdoor activities (e.g. activity type, start time, location) and resulting trips (e.g. travel mode, company). By use of the GPS loggers, more accurate information was obtained about traveled routes (trip distances, type of road, average speed) (Duncan, Badland, & Mummery, 2009) and the post-hoc processing of calculating traveled distances was facilitated. Moreover, the GPS logger was used as a mean of control to detect trips that were not filled out in the travel diaries (small or return trips), which can be important in PwMS because of their possible cognitive or adherence problems (Gosney, Scott, Snook, & Motl, 2007) (Hale, et al., 2007) (Smith & Young, 2000). The GPS logger, 747A+ 66-Channel GPS Trip Recorder (TranSystem Inc., Hsinchu, Taiwan), is a small device that uses signals from satellites to determine its current location and save these coordinates in memory. This logger had to be carried out for each outdoor trip in a handbag or trouser pocket, and persons were asked to charge it every three days. Both PwMS and healthy controls completed some questionnaires about their socio-demographic and mobility situation.

The collected data of the travel diaries and GPS loggers was combined in a trip database, of which a series of analyses was undertaken. Regarding the travel behaviour, the number of daily trips, the distribution of travel modes, the number of persons and trip distances were calculated. Regarding the activities, the time of day, the duration, the distinction between planned and spontaneous activities, and the activity types were analyzed. Activities were divided in one of the following categories: working, shopping (e.g. daily shopping or fun shopping), social and leisure (e.g. visiting friends, hobbies), bring or get activities (bringing or getting relatives or friends to somewhere, as well as bringing or getting things to somewhere, e.g. getting a package from the post office), personal care (e.g. rehabilitation, doctor), and other (e.g. services). Walking (either independently or with use of any

Table 2: Clinical characteristics of persons with MS by subgroup.

Variable	Subgroup 1 Mild (n=17)	Subgroup 2 Moderate (n=8)	Subgroup 3 Severe (n=11)	p-value for Mann Whitney comparison between subgroups		
				1-2	1-3	2-3
EDSS				< 0.01	< 0.01	< 0.01
+ Timed 25 Foot Walk (m/s)	3.1 ± 0.9 (1.5-4.0)	5.6 ± 0.8 (4.5-6.5)	7.1 ± 0.7 (6.5-8.0)			
Age	45.3 ± 9.3 (27-61)	47.8 ± 10.2 (34-62)	50.4 ± 7.8 (35-63)	0.638	0.164	0.535
Disease duration (years)	10.3 ± 6.1 (1-24)	17.0 ± 6.4 (9-28)	18.4 ± 11.2 (6-44)	< 0.05	< 0.05	0.836
MS Functional Composite						
+ Timed 25 Foot Walk (m/s)	1.3 ± 0.2 (1.0-1.6)	0.7 ± 0.4 (0.3-1.1)	0.1 ± 0.1 (0.0-0.3)	< 0.01	< 0.01	< 0.01
- 9 Hole Peg Test (s)	23.6 ± 5.1 (15.0-35.1)	35.1 ± 17.0 (22.4-69.0)	56.9 ± 41.6 (26.0-158.0)	< 0.05	< 0.01	0.100
+ Paced Visual Serial Addition Test	52.7 ± 11.7 (19-60)	50.3 ± 12.3 (28-60)	47.7 ± 15.6 (22-60)	0.459	0.573	0.922
Neurocognitive and psychosocial						
+ RBANS (Index score)	89.9 ± 12.2 (69-118)	86.5 ± 10.9 (74-105)	83.6 ± 15.2 (64-114)	0.448	0.239	0.620
Dot Cancellation Test						
- Dot Cancellation Time (s)	447.1 ± 93.1 (306-665)	565.5 ± 189.3 (366-839)	587.2 ± 223.3 (358-900)	0.244	0.097	0.789
+ Dot Cancellation Positives (n)	202.8 ± 10.6 (178-213)	186.8 ± 17.6 (160-209)	175.4 ± 39.5 (74-213)	< 0.05	< 0.01	0.657
Trail Making Test						
- TMT Numbers	30.2 ± 12.3 (19-54)	50.5 ± 23.8 (24-81)	58.6 ± 28.9 (20-112)	< 0.05	< 0.05	0.509
- TMT Numbers & Letters	61.7 ± 26.2 (17-99)	98.2 ± 47.3 (44-199)	146.9 ± 108.0 (45-356)	< 0.05	< 0.05	0.322

Variable	Subgroup 1 Mild (n=17)	Subgroup 2 Moderate (n=8)	Subgroup 3 Severe (n=11)	p-value for Mann Whitney comparison between subgroups		
				1-2	1-3	2-3
Modified Fatigue Impact Scale						
- Total MFIS	39.4 ± 10.7 (25-56)	38.0 ± 17.3 (16-62)	51.2 ± 9.0 (32-63)	1.000	< 0.01	0.126
- Physical component	20.0 ± 5.8 (11-30)	22.9 ± 6.4 (12-30)	24.9 ± 4.4 (20-36)	0.283	< 0.05	0.739
- Cognitive component	15.4 ± 5.7 (8-24)	11.8 ± 11.4 (0-29)	21.0 ± 6.6 (7-29)	0.220	< 0.05	0.082
- Psychosocial component	4.0 ± 1.8 (1-6)	3.4 ± 2.1 (0-6)	5.3 ± 1.0 (4-8)	0.514	0.132	< 0.05
Hospital Anxiety & Depression Scale						
- Total HADS	19.3 ± 3.5 (14-27)	10.5 ± 7.3 (1-22)	14.4 ± 5.1 (7-25)	< 0.01	< 0.01	0.185
- Anxiety component	10.4 ± 2.4 (7-16)	5.5 ± 4.1 (0-12)	6.8 ± 3.2 (4-13)	< 0.01	< 0.01	0.559
- Depression component	8.9 ± 2.0 (6-13)	5.3 ± 3.0 (1-10)	7.6 ± 2.7 (3-12)	< 0.01	0.175	0.100

Values are mean ± standard deviation (SD) (range).

assistive device), driving or cycling around without destination is also seen as a trip, and was classified as social and leisure activity.

2.3. Statistical analysis

Numerical data were analysed using SPSS Statistics version 17.0 for Windows. A series of descriptive analyses was undertaken on the basis of the questionnaires and travel diaries, where the results were presented as means, standard deviations (SD) and range. To examine the differences between the MS subgroups separately, as well differences between the MS subgroups and the healthy control sample, non-parametric Mann-Whitney tests for independent samples were used. Pearson Chi-Square Tests were used to examine differences in the distribution of socio-demographics characteristics between the MS subgroups and the healthy controls. Significance levels smaller than 0.05 (5%) were applied.

3. RESULTS

3.1. Socio-demographic and clinical characteristics of different MS subgroups

In Table 1, there were no significant differences between PwMS and healthy controls regarding their age, gender and educational level. As expected, significant differences could be observed between the MS subgroups regarding their arm/hand function, measured with the 9HTP, and their ambulatory function, measured with the T25FW (see Table 2). The level of sustained attention, as measured with the PVSAT, was not significant different between the MS subgroups, neither overall cognitive dysfunction as measured with the RBANS. Significant differences could be found in the sub-domains attention and concentration, as measured with the Dot Cancellation Test, and visual attention and task switching, measured with the Trail Making Test, both between MS subgroups mild - moderate and subgroups mild - severe. The impact of fatigue (MFIS) was significant higher in the severe MS subgroup compared to the mild subgroup for the total, physical and cognitive component, while the psychosocial component differed significantly between MS subgroups moderate - severe. Importantly, the level of anxiety and depression, according to the HADS results, showed a significant higher anxiety level for the mild MS subgroup compared to the other MS subgroups.

3.2. Travel behaviour

Table 3 shows the travel outcome measures of the PwMS and controls. The average daily number of trips was 4.2 (SD 1.4; range 2.0–6.86) in healthy controls, 91.2% of them traveled daily. The 36 PwMS performed a total of

836 trips during the one week monitoring period, of which the average daily number of trips per person amounted 3.3 (SD 2.0; range 0.1-8.3) and 80.2 % of them traveled daily. 29.4 % of the trips of PwMS were completed only with the GPS logger, compared to 9.1 % of the trips of healthy controls.

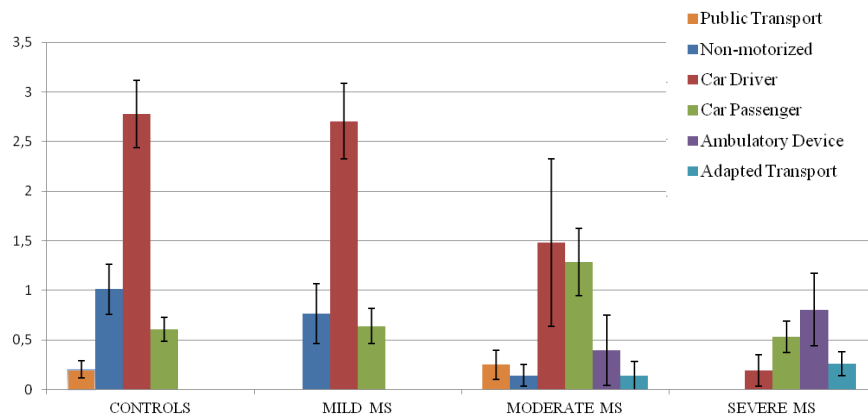


Figure 1: Average number of trips per day by travel mode by healthy controls and MS subgroups

No significant differences were found between persons in the mild MS subgroup and healthy controls regarding their number of trips, travel mode and company – except for the use of public transport. More than half of the trips was made alone, since persons in this MS subgroup were still able to walk or drive a car independently, with little interference with activities of daily living. Also persons in the moderate MS subgroup made most trips by car, as shown in Figure 1, but to a smaller extent as car driver. Short trips were mostly made by themselves in both MS subgroups (7.5 km and 8.1 km as car driver, respectively) but they appealed to family members for trips with longer distances (15.1 km and 22.3 km as car passenger). In healthy controls, distances traveled as car driver (average 9.2 km) and car passenger (9.9 km) were comparable. The average distance of all trips amounted 9.4 km for the mild MS subgroup, 13.1 km for both MS subgroups with moderate and severe disability level versus 9.0 km for healthy controls. Non-motorized travel modes like walking and cycling were used in 15.0% of all trips by persons with a mild severity, while these modes were barely used in the moderate subgroup and not used by persons with a severe disability. In the latter subgroup, adapted (wheelchair accessible) transport was mainly used for farther trips, while one third of the (mostly short) trips was made independently using an electric wheelchair or scooter. These trips, shorter than 0.5 km, were made by persons living in 'ADL-houses'

Table 3: Travel and activity outcome measures of persons with MS by subgroup and healthy controls.

Outcome measure	Controls (n=24)	Subgroup 1 Mild (n=17)	Subgroup 2 Moderate (n=8)	Subgroup 3 Severe (n=11)	p-value for Mann Whitney comparison between subgroups		
					1-2	1-3	2-3
TRAVEL BEHAVIOUR							
Number of trips per day	4.2 ± 1.4	4.2 ± 1.7	3.5 ± 2.3	1.8 ± 1.2 ^{††}	0.406	< 0.01	0.109
Travel mode (%)							
Car driver	62.3 ± 31.1	66.5 ± 28.5	25.4 ± 36.2 [†]	12.0 ± 31.6 ^{††}	< 0.05	< 0.01	0.360
Car passenger	13.7 ± 13.4	18.5 ± 20.7	54.2 ± 43.4 [†]	29.7 ± 27.1	0.066	0.386	0.237
Non-motorized	19.8 ± 20.7	15.0 ± 22.7	3.3 ± 7.3 [†]	0.0 ± 0.0 ^{††}	0.215	< 0.05	0.408
Public transport	4.3 ± 9.0	0.0 ± 0.0 [†]	5.2 ± 8.5	0.0 ± 0.0	0.140	1.000	0.203
Assistive device	0.0 ± 0.0	0.0 ± 0.0	8.6 ± 21.9 [†]	41.9 ± 45.4 [†]	0.344	< 0.05	0.203
Adapted transport	0.0 ± 0.0	0.0 ± 0.0	3.2 ± 9.1	16.4 ± 23.9 [†]	0.628	< 0.05	0.203
Number of persons (%)							
1 person	59.2 ± 20.8	64.1 ± 24.4	24.8 ± 33.2 [†]	34.6 ± 44.0	< 0.01	0.077	0.696
2 persons	31.0 ± 17.9	25.1 ± 19.7	63.2 ± 33.5 ^{††}	59.9 ± 40.7	< 0.01	< 0.05	0.897
More than 2 persons	9.8 ± 14.1	10.8 ± 11.7	12.1 ± 11.1	5.5 ± 9.3	0.742	0.286	0.237
Distance (%)							
Less than 0,5 km	4.0 ± 6.3	1.5 ± 4.0 [†]	1.0 ± 2.2	32.5 ± 42.9	0.887	0.223	0.408
0,5 km - 2 km	25.4 ± 19.7	25.1 ± 18.4	24.6 ± 23.9	10.0 ± 23.4 ^{††}	0.754	< 0.05	0.068
2 km - 10 km	40.1 ± 22.4	49.5 ± 25.5	57.8 ± 15.8 [†]	15.3 ± 14.2 ^{††}	0.288	< 0.01	< 0.01
10 km - 50 km	27.0 ± 21.6	22.4 ± 20.9	12.1 ± 14.9	37.6 ± 37.7	0.175	0.505	0.237
More than 50 km	3.5 ± 9.3	1.6 ± 4.0	45.0 ± 8.7	4.7 ± 12.6	0.440	0.902	0.633

Outcome measure	Controls (n=24)	Subgroup 1 Mild (n=17)	Subgroup 2 Moderate (n=8)	Subgroup 3 Severe (n=11)	p-value for Mann Whitney comparison between subgroups 1-2 1-3 2-3
ACTIVITIES					
Number of activities per day	2.6 ± 1.0	2.5 ± 1.1	2.1 ± 1.4	0.9 ± 0.6 ^{††}	0.344 < 0.01 0.075
Time of day (%)					
Before 12.00	47.7 ± 19.3	25.2 ± 17.0 ^{††}	38.9 ± 16.1	30.1 ± 30.3	0.086 0.786 0.573
12.00 - 17.00	32.2 ± 19.4	46.4 ± 22.9 [†]	45.5 ± 14.0	53.3 ± 22.9 [†]	0.798 0.749 0.696
After 17.00	20.2 ± 12.8	28.4 ± 24.9	15.7 ± 10.7	16.6 ± 20.1	0.262 0.115 0.897
Type of activity (%)					
Working	27.0 ± 22.5	4.0 ± 9.4 ^{††}	7.4 ± 14.0 [†]	5.0 ± 15.8 ^{††}	0.842 0.639 0.696
Shopping	24.4 ± 14.7	28.3 ± 21.6	15.6 ± 20.4	7.5 ± 9.1 ^{††}	0.075 < 0.05 0.460
Social and leisure	25.4 ± 18.3	36.8 ± 19.5	29.0 ± 19.2	47.2 ± 35.9	0.549 0.537 0.315
Bring / Get	12.8 ± 13.1	9.0 ± 12.1	16.5 ± 17.4	0.0 ± 0.0 ^{††}	0.344 < 0.05 < 0.01
Personal care	2.8 ± 4.7	12.0 ± 8.3 ^{††}	19.9 ± 12.7 ^{††}	31.7 ± 29.9 ^{††}	0.110 0.127 0.515
Other activities	7.7 ± 8.7	10.0 ± 6.7	11.6 ± 12.0	8.6 ± 11.9	0.887 0.309 0.573
Duration of activity (%)					
Less than 30 min	39.1 ± 22.1	26.2 ± 23.2	10.1 ± 13.8 ^{††}	3.6 ± 7.4 ^{††}	0.110 < 0.01 0.321
30 min - 1 hour	16.0 ± 11.2	27.5 ± 30.2	25.0 ± 10.7	17.0 ± 24.5	0.475 0.120 0.093
1 hour - 4 hours	22.6 ± 15.3	42.4 ± 32.2 [†]	50.8 ± 16.1 ^{††}	61.7 ± 28.9 ^{††}	0.315 0.164 0.423
More than 4 hours	22.4 ± 20.1	3.9 ± 6.9 ^{††}	14.1 ± 12.0	16.0 ± 20.0	< 0.05 0.127 0.829
Planning of activity (%)					
Planned	89.1 ± 12.4	81.6 ± 13.9	81.7 ± 22.8	91.4 ± 14.3	0.628 0.103 0.237
Spontaneous	10.9 ± 12.4	18.4 ± 13.9	18.3 ± 22.8	8.6 ± 14.3	0.628 0.103 0.237

Values are mean ± standard deviation (SD) (range).

Significant difference in result between healthy controls and MS subgroups: † p < 0.05; †† p < 0.01.

(adapted houses with assistance in their activities of daily living) nearby the Rehabilitation and MS Centre Overpelt, who went to the MS Centre for their daily rehabilitation, leisure or outdoor eating.

3.3. Activities

Most PwMS of this study didn't make work-related trips (anymore), but made frequently other recurrent trips to the fitness, physiotherapist or rehabilitation centre (i.e. the category 'personal care'), or performed some social or leisure activities as pastime. For persons who were still able to drive a car, a high number of trips was found for shopping, and bring or get activities. The average duration of all activities amounted 73.2, 107.0 and 129.2 minutes in the mild, moderate and severe MS subgroup respectively, compared to 108.5 minutes for healthy controls. While in the mild subgroup a quarter of the activities had a duration less than 30 minutes, hardly any activity in the severe subgroup took less than half an hour. Working, leisure and social activities had the largest duration. Most activities were performed during the day. Compared with other MS subgroups, more activities were taking place in the evening in the mild MS subgroup.

4. DISCUSSION

Persons with Multiple Sclerosis (PwMS) experience several physical and cognitive problems which can influence their activity and travel behaviour, however few data are available about their participation (restrictions) as well as its relation to their disease-related disability. This study investigated which, and how many, activities and trips were daily made by PwMS, and what transport modes were used (in)dependently, applying a comprehensive test battery including a combination of subjective self-report activity-related travel diaries and objective GPS tracking devices. 36 PwMS divided in three subgroups with different overall disability level and 24 healthy age- and sex-matched controls, were studied.

Persons with mild ambulatory dysfunction showed similar travel characteristics to healthy controls (number of daily trips and used travel modes), with few restrictions given that they were still physical active, and able to walk and/or drive independently. Statistically significant changes in activity and travel behaviour were detected in the moderate and severe MS subgroups, in line with previous literature about daily occupations (Lexell, Iwarsson, & Lexell, 2006) and employment in MS (Roessler, Rumrill, & Fitzgerald, 2004) (Phillips & Stuijbergen, 2006) (Paltamaa, Sarasoja, Wikström, & Mälikä, 2006). In the moderate MS subgroup, non-motorized travel modes were rarely used (usually because of fatigue, balance or other physical problems) and driving independently became more difficult,

resulting that more than half of the trips was made as a car passenger, in line with literature (Vaney, Blaurock, Gattlen, & Meisels, 1996) (Schultheis, Garay, & DeLuca, 2001). Significant more trips were made with company and the average duration of performed activities had increased. In the severe MS subgroup, a number of persons made an unexpected high number of independent trips by use of ambulatory devices (electric scooter or wheelchair). The discrepancy can be explained by the living environment, being their residence in the ADL-houses nearby the Rehabilitation and MS Centre, where several services (e.g. cafeteria, leisure activities, physiotherapy) in the immediate neighborhood could be reached by use of their ambulatory device. Other persons of this MS subgroup, not living in the ADL-houses, suffered from a very large dependency on family members for their trips, and had a significant lower average number of activities and trips compared to the mild MS subgroup and the healthy controls. Persons in this MS subgroup were relied on adapted transport for their travelling in 16% of the trips and only one tenth of the trips was made as a car driver with adapted car. The present methodology of travel diaries and GPS loggers was extensive, but offered detailed information about the actual outdoor travel behaviour of PwMS. Conventional used travel diaries are valuable as an important source of information on the (underlying motives of) activity types, which are the root cause of the making of trips. However, in patient profiles with a severe disability, cognitive dysfunctions might influence the accuracy of self-report diaries with more potential bias in reporting results (Gosney, Scott, Snook, & Motl, 2007) (Hale, et al., 2007) (Smith & Young, 2000). By use of the GPS logger, forgotten trips (received by the GPS logger but not filled out in the travel diaries) could be completed in the trip database, which appeared to provide added value for all subgroups. We discovered that indeed 29.4% of the trips of PwMS were completed only with the GPS logger, compared to 9.1% of the trips of healthy controls. In the former, this percentage was negatively correlated with the RBANS ($r = -0.42$; $p = 0.01$), indicating that PwMS with more cognitive decline forgot more often to fill out their trips in the travel diaries. The use of the GPS logger allowed obtaining more accurate information about traveled routes of the persons (trip distances, road types, average speed). As well, post-hoc processing of the data, i.e. calculating the traveled distances and trip duration, was facilitated because this could be done electronically. Otherwise, being required to carry the GPS logger and to remember switching it on during trips, as well as recharging frequently, was an additional burden for the persons. In a few PwMS it has happened that the GPS logger ran out of battery and some trips were not recorded. Furthermore, the data collection was dependent on the reception of satellite signals and loss of GPS data was possible due to signal drop out. Although

the GPS technology gives a much deeper understanding of the spatial activity and movement behaviour of persons (Shoval, et al., 2010), travel diaries should still be used complementary, as was shown in this study.

As travel limitations and choice of transport mode might not be solely caused by physical disability, also cognitive tests were applied. Both the Dot Cancellation Test and the Trail Making Test were able to differentiate between the MS subgroups. However, in this study, we don't think that overall cognitive dysfunction is a major factor explaining travel differences between MS subgroups. In each MS subgroup a number of persons with a clear cognitive dysfunction could be observed (as indicated by lower ranges on the PVSAT and RBANS) but there were no significant differences between the MS subgroups. The initial goal of this study was to determine whether cognitive or physical impairments contributed significantly to travel behaviour, but however, the number of PwMS in each subgroup proved to be too small to demonstrate statistical relationships. Therefore, a large number of tests were included, of which most showed significant differences between subgroups indicating the increasing (presence of) physical or cognitive dysfunction, which is a justification of our selection of tests. Advanced statistical analyses are needed in a follow-up research in a very large sample, to test the influence of cognitive or physical impairments on travel behaviour with a larger number of PwMS in each subgroup.

Trip data was complemented by objective GPS loggers, which provided the results to be more accurate. It is acknowledged that more impaired cognitive dysfunction related to visual attention, concentration and task switching was present in the more severe disabled subgroups, but data was accurate as also family members sometimes assisted in complementing the questionnaires. Another clinical observation may however have influenced the results of especially the mild MS subgroup, as anxiety feelings were greatest in this subgroup, in line with literature (Janssens, et al., 2003). Anxiety is, besides physical and cognitive dysfunction, recently demonstrated to affect driving ability (reduced divided attention) in MS (Devos, Brijs, Alders, Wets, & Feys, 2013). Persons in the mild subgroup, when driving themselves, made shorter distances compared to travelling as car passenger, that may be explained by uncertainty feelings about their physical and cognitive functioning.

A number of limitations need to be considered for follow-up research. With the small and unequal sample size in the different subgroups, caution must be applied, as the findings might not be generalized to the general MS population. Subgroup differences should not only be constrained to the

clinical characteristics of the persons, but also to their socio-demographic and environmental situation. Persons with mild ambulatory dysfunction didn't make use of public transport in this research, which was likely not (only) due to their physical health condition, but also because of the accessibility and/or availability of public transport in their living environment. Compared with healthy controls, significant differences regarding the activity timing, type and duration could be explained by the fact that most persons in the mild MS subgroup didn't work anymore (by which their work-related trips were mostly replaced by social or leisure activities). As such, the convenience sample of this pilot study may not be a perfect representative representation of PwMS (Kobelt, et al., 2006). In the severe MS subgroup, selection bias also affected the generalizability of the results, because of the major number of PwMS living nearby the Rehabilitation and MS Centre (see earlier) causing a high number of independent trips.

Future studies in larger samples are needed to be able to assess the specific and relative impact of disease-related psychological, visual, cognitive and physical factors on the activity and travel behaviour in patient profiles with various disability severity. As well, socio-demographic variables (like living and working condition) and environmental factors, such as accessibility, transportation or financial restrictions (Kobelt, et al., 2006), as well as other personal barriers, likely influence the activity and travel behaviour. When all key factors that influence the changed (decreased) activity and travel behaviour are correctly identified, suitable policy guidelines for interventions can be defined to optimize the travel behaviour, transport modality as well as supply in order to enhance social participation in daily life.

Implications for rehabilitation

- Activity and travel behaviour changes significantly in persons with Multiple Sclerosis (MS) with moderate to severe disability (EDSS greater than 4).
- Behavioral therapy could help to develop better coping and problem-solving skills to overcome anxiety in the making of trips by persons with MS with a mild severity.
- Enhancing community environments could serve as a promising approach to increase the outdoor participation of persons with (more severe) impairments.

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CHAPTER 2

Journal of Rehabilitation Medicine. 1st review.

Influence of health condition and contextual factors on activity-related travel behaviour in Multiple Sclerosis.

An Neven¹

Davy Janssens¹

Geert Wets¹

Karl Beirlant²

Barbara Willekens^{3,4}

Paul Van Asch⁵

Hilda Reijnders⁶

Peter Feys⁷

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² National MS Center, Melsbroek, Belgium.

³ Antwerp University Hospital (UZA), Edegem, Belgium.

⁴ De Mick, Rehabilitation Center, Brasschaat, Belgium.

⁵ Fit Up, Kontich, Belgium.

⁶ MS Society Flanders, Overpelt, Belgium.

⁷ REVAL - Rehabilitation Research Institute, BIOMED - Biomedical Research Institute, Faculty of Medicine and Life Sciences, Hasselt University, Diepenbeek, Belgium.

ABSTRACT

Objectives: 1. To investigate to which degree the activity-related travel behaviour in Multiple Sclerosis (MS) does decrease with increasing ambulatory dysfunction and 2. to assess the impact of health condition and contextual factors on activity-related travel behaviour in MS.

Methods: 108 persons with MS participated, distinguished in three disability subgroups. Health condition was assessed by standardized clinical tests about physical, cognitive and psychosocial functioning. Contextual factors (personal and environmental) were collected.

Activity-related travel diaries and GPS tracking devices were used to investigate activity-related travel behaviour in terms of number of trips and transport modes used. The influence of health condition measures and contextual factors with activity-related travel behaviour measures was analyzed using Spearman correlations and multiple linear regressions.

Results: 1. Activity-related travel behaviour in MS decreased significantly with increasing ambulatory dysfunction. Significant changes were found regarding travel modes, number, type and planning of activities. 2. Activity-related travel behaviour in MS correlated with both health condition measures and contextual factors. A limited number of standardized tests of health condition and contextual factors (driving ability, household size) can predict activity-related travel behaviour in MS.

Conclusion: Both health condition (mostly physical functioning) and contextual factors are predictive for activity-related travel behaviour in MS.

Key words

MS (Multiple Sclerosis), Participation, Travel, Activities of Daily Living.

1. INTRODUCTION

Multiple Sclerosis (MS), a progressive inflammatory and neurodegenerative disease of the central nervous system, is characterized by various physical, cognitive and psychosocial impairments that may impede social participation. Indeed, difficulties with activities related to all aspects of daily life (Salter, Cutter, Tyry, Marrie, & Vollmer, 2010) (Lexell, Iwarsson, & Lexell, 2006) (Einarsson, Gottberg, Frederikson, & von Koch, 2006), including its social and employment impact (Hakim, et al., 2000) (Phillips & Stuijbergen, 2006) and barriers obtaining adapted transportation (Roessler, et al., 2013), were previously described in persons with MS (PwMS) by using self-report methods. Community walking and physical activity in PwMS was shown, by means of questionnaires and accelerometry, to be decreased (Gijbels, et al., 2010) (Motl, McAuley, Snook, & Scott, 2006). Driving ability was investigated, mostly measured by tests in a driving simulator or by computerized driving tests, showing that PwMS performed worse than healthy controls on divided attention (Devos, Brijs, Alders, Wets, & Feys, 2013), and that cognitive impairment negatively affected driving-related skills (Schultheis, Garay, & DeLuca, 2001).

However, activity-related travel behaviour in MS in general, including the trips PwMS make in real-life, the use of travel modes (including trips by foot, bicycle, specialized transport, assistive devices), traveled distances, among others; has rarely been examined. Previous studies have been conducted with individuals after stroke by semi-structured interviews, indicating an affected use of modes of transport post-stroke (Wendel, Stahl, Risberg, Pessah-Rasmussen, & Iwarsson, 2010); but few data are available about the (changes in) activity-related travel behaviour in PwMS. Being able to travel is a prerequisite to participate in social life, as individuals have a need to perform activities, requiring travelling to the destination of this specific activity. If personal travel possibilities limit this participating, persons may suffer from inadequate integration on the labour market or other participation restrictions, with financial and social impact, leading to reduced quality of life (QoL).

Activity-related travel behaviour in MS has only been documented in a recently published small pilot study with 36 PwMS and 24 healthy controls (Neven, et al., 2013). It was shown that PwMS with mild ambulatory dysfunction had similar travel characteristics as healthy controls, while significant changes were detected in PwMS with more advanced stages of the disease. However, this descriptive study did not investigate the determinants of activity-related travel behaviour. Knowledge about these key factors influencing changes in activity-related travel behaviour is

necessary in rehabilitation, in order to define guidelines for interventions to optimize this, with social participation enhancement as ultimate goal. Measures of the activity-related travel behaviour may also be used as benchmarks in patients with different levels of ambulatory dysfunction, to detect whether patients are approximately participating as expected.

Previous studies in healthy persons found significant relationships between the activity-related travel behaviour and contextual (personal) factors like income level, age and household structure, among others (Contrino & McGuckin, 2009) (Syam, Khan, & Reeves, 2012). Previous studies with persons after stroke as well indicated that contextual personal and environmental factors (e.g. lack of company) influenced outdoor walking post-stroke (Barnsley, McCluskey, & Middleton, 2012). Therefore, we hypothesize that besides the health condition, also such contextual factors may impact the activity-related travel behaviour in MS.

Therefore, the present study 1. investigated to which degree the activity-related travel behaviour in MS does decrease with increasing ambulatory dysfunction. As well, this study 2. assessed the impact of health condition (physical, cognitive and psychosocial functioning) as well as contextual factors (personal and environmental) on the activity-related travel behaviour in MS. Activity-related travel behaviour was measured in terms of number of trips and transport modes used (in)dependently in their usual environment. A trip means an outdoor displacement which is identified by a clear activity motive (e.g. working, shopping), and can consist of one or several travel modes.

2. METHODS

2.1. Participants

108 persons with clinical definite MS, based on Poser diagnostic criteria (Poser, et al., 1983), gave written informed consent and participated. The study was approved by the ethical committees of Hasselt University, Rehabilitation Center Overpelt, Antwerp University Hospital and National MS Centre Melsbroek. PwMS were recruited based on databases of the REVAL (Rehabilitation Research Center, UHasselt), by neurologists of the rehabilitation centers, and after information sessions in an MS-specialized fitness center (Fit Up, Kontich) and support groups of the MS Society Flanders. PwMS had to make minimal one trip weekly, and were excluded if they were bedridden, or had a relapse or related corticosteroid treatment within one month before the study.

PwMS were divided in three subgroups, according to their Disease Steps (DS) describing ambulatory dysfunction (Hohol, Orav, & Weiner, 1995). The DS is a simple and brief clinical rating scale, based on a general physical examination and the assistive devices needed to walk 25 feet. Persons in the 'mild' subgroup (DS ≤ 2 , n=51) experienced no to mild limitations or might have a visible abnormal gait, but did not require ambulation aids. Persons in the 'moderate' subgroup (DS 3-4, n=27) required intermittent or continuous unilateral support to walk more than 25 feet; while persons in the 'severe' subgroup (DS 5-6, n=30) required bilateral support or were confined to a wheelchair. The division in subgroups indicated whether the number of trips, use of travel modes, type and planning of activities, among others; was dependent on the ambulatory dysfunction. The DS is highly associated with the EDSS (Expanded Disability Status Scale) (Kurtzke, 1983) (Hohol, Orav, & Weiner, 1999), but can also be completed by practitioners with the proper training. Since the present study is community-based by which recruitment was also made outside specialized MS centers, the EDSS was not always available in all patients, so the DS was then chosen.

2.2. Study design and outcome measures

The cross-sectional study design was similar as in the preceding pilot study (Neven, et al., 2013). During the first individual contact moment with the PwMS, measures of physical, cognitive and psychosocial functioning were taken (health condition). Contextual (personal and environmental) data were collected by means of a questionnaire. Activity-related travel behaviour measures were thoroughly explained. Then, during 7 consecutive days, activity-related travel behaviour was measured by completing a travel diary and wearing a GPS logger. These devices were additionally explained in a self-written manual and a permanent helpline was available. In the second meeting, the self-report indices and the GPS logger were returned.

Outcome measures were applied on various levels of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), the WHO framework for measuring health and disability. According to the ICF, disability is described as the interaction between features of the person (functioning), and the overall context in which the person lives (contextual factors). In the present study, we aim to assess the impact of both the health condition and contextual factors on the activity-related travel behaviour in MS. In this framework, health is defined as the complete physical, mental and social functioning of a person; by which functioning refers either to all body functions and structures, activities and participation. Therefore, outcome measures on each of these ICF levels

were applied in the present study in order to get a complete overview of the health condition of an individual: some measures were conducted on the body functions and structures level; some on the activity level (capacity - what a person can do in a standard environment); and others between the activity and participation level (performance - what a person actually does in his usual environment). An overview of the outcome measures used in this study, classified by the different levels of the ICF framework and along with its detailed ICF category, is shown in Figure 1.

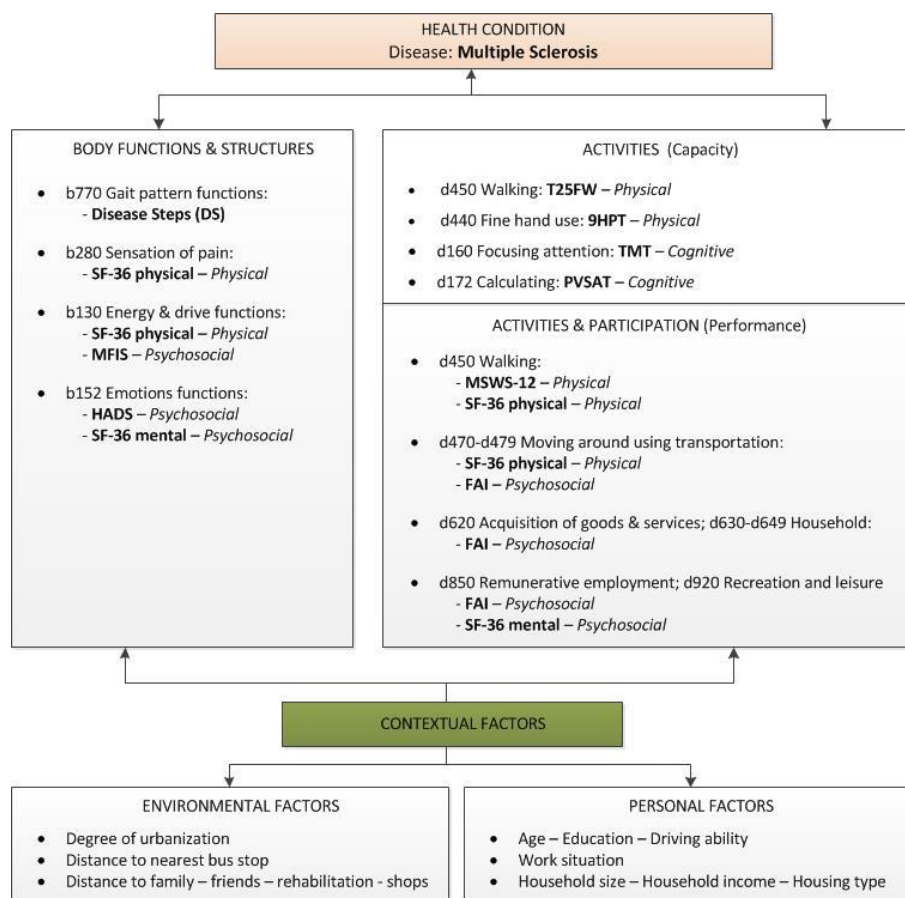


Figure 1: Outcome measures used in this study classified by the ICF framework

Health condition: In order to better understand the main focus of the outcome measures (applied on the different ICF levels), we have labeled the outcome measures of the health condition as being physical, cognitive, or psychosocial. These labels are also shown in Figure 1.

The multidimensional *Multiple Sclerosis Functional Composite* (MSFC) measured the ambulation/leg function by the *Timed 25-Foot Walk test* (T25FW), the arm/hand function by the *9-Hole Peg test* (9HPT) and cognition by the *Paced Visual Serial Addition Test* (PVSAT) (Nagels, et al., 2005). Intra- and inter-rater reliability of 0.99 and 1.0 (Rosti-Otajärvi, Hämäläinen, & Koivisto, 2008).

Physical functioning:

- During the T25FW, PwMS were instructed to walk 25 feet as quickly as possible, using their usual assistive devices. Intraclass correlation coefficient of 0.991 in PwMS (Learmonth, Dlugonski, Pilutti, Sandroff, & Motl, 2013).
- The *Multiple Sclerosis Walking Scale* (MSWS-12) measured the impact of MS on walking ability. The scale consists of 12 items which are summed to generate a total score with range 0-100. Intraclass correlation coefficient of 0.927 in PwMS (Learmonth, Dlugonski, Pilutti, Sandroff, & Motl, 2013).
- The 9HPT measured the time needed to put nine pegs in holes in a plastic board, and remove them again. Interrater reliability for right and left hands of $r=0.984$ and $r=0.993$ (Oxford, et al., 2003).
- The 36-item short-form health survey (SF-36) was used as self-assessment instrument for health related QoL, which yields an eight-scale profile of scores as well as physical and mental health summary measures. Reliability estimates for physical and mental summary scores usually exceed 0.90 (Ware, 2000).

Cognitive functioning:

- The PVSAT measured working memory, attention and arithmetic capabilities (information processing speed). Persons were shown a number every three seconds and asked to say aloud the sum of the second last. There is a significant correlation between the PASAT (Paced Auditory Serial Addition Test) and the PVSAT, the latter considered as useful alternative in the MSFC. Interrater reliability between 0.76-0.95; and test-retest coefficients for short and long test-retest intervals between 0.90-0.97 (Tombaugh, 2006).
- The *Trail Making Test* (TMT), measuring visual attention and task switching, recorded the time persons needed to connect 25 consecutive

Table 1: Health condition of PwMS by subgroup

	Mild MS (n=51) Subgroup 1	Moderate MS (n=27) Subgroup 2	Severe MS (n=30) Subgroup 3	Kruskal -Wallis ANOVA	Mann-Whitney post-hoc comparison		
					1-2	1-3	2-3
Disease Steps	1 (1-2)	3 (3-4)	5 (5-6)	< 0.01	< 0.01	< 0.01	< 0.01
Disease duration (yrs)	8.50 (4.75-16.75)	15.00 (10.00-18.00)	21.00 (12.50-26.50)	< 0.01	< 0.01	< 0.01	< 0.05
MSFC ↑	0.53 (0.30-0.75)	- 0.02 (- 0.2-0.31)	- 1.60 (- 5.38-(-0.65))	< 0.01	< 0.01	< 0.01	< 0.01
PHYSICAL FUNCTIONING							
T25FW (m/s) ↑	1.33 (1.13-1.63)	0.82 (0.65-1.05)	0.21 (0.00-0.46)	< 0.01	< 0.01	< 0.01	< 0.01
MSWS-12 ↓	25 (18.75-35.50)	48 (42-55)	59 (39.50-60.00)	< 0.01	< 0.01	< 0.01	ns
9HPT (s) ↓	22.16 (20.08-26.09)	27.04 (22.21-32.60)	36.41 (29.19-53.14)	< 0.01	< 0.01	< 0.01	< 0.01
SF36 physical ↑	40.35 (32.05-45.55)	28.40 (22.60-35.60)	20.60 (15.00-27.35)	< 0.01	< 0.01	< 0.01	< 0.01
COGNITIVE FUNCTIONING							
TMT (s) ↓	44.79 (33.19-59.16)	55.76 (42.58-70.67)	75.47 (60.40-163.28)	< 0.01	< 0.05	< 0.01	< 0.01
PVSAT ↑	54 (49-59)	53 (45-57)	35 (29-55)	< 0.01	ns	< 0.01	< 0.05
PSYCHOSOCIAL FUNCTIONING							
MFIS ↓	31 (16.50-43.50)	46 (38-59)	40 (20.50-52.25)	< 0.01	< 0.01	ns	< 0.05
HADS ↓	8 (5-14)	14 (7-20)	11 5-18.25)	< 0.05	< 0.05	ns	ns
FAI ↑	30 (24-35)	26 (21-30)	17 (12-24)	< 0.01	< 0.01	< 0.01	< 0.01
SF36 mental ↑	52.40 (44.05-58.80)	49.40 (38.30-59.60)	55 (48-60)	ns	/	/	/

Values are median (IQR). Ns: not significant. Upward arrows indicate better performance with higher scores; downward arrows indicate worse performance with higher scores.

PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis; ANOVA, Analysis of variance.
 MSFC, Multiple Sclerosis Functional Composite; T25FW, Timed 25-Foot Walk test; MSWS-12, Multiple Sclerosis Walking Scale;
 9HPT, 9-Hole Peg test; SF-36, 36-item short-form health survey; TMT, Trail Making Test; PVSAT, Paced Visual Serial Attention Test; MFIS, Modified Fatigue Impact Scale; HADS, Hospital Anxiety and Depression Scale; FAI, Frenchay Activities Index.

dots on a sheet of paper (numbers in Part A, numbers/letters in Part B). Retest reliability of TMT A and TMT B between 0.76-0.89, and 0.86-0.94 (Wagner, Helmreich, Dahmen, Klaus, & Tadic, 2011).

Psychosocial functioning:

- The impact of fatigue on daily functioning was measured by the *Modified Fatigue Impact Scale* (MFIS), an ordinal outcome measure. Dutch version of the MFIS has intraclass correlation coefficient of 0.729 (Kos, et al., 2003).
- The level of depression and anxiety was measured by the *Hospital Anxiety and Depression Scale* (HADS). A threshold score of ≥ 8 on the depression subscale provides a sensitivity of 90% and specificity of 87.3% in PwMS. The same cut-off score gives a sensitivity of 88.5% and a specificity of 80.7% on the anxiety subscale for generalized anxiety disorder (Honarmand & Feinstein, 2009).
- The *Frenchay Activities Index* (FAI) measured instrumental activities of daily living (ADL; e.g. housework, activities outside) which required some initiative from the patient in the last three and six months. Test-retest reliability of 0.96 in the general population (Turnbull, et al., 2000).
- The mental health summary measure of the SF-36 is labeled as psychosocial functioning.

Health condition of PwMS by subgroup is shown in Table 1, in terms of physical, cognitive and psychosocial functioning.

Contextual factors: Participants completed a questionnaire about their personal (socio-demographic) situation, e.g. age, education and household. The environmental situation was queried by asking the degree of urbanization (rural areas, regional urban areas,...); as well as questions about the distance to the nearest bus stop from the home location (0-500m, 500m-1km, 1km-5km, >5km), and the distances to family, friends, shops and rehabilitation (physiotherapist, specialized MS center) (0-500m, 500m-1km, 1km-5km, 5km-10km, 10km-20km, >10km). Contextual factors are summarized in Table 2.

Activity-related travel behaviour: Both self-reported activity-related travel diaries and objective GPS tracking devices were used (Neven, et al., 2013) (Bellemans, Kochan, Janssens, Wets, & Timmermans, 2008). In the diaries, persons had to indicate all information about their outdoor activities (e.g. activity type, start time and location) and resulting trips (e.g. travel mode and company). Participants were asked to carry out the GPS logger

Table 2: Contextual (personal and environmental) factors of PwMS by subgroup

	Mild (n = 51) *	Moderate (n = 27)	Severe (n = 30)	Total (n=108)
PERSONAL FACTORS				
Gender (M/F)	16/34	13/14	12/18	41/66
Age (22-34/35-44/45-54/55-64)	7/15/20/8	1/4/8/12/2	0/5/6/7/12	8/24/34/27/14
Type of MS (RR/SP/PP/unknown)	39 /1/4/6	10/6/9/2	2/11/13/4	51/18/26/12
Education (primary/secondary/higher)	3/25/22	1/17/9	4/19/7	8/61/38
Driving ability (no/uncertain/yes)	7/4/39	5/4/18	18/2/10	30/10/67
Work (not working/half-time/full-time)	31/10/9	22/5/0	28/1/1	81/16/10
Housing type (apartment/house)	8/42	6/21	6/24	20/87
Household size (1 pers/2 pers/more than 2)	5/17/28	3/13/11	10/13/7	18/43/46
Household income (< €1000/€1000-€2500/€2500-€5000/> €5000/ unknown)	0/20/21/1/8	0/10/10/0/7	1/12/5/0/12	1/42/36/1/27
ENVIRONMENTAL FACTORS				
Degree of urbanization (Flemish Periphery around Brussels/metropolitan areas/regional urban areas/structure supporting small urban areas/small urban areas at provincial level/rural areas)	0/6/11/3/ 13/17	1/8/4/2/ 3/9	1/2/7/2/ 8/10	2/16/22/7/ 24/36

Values are number of PwMS. *Missing data of 1 PwMS in mild subgroup.
PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis.
RR: relapsing-remitting; SP: secondary progressive; PP: primary progressive.

for each trip, by which the current location could be determined and saved in memory. This combination offered detailed information about the actual activity-related travel behaviour in PwMS: the travel diaries revealed information on the activity types, while GPS logging (TranSystem Inc., Hsinchu, Taiwan)^a allowed obtaining accurate information about traveled routes (e.g. distances), as well as detecting and complementing trips that were not filled out in the travel diaries. In order to limit the day-to-day variability in health condition or in number of external appointments, we have measured during 7 consecutive days including both week and weekend days, identical to guidelines of measuring walking behaviour and physical activity in MS (Motl, et al., 2007). The outcome measures that were analyzed were: number of trips and activities, travel mode, number of persons, average distances, type and planning of activities, and average duration of activities.

2.3. Statistical analysis

Numerical data were analyzed using SPSS Statistics ($p < 0.05$).

Changes in activity-related travel behaviour: Descriptive analyses were used for the standardized tests of the health condition (presented as median and interquartile range (IQR)) and travel diaries (presented as means, SDs and range). The Shapiro-Wilk test indicated non-normal distributions of most health condition variables and therefore, non-parametric Kruskal-Wallis analysis of variance (ANOVA), and post-hoc Mann-Whitney tests for independent samples, were used to examine differences between disability subgroups, regarding both the health condition variables and the activity-related travel behaviour.

Assessing the impact of health condition and contextual factors: Bivariate Spearman correlation coefficients were calculated to assess the level of association between the travel outcome measures (number of trips, number of trips made alone, number of trips as car driver), and both the health condition variables and the contextual variables. Hereby, a correlation was considered as poor (< 0.30), low ($0.30-0.50$), moderate ($0.50-0.70$), high ($0.70-0.89$), or very high (> 0.90). To investigate the predictability of the travel outcome measures by both the health condition variables and the contextual variables, multiple regression analyses with a forward stepwise selection procedure were performed. The highest correlating significant variables (of the health condition and contextual variables) were included as independent variables, and the travel outcome measures as dependent variables. Multicollinearity was checked for all models.

3. RESULTS

3.1. Description of subgroups

The overall significant disparity among subgroups justified the selected cut-off scores 2 and 5 (DS) for differentiating between patients with various ambulatory dysfunction (Table 1). Significant differences were found in disease duration, MSFC, all physical and cognitive functioning measures and almost all psychosocial functioning measures. Fatigue was significantly higher in the moderate subgroup.

3.2. Changes in activity-related travel behaviour

Table 3 presents the travel outcomes measures. Significant differences between subgroups were found regarding the number of trips and associating travel mode, and the number, type and planning of activities. PwMS in the mild subgroup made significantly more trips and had a higher share of working trips, and a lower share of social and leisure trips. Both participants in the mild and moderate subgroup made more trips as car driver or with non-motorized travel modes, and performed more bring/get activities. PwMS in the severe subgroup made a high number of trips for rehabilitation, and made more use of assistive devices or adapted transport, while their activities were less spontaneously.

3.3. Assessing the impact of health condition and contextual factors

Table 4 displays the correlation coefficients between the travel outcome measures (number of trips per day, number of trips made alone, number of trips as car driver) and both the health condition and the contextual variables. These travel outcome measures were selected because they demonstrate if a person can travel independently. Within the total sample, *the total number of trips* correlated moderately negative with the ambulatory dysfunction ($r=-0.52$) as measured by the Disease Steps; and positive with the walking ability (T25FW - $r=0.56$). The total number of trips was lowly correlated with the upper extremity function (9HPT); with the physical part of the health-related QoL (SF36); with divided attention (TMT); and with the frequency of instrumental ADL (FAI). Personal variables correlated poor to low with the total number of trips: negative correlation with age; and positive correlations with education, driving ability, household size and housing type. Associations with environmental factors were absent. The significance level and magnitude of the correlation coefficients were dissimilar among subgroups. In the mild subgroup, the frequency of instrumental ADL (FAI), the educational degree and household size correlated lowly positive with the total number of trips; and the distance to friends and shops negatively. In the moderate subgroup, moderate negative

Table 3: Travel and activity outcome measures of PwMS by subgroup

	Mild MS (n=51) Subgroup 1	Moderate MS (n=27) Subgroup 2	Severe MS (n=30) Subgroup 3	Kruskal- Wallis ANOVA	Mann-Whitney post-hoc comparison		
					1-2	1-3	2-3
TRAVEL BEHAVIOUR							
Number of trips per day	5.0 ± 1.8 (0.9-9.7)	3.4 ± 1.3 (1.3-7.1)	2.7 ± 1.5 (0.6-6.6)	< 0.01	< 0.01	< 0.01	< 0.05
Travel mode (%)							
Car driver	45.7 ± 29.9 (0.0-96.6)	41.1 ± 35.4 (0.0-100.0)	21.2 ± 31.7 (0.0-100.0)	< 0.01	ns	< 0.01	< 0.05
Car passenger	17.0 ± 17.6 (0.0-73.5)	24.1 ± 27.1 (0.0-100.0)	33.4 ± 35.5 (0.0-100.0)	ns	/	/	/
Car unknown *	8.2 ± 13.9 (0.0-54.3)	4.7 ± 6.9 (0.0-27.3)	3.6 ± 9.0 (0.0-33.3)	< 0.05	ns	< 0.01	0.10
Non-motorised	20.7 ± 25.6 (0.0-83.3)	14.4 ± 20.1 (0.0-66.7)	4.9 ± 12.5 (0.0-50.0)	< 0.01	ns	< 0.01	< 0.01
Public transport	3.4 ± 11.8 (0.0-80.0)	6.9 ± 18.6 (0.0-87.5)	0.6 ± 1.8 (0.0-6.3)	ns	/	/	/
Assistive device	0.0 - 0.0 (0.0-0.0)	5.6 ± 19.4 (0.0-100.0)	26.2 ± 36.8 (0.0-95.5)	< 0.01	< 0.01	< 0.01	< 0.05
Adapted transport	0.2 ± 1.7 (0.0-11.8)	0.3 ± 1.4 (0.0-7.4)	3.9 ± 7.8 (0.0-27.8)	< 0.01	ns	< 0.01	< 0.05
Other/unknown	4.9 ± 14.5 (0.0-100.0)	2.9 ± 6.3 (0.0-30.0)	6.2 ± 17.7 (0.0-70.6)	ns	/	/	/
Number of persons (%)							
1 person	46.7 ± 21.6 (0.0-91.4)	47.0 ± 25.7 (0.0-100.0)	35.5 ± 34.9 (0.0-92.0)	ns	/	/	/
2 persons or more	34.2 ± 20.2 (0.0-67.6)	37.3 ± 22.5 (0.0-81.8)	46.1 ± 33.5 (0.0-100.0)	ns	/	/	/
Unknown	19.1 ± 26.5 (0.0-100.0)	15.8 ± 14.9 (0.0-50.0)	18.5 ± 24.9 (0.0-100.0)	ns	/	/	/
Average distance (km)	7.68 ± 4.27 (1.47-21.56)	8.24 ± 4.28 (2.02-17.75)	7.90 ± 7.26 (0.83-33.60)	ns	/	/	/

ACTIVITIES							
Number of activities per day	3.0 ± 1.1 (0.4-5.6)	2.0 ± 0.8 (0.7-4.4)	1.5 ± 0.9 (0.3-3.7)	< 0.01	< 0.01	< 0.01	< 0.05
Type of activity (%)							
Working	8.5 ± 14.3 (0.0-80.0)	3.9 ± 9.8 (0.0-40.0)	0.8 ± 4.1 (0.0-22.2)	< 0.01	< 0.01	< 0.05	ns
Education	3.1 ± 7.3 (0.0-38.5)	0.5 ± 1.8 (0.0-8.3)	0.4 ± 2.1 (0.0-11.1)	< 0.05	0.07	< 0.05	ns
Shopping	19.9 ± 14.7 (0.0-66.7)	20.7 ± 15.3 (0.0-66.7)	21.5 ± 25.3 (0.0-100.0)	ns	/	/	/
Services	7.0 ± 7.9 (0.0-27.3)	9.4 ± 13.6 (0.0-60.0)	4.7 ± 9.1 (0.0-37.5)	ns	/	/	/
Social and leisure	23.7 ± 17.2 (0.0-71.4)	31.1 ± 15.5 (0.0-61.5)	37.0 ± 23.9 (0.0-80.0)	< 0.05	< 0.05	< 0.05	ns
Bring / Get	9.4 ± 13.4 (0.0-54.2)	6.3 ± 8.4 (0.0-26.7)	2.2 ± 6.0 (0.0-22.7)	< 0.01	ns	< 0.01	< 0.05
Rehabilitation	7.1 ± 7.0 (0.0-26.3)	13.2 ± 10.6 (0.0-33.3)	16.5 ± 14.4 (0.0-50.0)	< 0.01	< 0.05	< 0.01	ns
Walking	7.3 ± 13.1 (0.0-47.8)	4.6 ± 8.0 (0.0-25.0)	7.6 ± 12.0 (0.0-37.5)	ns	/	/	/
Other / Unknown	14.2 ± 19.6 (0.0-100.0)	10.5 ± 11.6 (0.0-41.7)	9.3 ± 12.6 (0.0-40.0)	ns	/	/	/
Average duration (min)	92.7 ± 76.7 (16 456)	87.1 ± 50.4 (21-225)	76.1 ± 34.9 (26-149)	ns	/	/	/
Planning of activity (%)							
Planned	69.8 ± 22.9 (0.0-100.0)	69.2 ± 22.5 (0.0-100.0)	65.3 ± 35.2 (0.0-100.0)	ns	/	/	/
Spontaneous	17.0 ± 14.4 (0.0-47.4)	18.4 ± 14.9 (0.0-68.8)	11.1 ± 24.1 (0.0-100.0)	< 0.01	ns	< 0.01	< 0.01
Unknown	13.3 ± 21.8 (0.0-100.0)	12.5 ± 18.3 (0.0-58.3)	20.9 ± 28.3 (0.0-100.0)	ns	/	/	/

Values are mean ± SD (range). Ns: not significant.

* Car driver or passenger unknown because not reported in travel diary.

PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis; ANOVA, Analysis of variance.

Table 4: Bivariate Spearman correlation analysis between travel behaviour and health condition and contextual factors of PwMS by subgroup

MS subgroup	Nr of Trips per Day			Nr of Trips Made Alone		Nr of Trips as Car Driver	
	Total	Mild	Mod	Sev	Total	Total	Total
HEALTH CONDITION							
Disease Steps	-0.52 †	ns	ns	ns	ns	-0.44 †	
Disease duration	-0.29 †	ns	-0.41 *	ns	0.24 *	-0.43 †	
MSFC	0.47 †	ns	0.41 *	ns	0.38 †	0.50 †	
Physical functioning							
T25FW	0.56 †	ns	ns	ns	0.43 †	-0.50 †	
MSWS-12	-0.40 †	ns	ns	ns	-0.30 †	-0.22 *	
9HPT	-0.41 †	ns	-0.60 †	ns	-0.39 †	-0.41 †	
SF36 physical	0.40 †	ns	ns	ns	0.31 †	0.27 †	
Cognitive functioning							
TMT	-0.30 †	ns	ns	ns	-0.27 †	-0.39 †	
PVSAT	ns	ns	ns	ns	ns	-0.29 †	
Psychosocial functioning							
MFIS	ns	ns	ns	ns	-0.20 *	ns	
HADS	ns	ns	ns	ns	ns	ns	
FAI	0.44 †	0.31 *	ns	ns	0.36 †	0.42 †	
SF36 mental	ns	ns	ns	ns	ns	ns	

	Nr of Trips per Day				Nr of Trips Made Alone	Nr of Trips as Car Driver
	Total	Mild	Mod	Sev		
MS subgroup						
CONTEXTUAL †						
Personal factors						
Age	- 0.36 †	ns	ns	ns	- 0.32 †	- 0.30 †
Education	0.21 *	0.39 †	ns	ns	0.31 †	ns
Driving ability	0.25 *	ns	ns	ns	ns	0.65 †
Work situation	ns	ns	ns	ns	0.20 *	0.21 *
Household size	0.33 *	0.38 †	ns	ns	ns	0.33 †
Household income	ns	ns	ns	ns	ns	ns
Housing type	0.19 *	0.33 *	ns	ns	ns	ns
Environmental factors						
Degree of urbanization	ns	ns	ns	ns	ns	0.22 *
Distance to bus stop	ns	ns	- 0.54 †	ns	ns	ns
Distance to family	ns	ns	ns	ns	ns	ns
Distance to friends	ns	- 0.35 *	ns	ns	ns	ns
Distance to rehab	ns	ns	ns	- 0.48 †	ns	ns
Distance to shops	ns	- 0.29 *	ns	ns	ns	ns

Ns: not significant. Significant correlation coefficient: * p < 0.05, † p < 0.01

‡ Categories of these variables are described in table 2 and in 'Study design and outcome measures'.

PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis.

Outcome measures: MSFC, Multiple Sclerosis Functional Composite; T25FW, Timed 25-Foot Walk test;

MSWS-12, Multiple Sclerosis Walking Scale; 9HPT, 9-Hole Peg test; SF-36, 36-item short-form health

survey; TMT, Trail Making Test; PVSAT, Paced Visual Serial Attention Test; MFIS, Modified Fatigue Impact

Scale; HADS, Hospital Anxiety and Depression Scale; FAI, Frenchay Activities Index.

association values were found for the upper extremity function (9HPT) and the distance to the nearest bus stop. In the severe subgroup, the distance to rehabilitation services correlated negatively ($r=-0.48$) with the total number of trips.

Trips made alone (independently) correlated with the majority of the health condition measures in the total sample, except for information processing speed (PVSAT), the level of anxiety and depression (HADS) and the mental part of the health-related QoL (SF36 mental subscore). The number of trips made alone also correlated with some personal factors: negative correlation with age; and positive correlation with education and work situation.

Regarding *the number of trips as car driver*, all physical and cognitive outcome measures correlated significantly in the total sample (walking ability, upper extremity function, divided attention and information processing speed), while there was no significant influence of the level of fatigue, anxiety or depression (psychosocial functioning). There was a moderately positive correlation with the driving ability ($r=0.65$), as well a significant (lower) correlation with the household size and degree of urbanization.

Table 5 shows the results of the multiple linear regression analyses, performed within the total sample. The walking ability (T25FW) and the frequency of instrumental ADL (FAI) were significant predictors in both the total number of trips and the number of trips made alone. The total number of trips, and those as car driver, were, among others, determined by the household size. The daily number of trips made alone could be predicted by only the physical functioning component of the health condition (T25FW and FAI). Overall, the models better explained variability in the total number of trips, and the number of trips as car driver (respectively 39.4% and 37.6%), which were the models with besides health condition variables also contextual factors as significant predictors.

4. DISCUSSION

The present study 1. investigated to which degree the activity-related travel behaviour in MS does decrease with increasing ambulatory dysfunction, and 2. assessed the impact of health condition (physical, cognitive and psychosocial functioning) and contextual factors (personal and environmental) on the activity-related travel behaviour in MS. This study demonstrated that PwMS with moderate to severe ambulatory dysfunction showed significant decreased activity-related travel behaviour compared to

Table 5: Multiple linear regression: health condition and contextual factors related to activity-related travel behaviour

	DAILY NUMBER OF TRIPS			NUMBER OF TRIPS MADE ALONE			NUMBER OF TRIPS AS CAR DRIVER		
	β	SE	t	β	SE	t	β	SE	t
HEALTH CONDITION									
Disease duration							-0.05	0.02	-3.46 †
T25FW	1.34	0.38	3.55 †	0.68	0.30	2.25 *			
FAI	0.06	0.02	2.47 *	0.04	0.02	2.11 *			
CONTEXTUAL FACTORS									
Driving ability							0.74	0.16	4.51 †
Household size	0.46	0.23	2.04 *				0.41	0.19	2.17 *
OVERALL MODEL									
R ²	0.394			0.197			0.376		
Adjusted R ²	0.374			0.180			0.356		
β constant	0.22			0.15			0.47		
Standard error	0.65			0.41			0.54		
p	< 0.001			< 0.001			< 0.001		

R²: predictive value; β : estimate; SE: standard error; t: t-value.

Significant regression coefficient: * p < 0.05, † p < 0.01.

Outcome measures: T25FW, Timed 25-Foot Walk test; FAI, Frenchay Activities Index.

those with mild dysfunction, confirming previous pilot findings (Neven, et al., 2013) and literature about daily activities and employment (Lexell, Iwarsson, & Lexell, 2006) (Einarsson, Gottberg, Frederikson, & von Koch, 2006) (Phillips & Stuijbergen, 2006). Generally, the number of trips correlated with health condition variables as well as contextual factors.

The overall significant associations with the physical functioning measures indicated that the number of trips decreased with increasing ambulatory dysfunction. The 9HPT showed negative correlations, confirming that manual dexterity was also a good predictor of activity and/or participation in MS (Kierkegaard, Einarsson, Gottberg, von Koch, & Holmqvist, 2012). Previous studies showed a relation between cognitive tests and impaired driving ability (Schultheis, Garay, & DeLuca, 2001) (Lincoln & Radford,

2008) (Gudesblatt, et al., 2014); but the relation between cognitive function and activity-related travel behaviour was less obvious in the present study. Information processing speed (PVSAT) was not consistently related to the total number of trips. The fact that a decreased processing speed has no significant impact on the activity-related travel behaviour, may be explained by the 'compensating' behavioural strategies of the participants: the results show that the majority of the trips is planned beforehand, averages distances are relatively small, and almost half of the trips is made with company. On the other hand, the TMT was significantly associated with the number of trips (in total, made alone and as car driver), indicating that visual attention and task switching plays an important role in the activity-related travel behaviour in MS. Persons suffering from this subdomain of cognitive dysfunction may have difficulties with organizing multiple activities on a single day; leading to a decreased number of trips. Both tests measured different subdomains of cognition, with apparently varying impact on activity-related travel behaviour. Besides cognitive function, previous studies found that psychosocial components like fatigue (Chipchase, Lincoln, & Radford, 2003) and anxiety (Devos, Brijs, Alders, Wets, & Feys, 2013) affected driving ability in MS; but those were also not significantly related with the number of trips (in total neither as car driver) in the present study. It is conceivable that contextual personal factors, like social support from household members, may prevent that specific cognitive or psychosocial functioning problems (e.g. decreased processing speed or anxiety feelings) would lead to a decreased activity-related travel behaviour. Indeed, the household size seemed influential for the number of trips in the present study, which can be explained by the fact that households with children, affect individual activity-related travel behaviour (Ryley, 2006).

In the moderate subgroup, a moderate correlation was found between the total number of trips and the distance to the nearest bus stop. Although Flemish legislation, based on the urbanization degree, restricts the maximal distance between the home location and the nearest bus stop that needs to be traveled (500-750m), our results may indicate that more physically impaired PwMS were not able to cover these distances. To obtain an increased use of public transport by PwMS, it is therefore important that the accessibility to the stops is improved, e.g. by providing stops closer to the residence of physically impaired persons. A high number of trips in the severe subgroup were made for rehabilitation. However, PwMS living farther away from these rehabilitation services had a lower probability of going to these services, indirectly confirming previous findings (Neven, et al., 2013) (Minden, et al., 2008). In the mild subgroup, the number of trips was

dependent on the distance to friends or the nearest shops. Similarly, these destinations were visited more frequently if they were located closer. Thus, also contextual environmental factors (e.g. distances to bus stops or to family or services) may influence the activity-related travel in behaviour in MS. Therefore, enhancing community environments (i.e. integrating medical and other services in the community) could be considered as approach to increase the social participation in MS. Patients could also be advised to consider moving to a housing location closer to medical and rehabilitation services for optimal use.

The multiple regression analyses confirmed that, to measure the activity-related travel behaviour in MS, it is important to take into account not only the health condition (mostly physical functioning), but as well contextual factors. The distance to specific facilities or to family or friends, significantly influences the number of (independent) trips. Respondents were recruited in both rural and urban areas in various provinces in Flanders, and living in both residential and community settings. As well, the disability distribution of PwMS was in line with that of disease severity in Flanders (Kobelt, et al., 2006).

In conclusion, measuring activity-related travel behaviour in persons with neurological conditions seems essential in rehabilitation, given that its goal is to improve activity and participation in daily life. In order to enhance social participation, the present study has demonstrated, besides mainly (physical functioning components of the) health condition, potential contextual personal and environmental key factors. Based on the present study, multi-disciplinary teams should include counselling on living situation or on advice regarding environmental factors. In this study performed in Flanders, environmental factors, e.g. the distance to facilities, were shown to influence the activity-related travel behaviour. Previously, environmental facilities were similarly related to levels of physical activity (Doerksen, Motl, & McAuley, 2007). The present results should also motivate policy makers to integrate medical and other services in the community. Eventually, nearby friends and family appeared also key factors in order to enhance participation.

The supplied results of activity-related travel behaviour may also be used as benchmarks in patients with different levels of ambulatory dysfunction, to detect whether patients are approximately participating as expected.

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CHAPTER 3

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Data quality of travel behaviour studies: factors influencing the reporting rate of self-reported and GPS-recorded trips in persons with disabilities.

An Neven¹

Ine De Schutter²

Geert Wets¹

Peter Feys³

Davy Janssens¹

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² Hasselt University, Diepenbeek, Belgium

³ REVAL - Rehabilitation Research Institute, BIOMED - Biomedical Research Institute, Faculty of Medicine and Life Sciences, Hasselt University, Diepenbeek, Belgium.

ABSTRACT

In persons with disabilities, the accuracy of self-report data collection methods in travel behaviour studies may be influenced by disease-related dysfunctions. The present study determines in detail whether disease-related physical, cognitive or psychosocial impairments contribute to the reporting rate of subjective self-report travel diaries and objective GPS tracking devices, besides socio-demographic and trip-related characteristics. The reporting rate of both data collection methods was analysed in 108 persons with Multiple Sclerosis with various disability severities during a seven days data collection period. The results demonstrated that there was only limited influence of disease-related dysfunctions, and that self-report travel diaries seemed to be better suitable for persons with a higher disability severity.

Key words

Travel behaviour, Data collection methods, Reporting rate, Persons with disabilities.

1. INTRODUCTION

Physical activity (PA) levels are often measured in order to identify current levels and changes in PA of (specific groups of) the population, and to evaluate the effectiveness of interventions designed to increase activity levels (Prince, et al., 2008); which is an important part of health promotion research (Bauman, Phongsavan, Schoeppe, & Owen, 2006). The measurement method may have a significant impact on the observed levels of PA, as self-report measures of PA generally differ with direct, objective measures of PA (Prince, et al., 2008). While self-report methods like questionnaires, interviews or diaries are often preferred as they are cheap to administer and offer additional information on the context of activities, objective measurement devices like pedometers or accelerometers provide more accurate measurement of PA and are not prone to certain biases in self-report methods such as individual-level recall bias (Haskell, 2012). Especially, in research studies of persons with disabilities (PWD), the accuracy of self-report surveys for measuring PA can be influenced by cognitive dysfunctions like memory or emotional problems, e.g. depressions (Gosney, Scott, Snook, & Motl, 2007). Commonly used activity questionnaires and diaries rely on recall and honest reporting, and require individuals to have no or limited cognitive deficits to reduce potential bias in reporting results (Hale, et al., 2007). According to research conducted by (Shephard, 2003) (Dewulf, Neutens, Van Dyck, de Bourdeaudhuij, & Van de Weghe, 2012) (Helmerhorst, Brage, Warren, Besson, & Ekelund, 2012), self-report subjective PA questionnaires show only limited reliability and validity regarding the frequency of different activity types (e.g. respondents tend to indicate their highest recent, or their desired, rather than their true average frequency of participation) and the duration and amount of PA (which is usually overestimated). On the other hand, data of objective monitors as well may sometimes yield incomplete data, e.g. because participants may forget to wear or carry their monitors, or because external device limitations such as low battery life, signal interference or malfunction (Dunton, et al., 2014).

Recently, travel behaviour studies have been increasingly used in public health studies to assess PA levels, as interventions to encourage car use and substitute active travel alternatives (such as walking and cycling) are motivated by concerns to improve health through increased PA (de Nazelle, et al., 2011). In this respect, traditional travel behaviour studies make use of self-report activity-related 'travel diaries', which typically require participants to provide information about the activity purpose, travel mode, start and end time, location of the trip origin and destination, and company of the trip. Over the past decade, recent advances in GPS technology and mobile positioning data have resulted in supplementing (and sometimes replacing) of conventional paper self-report activity-related travel diaries as a collection method with GPS tracking devices to record travel behaviour

(Bellemans, Kochan, Janssens, Wets, & Timmermans, 2008) (Cich, Knapen, Bellemans, Janssens, & Wets, 2015) (Raza, Knapen, Declercq, Bellemans, & Janssens, 2015) (Ahas, Witlox, & Miller, 2014). In the context of health promotion, accurate measurement of travel behaviour by means of this combination of self-report and objective estimates allows e.g. a detailed assessment of the time spent using active and motorized sedentary modes of transport (Panter, Costa, Dalton, Jones, & Ogilvie, 2014), or the classification of accelerometer-derived PA bouts into walking or non-walking behaviour (Kang, Moudon, Hurvitz, Reichley, & Saelens, 2013).

Similar to problems with self-report PA questionnaires, it has been documented previously that traditional travel behaviour survey data suffer from incompleteness and inaccuracies of reported trips (Bricka, Sen, Paleti, & Bhat, 2012), because of the detailed required trip-level information. Under-reporting of trips in travel studies has been documented by comparing self-reported trips with travel data collected by GPS tracking devices, to identify those trips recorded in the GPS data that were not reported by the respondents in the travel diaries. A number of key demographic factors were found in several studies (Zmud & Wolf, 2003) (Pierce, Casas, & Giaimo, 2003) (Forrest & Pearson, 2005) (Houston, Luong, & Boarnet, 2014) to significantly contribute to the misreporting of trips: younger respondents (adults \leq 25-30 years), men, individuals with a lower educational degree, unemployed individuals, low-income households, households with \geq 3 vehicles, or households with \geq 3 workers, were more likely to under-report their trips. As well, trip-related characteristics were found to significantly influence trip under-reporting (Bricka, Sen, Paleti, & Bhat, 2012). Short duration activities or trips, discretionary trips (e.g. social visits), trips made at the end of the travel day, among others, were more often forgotten or omitted in paper travel diaries (Wolf, 2000) (Bricka & Bhat, 2006) (Forrest & Pearson, 2005). Individuals who made many trips in one day, were also more likely to underreport their travel (Stopher, FitzGerald, & Xu, 2007).

On the other hand, there are also some (but fewer) studies that focused on situations, and/or associated factors, where fewer trips were recorded by GPS tracking devices than as reported by the respondents in the travel diary. Missing data with GPS devices may encounter device limitations such as signal drop insides buildings or low battery life; as well as user errors like forgetting carrying the device (Dunton, et al., 2014). Previous studies showed that trips occurring before respondents went to work (early morning), or after they left work (late evening); as well as trips on Saturday or Thursday (compared to other days), were more often forgotten to be recorded by GPS (Stopher & Shen, 2011).

While there are studies available comparing diaries and GPS tracking for the estimation of travel behaviour of healthy persons, there is relatively little research available about the reliability of travel behaviour studies in PWD (Neven, et al., 2013) (Risser, Iwarsson, & Stahl, 2012) (Shoval, et al., 2010). It may be expected that the accuracy of self-report data collection methods in travel behaviour studies of PWD may be influenced by disease-related cognitive dysfunctions as well, e.g. because of problems remembering (details of) all performed trips. Therefore, the present study contributes to the field by determining in detail whether disease-related physical, cognitive or psychosocial impairments also contributed significantly to changes in reporting in activity-related travel diaries and recording by GPS tracking devices by PWD.

Participants of this study were all diagnosed with Multiple Sclerosis (MS), a progressive inflammatory and neurodegenerative chronic disease of the central nervous system, and had a various degree of disability. As MS is characterized by a combination of physical, cognitive and psychosocial symptoms, the cognitive status of persons with MS (PwMS) may interfere with its ability to accurately recall and report the locations, distances, and frequencies of her/his community mobility (Gosney, Scott, Snook, & Motl, 2007). In MS, cognitive impairment occurs in 40-65% of its patients (Jongen, Ter Horst, & Brands, 2012). In this study, the differences between both travel behaviour data collection methods (travel diaries and GPS tracking devices) were analysed during a seven days data collection period. A large number of both physical, cognitive and psychosocial function tests were included, to investigate their specific and relative impact to the misreporting. The study is part of a large-scale research about influencing factors in travel behaviour in MS (Neven, et al.).

2. METHODOLOGY

2.1. Participants

108 persons with clinical definite MS gave written informed consent and participated. The study was approved by the ethical committees of Hasselt University, Antwerp University Hospital (UZA) and National MS Centre Melsbroek (NMSC). PwMS were recruited based on databases of the REVAL (Rehabilitation Research Center, UHasselt), by neurologists of the rehabilitation centers, and after information sessions in an MS-specialized fitness center (Fit Up, Kontich) and support groups of the MS Society Flanders; leading to a reasonable large group of participants (compared to other studies of PWD). PwMS were included if they made minimal one trip weekly, and were excluded if they were bedridden, or had a relapse or related corticosteroid treatment within one month before the study.

Participating PwMS were further divided in three subgroups, according to their Disease Steps (DS) (Hohol, Orav, & Weiner, 1995) describing ambulatory dysfunction. The DS is a simple and brief clinical rating scale, based on a general physical examination and the assistive devices needed to walk 25 feet (7.62 meters). Persons in the 'mild' subgroup (DS ≤ 2 , n=51) experienced no to mild limitations or might have a visible abnormal gait, but did not require ambulation aids. Persons in the 'moderate' subgroup (DS 3-4, n=27) required intermittent or continuous unilateral support to walk more than 25 feet; while persons in the 'severe' subgroup (DS 5-6, n=30) required bilateral support or were confined to a wheelchair.

The division in subgroups was based on ambulatory (physical) dysfunction, because it was showed previously that changes in activity and travel behaviour in MS were (mainly) related to increasing ambulatory dysfunction (Neven, et al., 2013). Hereby, it was possible to examine the influence of trip-related factors (e.g. the number of trips, the type of activities, used travel modes) on the reporting rate; as well as to determine to what extent the agreement between objective GPS devices and self-reported diaries would differ between disability status. Socio-demographic characteristics of PwMS by subgroup are summarized in Table 1.

2.2. Experimental design and outcome measures

A detailed overview of the experimental design can be found in Neven et al. (Neven, et al., 2013). During the first individual contact moment with the PwMS, measures of physical, cognitive and psychosocial functioning were taken. Socio-demographic data was collected by means of a questionnaire, and activity-related travel behaviour measures were thoroughly explained. Then, during 7 consecutive days, activity-related travel behaviour was measured by completing a travel diary and wearing a GPS logger. These devices were additionally explained in a self-written manual and a permanent helpline was available. In the second meeting, the self-report indices and the GPS logger were returned.

2.2.1. Travel behaviour outcome measures

Both subjective self-reported activity-related travel diaries and objective GPS tracking devices were used to obtain a comprehensive understanding of the activity-related travel behaviour of PwMS. In the diaries, persons had to indicate all information about their outdoor activities (e.g. activity type, start time and location) and resulting trips (e.g. travel mode and company). Participants were asked to carry out the GPS logger for each outdoor trip in a handbag or trouser pocket, by which the current location could be determined and saved in memory. The GPS logger, 747Pro 66-Channel GPS Trip Recorder with motion sensor (TranSystem Inc., Hsinchu, Taiwan) allowed obtaining more accurate information about traveled routes (e.g. distances and duration of trips), as well as detecting trips that were not

filled out in the travel diaries (see further for the description of detecting trips by GPS). A trip means an outdoor displacement which is identified by a clear activity motive (e.g. working and shopping), and can consist of one or several travel modes.

Activities were divided in one of the following categories: working/education, shopping/services (e.g. daily shopping or fun shopping), social (e.g. visiting friends or family), leisure (e.g. hobbies), bring or get activities (bringing or getting relatives or friends to somewhere, as well as bringing or getting things to somewhere, e.g. getting a package from the post office), personal care (e.g. rehabilitation and doctor), other (not belonging to one of the previous activity types) and home-based trips. Walking (either independently or with use of any assistive device), driving or cycling around without destination was also seen as a trip, and was classified as 'travelling'. The outcome measures that were analyzed in this study were: research day, week day, departure time, trip duration, activity type, transport mode, planning of trips, and chain of trips.

2.2.2. Clinical outcome measures

Clinical characteristics of PwMS by subgroup are shown in Table 2. Physical, cognitive and psychosocial functions were assessed in order to investigate their specific and relative impact on the reporting rate of the data collection methods in patient profiles with various disability severity. The multidimensional Multiple Sclerosis Functional Composite (MSFC) measured the ambulation/leg function by the Timed 25-Foot Walk test (T25FW), the arm/hand function by the 9-Hole Peg test (9HPT) and cognition by the Paced Visual Serial Addition Test (PVSAT) (National Multiple Sclerosis Society, 2001).

Physical functioning:

- *Timed 25-Foot Walk test* (T25FW): measured the time PwMS needed to walk 25 feet as quickly as possible, using their usual assistive devices (National Multiple Sclerosis Society, 2001).
- *Multiple Sclerosis Walking Scale* (MSWS-12): measured the impact of MS on walking ability by means of a questionnaire consisting of 12 items (Hobart, Riazi, Lamping, Fitzpatrick, & Thompson, 2003).
- *9 Hole Peg test* (9HPT): measured the time PwMS needed to put nine pegs in holes in a plastic board, and remove them again (National Multiple Sclerosis Society, 2001).
- *36-item Short-Form Health Survey* (SF-36): measured the self-reported health related quality of life, resulting in a physical health summary score (Ware & Sherbourne, 1992).

Table 1: Socio-demographic characteristics of PwMS by subgroup

Variable	Mild MS (n = 51) *	Moderate MS (n = 27)	Severe MS (n = 30)	Total MS (n=108)
Age (22-34/35-44/45-54/55-64)	7/15/20/8	1/4/8/12/2	0/5/6/7/12	8/24/34/27/14
Gender (M/F)	16/34	13/14	12/18	41/66
Education (primary/secondary/higher)	3/25/22	1/17/9	4/19/7	8/61/38
Work (not working/half-time/full-time)	31/10/9	22/5/0	28/1/1	81/16/10
Driving ability (no/uncertain/yes)	7/4/39	5/4/18	18/2/10	30/10/67
Household size (1 pers/2 pers/more than 2)	5/17/28	3/13/11	10/13/7	18/43/46
Household income (< €1000/€1000-€2500/ €2500-€5000/> €5000/ unknown)	0/20/21/1/8	0/10/10/0/7	1/12/5/0/12	1/42/36/1/27
Cars in household (0/1/2 or more)	4/24/22	2/22/3	7/16/7	13/62/32

Values are number of PwMS. * Missing data of 1 PwMS in mild subgroup.

Cognitive functioning:

- *Paced Visual Serial Addition Test (PVSAT)*: measured working memory, arithmetic capabilities (information processing speed) and attention, by which PwMS were shown a number every three seconds and asked to say aloud the sum of the second last (National Multiple Sclerosis Society, 2001) (Nagels, et al., 2005).
- *Trail Making Test (TMT)*: measured visual attention and task switching by recording the time PwMS needed to connect 25 consecutive dots on a sheet of paper (numbers in part A, numbers and letters in part B) (Tombaugh, 2004).

Psychosocial functioning:

- *Modified Fatigue Impact Scale (MFIS)*: measured the impact of fatigue on daily functioning (Kos, Nagels, D'Hooghe, Duportail, & Kerckhofs, 2006).
- *Hospital Anxiety and Depression Scale (HADS)*: measured the level of depression and anxiety (Bambauer, Locke, Aupont, Mullan, & McLaughlin, 2005).
- *Frenchay Activities Index (FAI)*: measured instrumental activities of daily living (e.g. housework, activities outside) which required some initiative from the patient in the last three and six months (Schuling, de Haan, Limburg, & Groenier, 1993).
- *36-item Short-Form Health Survey (SF-36)*: measured the self-reported health related quality of life, resulting in a mental health summary score (Ware & Sherbourne, 1992).

2.3. Data processing and statistical analysis

As a first step, the data of the travel diaries were implemented in a database. Next, all individual trips were manually compared by the researcher, by viewing the GPS traces of the participants in the geographic information system software package ArcGIS and visually comparing them with the information from the travel diary. If the trip was forgotten in the diary, the database was complemented with the trips detected by the GPS data. As such, the final database consisted of all trips made during the data collection period. Every trip was labelled if it was either (i) registered in the diary alone, (ii) by means of the GPS tracking device alone, or (iii) by both data collection instruments. If a trip was forgotten by both instruments (e.g. a homewards trip) but could be logically deduced (e.g. if the next trip again started from the home location), it was complemented in the database and labelled as 'forgotten by GPS and diary'.

Numerical data were analyzed using SPSS Statistics ($p < 0.05$). Descriptive analyses were used for the questionnaires and travel diaries. The Shapiro-Wilk test indicated non-normal distributions of most variables and therefore, non-parametric Kruskal-Wallis analysis of variance (ANOVA), and post-hoc Mann-Whitney tests for independent samples were used to examine differences between MS subgroups. The Wilcoxon test was applied to determine differences in outcome measures for each data collection method (e.g. 'Was research day 1 better filled in in the diary than research day 2?'). Bivariate Spearman correlation coefficients were calculated to assess the level of association between variables, by which a correlation was considered as poor (< 0.30), low ($0.30-0.50$), moderate ($0.50-0.70$), high ($0.70-0.89$), and very high (> 0.90). Multiple regression analyses with a stepwise selection procedure were performed to determine the most predictive outcome measures for the reporting rate of the travel diary and the GPS. Multicollinearity was checked for all models.

3. RESULTS

3.1. Differences between MS subgroups: clinical characteristics

Table 2 shows that the overall significant disparity among MS subgroups justified the selected DS cut-off scores 2 and 5 for differentiating between patients with various ambulatory dysfunction. Significant differences were found in disease duration, MSFC, all physical and cognitive functioning measures outcomes and almost all outcomes on the psychosocial functioning measures; meaning that the moderate, and especially the severe MS subgroup, suffered more from physical, cognitive and psychosocial (e.g. fatigue) symptoms than the mild MS subgroup.

3.2. Baseline results – Reporting rate of data collection methods

The 108 individuals reported a total of 2562 trips in their diaries, while the GPS tracking devices carried by these individuals recorded a total of 2311 trips. In general, 71 individuals (66%) reported more trips in the diary than were detected by GPS; 8 individuals (8%) reported the same number of trips in both data collection methods; and 28 individuals (26%) reported fewer trips in the diary.

Table 3 shows that the majority of trips (66%) were reported in both data collection methods. In general, more than one fifth of all trips (21%) were only reported by diary and thus forgotten to be registered by GPS (e.g. forgotten to carry or to switch on the GPS); compared to 11% of trips that were only registered by GPS and thus forgotten to be reported in the diary. Overall, as well as across MS subgroups, the data quality of the diary was higher than the quality of the GPS data. In the severe MS subgroup, more

trips were forgotten to be registered by GPS, while no significant difference was found between subgroups.

3.3. Reporting rate of data collection methods across research days and travel outcome measures

Wilcoxon signed-rank tests were applied to determine if the travel outcome measures influenced the reporting rate of the different data collection methods. Figure 1 shows that trips were less registered by GPS on the first research day compared to the next days, which appeared to be significant (Wilcoxon signed-rank test, $p < 0.05$). There were no significant differences between reporting on weekdays or weekend days, neither in the diary nor by GPS. Registration by GPS was more often forgotten in trips in the afternoon (16h-20h) compared to other time periods, in trips of short trip duration (< 10 min) compared to longer trip durations, and in trips that did not occur as part of a trip chain. Reporting in the diary was less complete in home-wards trips compared to other activity types, and in trips by bicycle or public transport compared to trips by car. The planning of the trips (planned vs. spontaneously) did not influence the reporting rate of the data collection methods.

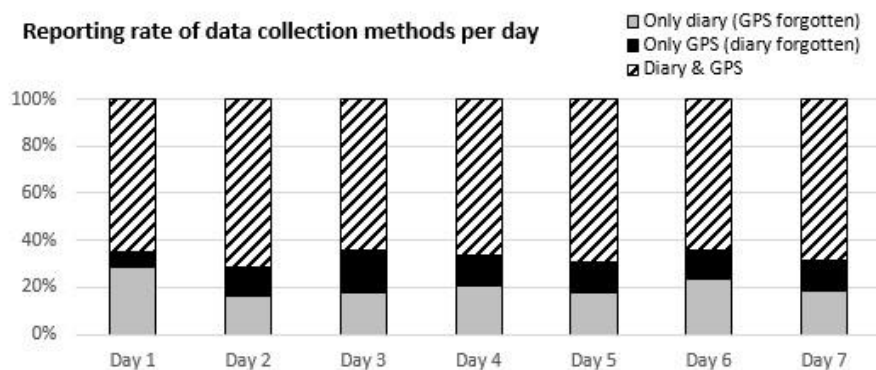


Figure 1: Reporting rate of data collection methods per day

Table 2: Clinical characteristics of PwMS by subgroup

Disability variable	Mild MS (n=51) Subgroup 1	Moderate MS (n=27) Subgroup 2	Severe MS (n=30) Subgroup 3	Kruskal-Wallis ANOVA	Mann-Whitney post-hoc comparison between subgroups		
					1-2	1-3	2-3
Disease Steps	1.4 ± 0.6 (0-2)	3.4 ± 0.5 (3 - 4)	5.4 ± 0.5 (5-6)	< 0.01	< 0.01	< 0.01	< 0.01
Disease duration	10.6 ± 7.6 (1-30)	15.3 ± 7.7 (5 - 32)	21.4 ± 11.1 (2-48)	< 0.01	< 0.01	< 0.01	< 0.05
MSFC ↑	0.5 ± 0.4 (-0.4-1.3)	-0.1 ± 0.6 (-2.3 - 0.9)	-2.9 ± 2.5 (-6.6-0.3)	< 0.01	< 0.01	< 0.01	< 0.01
Physical							
T25FW (m/s) ↑	1.4 ± 0.3 (0.9-2.0)	0.8 ± 0.3 (0.3-1.3)	0.2 ± 0.3 (0.0-0.9)	< 0.01	< 0.01	< 0.01	< 0.01
MSWS-12 ↓	27.4 ± 11.2 (12-58)	47.1 ± 9.7 (21-60)	46.6 ± 21.1 (0-60)	< 0.01	< 0.01	< 0.01	ns
9HPT (s) ↓	23.4 ± 5.2 (15.0-39.9)	29.5 ± 10.4 (17.5-60.2)	41.1 ± 15.8 (17.2-76.0)	< 0.01	< 0.01	< 0.01	< 0.01
SF36 physical ↑	39.6 ± 10.2 (15.9-59.1)	28.7 ± 8.1 (12.40-43)	22.3 ± 9.0 (9.1-51.5)	< 0.01	< 0.01	< 0.01	< 0.01
Cognitive							
PVSAT ↑	51.8 ± 9.7 (22-60)	47.8 ± 13.2 (0-60)	38.5 ± 16.0 (0-60)	< 0.01	ns	< 0.01	< 0.05
TMT (s) ↓	47.5 ± 20.3 (18.9-106.6)	58.2 ± 21.2 (32.8-137.0)	106.6 ± 66.0 (32.6-257)	< 0.01	< 0.05	< 0.01	< 0.01
Psychological							
MFIS ↓	31.7 ± 17.9 (2-74)	46.7 ± 15.0 (13-72)	36.3 ± 19.9 (0-70)	< 0.01	< 0.01	ns	< 0.05
HADS ↓	10.2 ± 7.9 (1-33)	14.0 ± 6.9 (1-27)	11.7 ± 7.6 (0-25)	< 0.05	< 0.05	ns	ns
FAI ↑	29.0 ± 7.2 (12-42)	24.2 ± 7.2 (7-35)	17.9 ± 7.8 (5-31)	< 0.01	< 0.01	< 0.01	< 0.01
SF36 mental ↑	50.4 ± 10.6 (20.8-66.1)	47.1 ± 12.9 (20.2-63.7)	53.5 ± 10.2 (25-73.1)	ns	/	/	/

Values are mean ± SD (range). ANOVA: Analysis of Variance. Ns: not significant. Upward arrows indicate better performance with higher scores (e.g. a higher score on the T25FW (m/s) means that the participant has a better ambulation/leg function); downward arrows indicate worse performance with higher scores (e.g. a higher score on the MSWS-12 means that the participant experiences more (negative) impact of MS on his walking ability).

Table 3: Reporting rate by data collection method of PwMS by subgroup

Reporting method (%)	Total MS (n=108)	Mild MS (n=51) Subgroup 1	Moderate MS (n=27) Subgroup 2	Severe MS (n=30) Subgroup 3	Kruskal-Wallis ANOVA	Mann-Whitney post-hoc comparison between subgroups		
						1-2	1-3	2-3
Diary	87.65 ± 18.09 (0-100)	84.94 ± 21.39 (0-100)	87.78 ± 15.93 (50-100)	92.29 ± 12.28 (50-100)	ns	/	/	/
GPS	76.95 ± 23.00 (0-100)	78.59 ± 20.58 (0-100)	80.56 ± 16.35 (41-100)	70.70 ± 30.66 (0-100)	ns	/	/	/
Diary + GPS	66.31 ± 25.46 (0-100)	65.35 ± 26.24 (0-97)	69.50 ± 20.36 (25-100)	65.04 ± 28.76 (0-100)	ns	/	/	/
Only diary (GPS forgotten)	21.34 ± 21.77 (0-100)	19.59 ± 20.12 (0-97)	18.28 ± 15.79 (0-59)	27.26 ± 28.07 (0-100)	ns	/	/	/
Only GPS (diary forgotten)	10.64 ± 16.60 (0-100)	13.24 ± 20.36 (0-100)	11.06 ± 14.19 (0-47)	5.66 ± 8.84 (0-35)	ns	/	/	/
Forgotten trips by GPS & diary	1.71 ± 5.49 (0-50)	1.82 ± 3.16 (0-14)	1.16 ± 3.14 (0-15)	2.05 ± 9.32 (0-50)	< 0.05	ns	< 0.05	ns

Values are mean ± SD (range). Ns: not significant.

3.4. Reporting rate of data collection methods by travel outcome measure and MS subgroup

Table 4 shows the reporting rate per outcome measure, indicating only limited significant differences between MS subgroups. Persons with mild MS more often forgot to carry their GPS device for short trips or for (single) trips that did not occur as part of a trip chain, compared to other subgroups. As well, they more often forgot to report trips in the morning (6h-12h), trips as car passenger and spontaneous trips, in their diary. On the other hand, persons with mild MS better reported their leisure trips in both data collection methods compared to other subgroups. Persons with severe MS better reported trips in the morning and afternoon in their diary, and reported their trips as car passenger better compared to the other subgroups. There was no difference between the reporting rate of MS subgroups regarding the research day or the type of day (weekday versus weekend day). It was notable that none of the work or educational trips was forgotten to be filled in the travel diary in none of the subgroups.

3.5. Influencing (disease-related) clinical, socio-demographic and trip-related factors

Table 5 shows the correlation coefficients between the reporting rate of both data collection methods, and clinical, socio-demographic and trip-related outcome measures by MS subgroup. Within the total sample, associations with clinical measures were absent for both data collection methods. In the mild MS subgroup, persons with a higher MSFC (indicating persons with a lower overall disability severity) score better filled out their travel diary. In the moderate MS subgroup, there was a lowly positive correlation between the DS and the reporting rate of the GPS, while the T25FW correlated negatively moderate. Persons in the moderate MS subgroup who had more ambulatory (walking) problems, seemed thus to register their trips better by GPS. There was a low correlation between the physical component of the SF36 in the severe MS subgroup and the reporting rate of the diary, indicating that persons with severe MS who experienced a higher (physical) quality of life, worse reported their trips in the diary.

Regarding the socio-demographic factors, the educational level correlated poorly with the reporting rate of the diary within the total sample, and moderately in the moderate and severe MS subgroup. Persons with a higher educational level seem to better report their trips in the diary. The work situation was positively associated with the reporting rate of the diary (PwMS who worked better filled out their diary), while the household size seemed to correlate negatively (PwMS with a larger household size filled out their diary worse). In the moderate MS subgroup, the registration of trips by GPS was positively influenced by a higher age. Overall, PwMS who performed more trips reported their trips worse in their travel diary. In the

mild MS subgroup, planned trips were reported better in the diary but however, worse registered by GPS. The correlation coefficients between trips by public transport and the reporting rate of the GPS were dissimilar between the subgroups. However, it should be noted that a bad registration by GPS when travelling by public transport, can also be due to external factors like signal interference (e.g. in trains).

Results of the multiple regression analyses, performed with the total sample and the subgroups separately, are presented in Table 6. Overall, the models better explained variability in the mild subgroup regarding the reporting rate of the diary, and in the moderate subgroup regarding the reporting rate by GPS (respectively 57.7% and 38.6%), which were the models with as well clinical variables as significant predictors. In the mild MS subgroup, the overall disability severity (measured by the MSFC) and trip-related factors like the share of planned trips and trips performed as car passenger, determined the reporting rate of the diary. In the moderate MS subgroup, the reporting rate by GPS was influenced by the perceived quality of life (measured by the SF-36) and the age of the participants. Within the total sample, only trip-related factors (number of trips, share of planned trips and trips to shops or services) were of importance; while clinical or socio-demographic factors did not contribute in explaining the variability regarding the reporting rate of the diary.

4. DISCUSSION

The present study investigated the influence of disease-related physical, cognitive and psychosocial characteristics, besides socio-demographic and trip-related variables, on the data quality of different data collection methods in a travel survey in PWD (more specific PwMS). This study demonstrated that there was only limited influence of clinical variables on the reporting rate (and associating data quality) of subjective travel diaries and objective GPS tracking devices, as well as only limited significant differences between subgroups with various disability severity. 66% of the trips were reported in both data collection methods, while overall more than one fifth of all trips were forgotten to be registered by GPS, and 11% were forgotten to be reported in the diary.

Within the total sample, it was interesting (but unexpected) that no clinical variable correlated with the reporting rate of neither the travel diary nor the GPS device. Since there was overall significant disparity among subgroups regarding the cognitive tests (Table 2), we expected more potential bias in reporting results by PwMS with severe dysfunction. Persons in this subgroup more often forgot to carry their GPS, but however, better reported their trips in their travel diary (although not significant different between subgroups).

Table 4: Reporting rate of data collection instrument by travel outcome measure and MS subgroup

REPORTING RATE (%)	MS SUBGROUP	Only diary (GPS forgotten)						Only GPS (diary forgotten)						Diary & GPS						Mann-Whitney comparison between subgroups						
		Tot		Mild		Sev		Tot		Mild		Sev		Tot		Mild		Sev		Only diary		Only GPS		Diary & GPS		
		1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	1-2	1-3	
Research day																										
	Day 1	31.7	24.2	35.3	42.7	6.6	7.0	5.1	7.3	61.6	68.7	59.6	50.0	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 2	18.2	16.5	15.6	25.0	9.2	11.2	9.9	3.7	72.7	72.3	74.5	71.2	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 3	21.5	16.0	22.6	33.3	13.3	17.1	12.4	5.3	65.2	67.0	65.0	61.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 4	20.7	22.0	11.8	27.5	11.3	11.2	14.4	8.2	68.0	66.8	73.8	64.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 5	19.7	22.5	7.4	23.1	11.9	13.3	15.1	6.6	68.4	64.2	77.5	70.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 6	23.1	25.6	21.6	17.7	11.1	10.9	14.4	7.0	65.8	63.5	64.0	75.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Day 7	21.6	23.3	22.1	17.6	11.1	14.0	12.9	3.8	67.3	62.7	65.0	78.6	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
Week day																										
	Weekday	22.3	21.7	19.8	25.5	10.2	12.9	9.6	5.9	67.7	65.4	70.6	69.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Weekend day	22.0	20.0	18.7	28.6	12.6	12.4	19.8	6.6	65.4	67.6	61.5	64.8	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
Departure time																										
	6h-12h	24.2	22.4	21.1	30.5	7.0	10.0	4.6	3.7	68.8	67.6	74.4	65.8	ns	ns	ns	ns	ns	ns	ns	*	ns	ns	ns	ns	ns
	12h-16h	20.6	17.0	15.4	31.9	9.9	13.1	11.3	3.2	69.5	70.0	73.3	65.0	ns	ns	ns	ns	ns	ns	ns	ns	ns	*	ns	ns	ns
	16h-20h	26.3	22.4	24.8	35.1	12.8	15.8	13.6	6.3	61.0	61.9	61.6	58.6	ns	ns	ns	ns	ns	ns	ns	ns	*	ns	ns	ns	ns
	20h-6h	19.7	14.9	17.5	33.1	18.2	23.1	18.9	6.4	62.1	62.0	63.6	60.5	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
Trip duration																										
	< 10 min	21.0	23.0	15.7	22.6	13.2	14.9	14.5	8.2	65.9	62.2	69.8	69.3	*	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	11-20 min	18.4	14.7	19.9	25.0	12.8	13.1	16.6	7.7	68.8	72.2	63.6	67.3	ns	ns	ns	ns	ns	ns	ns	ns	ns	*	ns	ns	ns
	> 20 min	15.2	14.0	11.7	21.0	7.7	10.4	6.8	3.3	77.1	75.6	81.6	75.7	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
Activity type																										
	Work/Education	26.3	31.7	0.0	33.3	0.0	0.0	0.0	0.0	73.7	68.3	100.0	66.7	*	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Shops/services	19.6	16.5	12.5	34.2	1.5	2.6	0.0	1.1	78.9	80.9	87.5	64.7	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	*
	Leisure	21.6	16.2	25.9	28.8	2.8	1.4	6.1	2.1	75.7	82.4	68.0	69.2	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	*	ns
	Social	27.2	30.0	22.0	26.7	2.9	1.8	4.6	3.5	69.9	68.2	73.4	69.8	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Personal care	29.5	24.0	31.2	37.4	0.9	0.9	1.7	0.0	69.6	75.0	67.2	62.6	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns
	Walking	23.0	31.2	12.5	17.2	4.0	3.0	10.0	0.0	73.0	65.8	77.5	82.8	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns	ns

Table 5: Bivariate Spearman correlation analysis between reporting rate and clinical, socio-demographic and trip-related variables by MS subgroup

REPORTING RATE (%) MS SUBGROUP	DIARY				GPS			
	Total	Mild	Mod	Sev	Total	Mild	Mod	Sev
CLINICAL								
Disease Steps	ns	ns	ns	ns	ns	ns	0.44 *	ns
Disease duration (yrs)	ns	ns	ns	ns	ns	ns	ns	ns
MSFC	ns	0.33 *	ns	ns	ns	ns	ns	ns
Physical functioning								
T25FW (m/s) ↑	ns	ns	ns	ns	ns	ns	-0.51 †	ns
MSWS-12 ↓	ns	ns	ns	ns	ns	ns	ns	ns
9HPT (s) ↓	ns	ns	ns	ns	ns	ns	ns	ns
SF36 physical ↑	ns	ns	ns	-0.39 *	ns	ns	ns	ns
Cognitive functioning								
TMT (s) ↓	ns	ns	ns	ns	ns	ns	ns	ns
PVSAT ↑	ns	ns	ns	ns	ns	ns	ns	ns
Psychosocial functioning								
MFIS ↓	ns	ns	ns	ns	ns	ns	ns	ns
HADS ↓	ns	ns	ns	ns	ns	ns	ns	ns
FAI ↑	ns	ns	ns	ns	ns	ns	ns	ns
SF36 mental ↑	ns	ns	ns	ns	ns	ns	0.47 *	ns
SOCIO-DEMOGRAPHIC								
Age	ns	ns	ns	ns	ns	ns	0.56 †	ns
Gender	ns	ns	ns	ns	ns	ns	ns	ns
Education	0.28 †	ns	0.50 †	0.61 †	ns	ns	ns	ns
Work situation	0.23 *	0.36 *	ns	ns	ns	ns	ns	ns
Driving ability	ns	ns	ns	ns	ns	ns	ns	ns
Household size	-0.22 †	ns	ns	ns	ns	ns	-0.41 *	ns
Household income	ns	ns	ns	ns	ns	ns	ns	ns
Cars in household	ns	ns	ns	ns	ns	ns	ns	ns
TRIP-RELATED								
Number of trips	-0.25 †	-0.31 *	ns	ns	ns	ns	ns	ns
Car passenger	ns	0.29 *	ns	ns	ns	ns	ns	ns
Public transport	ns	ns	ns	ns	-0.25 †	-0.28 *	0.44 *	ns
Planned trips	0.25 *	0.37 †	ns	ns	ns	-0.30 *	ns	ns
Trips to work	ns	0.37 †	ns	ns	ns	ns	ns	ns
Trips to shops/services	0.29 †	ns	0.54 †	ns	ns	ns	ns	ns
Trips personal care	0.20 *	ns	ns	ns	ns	ns	ns	ns
Trips 12h-16h	ns	ns	ns	ns	0.26 †	ns	ns	ns

Ns: not significant. Significant correlation coefficient: * p < 0.05, † p < 0.01

Table 6: Multiple linear regression: clinical, socio-demographic and trip-related factors related to reporting rate

REPORTING RATE (%)	DIARY						GPS		
	Total		Mild		Severe		Moderate		
MS SUBGROUP	β	SE	t	β	SE	t	β	SE	t
Clinical									
MSFC				0.16	0.05	3.37 †			
SF-36 mental							0.01	0.00	2.25 *
Socio-demographic									
Age							0.01	0.00	2.71 *
Education									
Trip-related									
Number of trips	- 0.02	0.01	- 2.35 *						
Car passenger				0.29	0.10	2.94 †			
Planned trips	0.22	0.06	4.01 †	0.51	0.08	6.13 †			
Trips to shops/services	0.20	0.08	2.61 *				0.04	0.02	2.40 *
OVERALL MODEL									
R ²	0.224				0.577			0.176	0.386
Adjusted R ²	0.201				0.550			0.146	0.335
β constant	0.757				0.381			0.775	0.154
Standard error	0.056				0.065			0.065	0.173
p	< 0.001				< 0.001			< 0.05	< 0.01

R²: predictive value; β : estimate; SE: standard error; t: t-value.
 Significant regression coefficient: * p < 0.05, † p < 0.01

This could be explained by family members assisting in complementing the diaries. However, it seemed that the household size negatively influenced the reporting rate of the diary, possibly because of other household activities with higher priority. In the moderate MS subgroup, persons with a higher perceived health-related quality of life (as measured by the mental component of the SF-36) better registered trips by GPS. Persons with a lower perceived quality of life might have more difficulties with making an (independent) trip, and therefore likely might less think of carrying the GPS device with them.

Confirming previous literature (Bricka, Sen, Paleti, & Bhat, 2012), the educational level and work situation positively correlated, however dissimilar among subgroups, with the reporting rate of the travel diary. Education seemed to correlate moderately in the more advanced stages of the disease, while the work situation was only of importance in the mild MS subgroup and the total sample. It was somewhat surprising that, in the moderate subgroup, older persons better registered their trips by GPS, in contrast with literature (Bricka, Sen, Paleti, & Bhat, 2012) stating that GPS should be used for the younger generation. The number of trips negatively influenced the reporting rate of the travel diary in the total sample and mild subgroup, likely because it is too difficult to remember a high number of trips, or perhaps because of the amount of time involved to report in detail each performed trip. As well in the mild subgroup and within the total sample, persons who planned more trips in advance better reported their trips in the diary – probably because it is easier to recall trips that were planned before.

Overall, using GPS tracking devices (the current standard method) only for collecting data in PwMS and more generally PWD, should be undertaken with caution, as more than one fifth of all trips was not registered in this study, and even 29% in the severe subgroup. Persons were allowed to keep the device switched on during the day (only at night they were asked to switch it off), as the logger automatically switched to the stand-by function when no movement was detected for more than 5 minutes (by means of a motion sensor) and similarly, started recording when the person moved again. However, persons had to remember to take the device with them at the moment they started travelling, which often appeared to be problematic. Besides possible cognitive problems, PWD likely have to think about a number of organizational issues when making a trip (e.g. carrying assistive mobility devices, making a reservation of adapted transport) because of their mobility limitations, which may explain why they forgot to take their GPS with them more often than persons without limitations. A (straightforward) solution may be to attach the GPS device to another attribute they usually carry while moving outdoors (handbag, mobile phone), e.g. by means of a keychain.

The results suggest that traditional (subjective) paper and pencil diaries may be better suitable for PWD with more advanced stages of the disease. The difference hereby is that persons do not have to think about filling in the diary immediately, but are able to do this at a later time (e.g. in the evening) when they have less organizational things on their mind. On the other hand, this longer time period may cause delayed memory problems with more potential bias in reporting results. Informing family members or caregivers about the research could be helpful to achieve more complete results.

In summary, we recommend the complemented use of both subjective self-report and objective GPS tracking devices to obtain detailed information about the actual activity-related travel behaviour in PWD. Despite recent advances in GPS technology, self-report diaries remain an important source of information for understanding why and how people make their trips (e.g. for which purpose, with whom, spontaneous or planned, among others), at least for persons for whom it is possible to use this method. Persons suffering from problems with physical problems like fine hand motor skills, as well as some persons with intellectual impairments, may not be able to fill in diaries or questionnaires. For these persons, GPS devices may provide a convenient solution to capture their travel behaviour, but it must be ensured that this device will not be forgotten during the trips, e.g. by sending a daily message to the participants to remember them to carry their GPS when they leave their home. As well, new technologies that enable researchers to collect objective data about underlying activity types and accompanying persons, like visual life-logging technologies capturing every day activities by digital cameras, may potentially make self-report diaries redundant (Mavoa, Oliver, Witten, & Badland, 2011).

Therefore, in order to make a substantiated choice of data collection instrument in travel behaviour studies in PWD, the (disease-related) capabilities of the participants should be taken into account and the selected method should be targeted towards the (disability level) of the target group. The present study may give initial indications about how this can be done.

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CHAPTER 4

NeuroRehabilitation. 1st review.

Understanding walking activity in Multiple Sclerosis: step count, walking intensity and uninterrupted walking activity duration related to degree of disability.

An Neven¹

Annelien Vanderstraeten²

Davy Janssens¹

Geert Wets¹

Peter Feys³

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² Hasselt University, Diepenbeek, Belgium

³ REVAL - Rehabilitation Research Institute, BIOMED - Biomedical Research Institute, Faculty of Medicine and Life Sciences, Hasselt University, Diepenbeek, Belgium.

ABSTRACT

Background: In Multiple Sclerosis (MS), physical activity (PA) is most commonly measured as number of steps, while also walking intensity and walking activity duration are keys for a healthy lifestyle.

Objective: To investigate (1) the number of steps persons with MS (PwMS) take; (2) the number of steps they take at low and moderate intensity; and (3) their walking activity duration for 2, 3, 6, 10, 12 and 14 uninterrupted minutes; all related to the degree of disability.

Methods: 64 PwMS participated, distinguished in a mild (n=31) and moderate MS subgroup (n=34) based on their ambulatory dysfunction (Disease Steps). Standardized clinical tests were performed. Step data from the StepWatch Activity Monitor were collected for 7 consecutive days.

Results: (1) Step count in PwMS was lower than PA recommendations, and is negatively influenced by a higher disability degree. (2) PwMS are 77% of the day inactive, and making steps for 22% at low and only 1% at moderate intensity. (3) Both MS subgroups rarely walk for more than 6 uninterrupted minutes, especially not at moderate intensity.

Conclusions: PwMS need to be motivated to make steps at moderate intensity, and to make steps for longer periods of time (minimal 10 uninterrupted minutes).

Key words

Physical Activity, Multiple Sclerosis, Walking.

1. INTRODUCTION

Persons with Multiple Sclerosis (PwMS), a progressive inflammatory and neurodegenerative disease of the central nervous system, are characterized by multiple neurological dysfunctions, amongst other motor impairments such as muscle weakness, hypertonia, ataxia as well as visual or cognitive dysfunction; all being considered as valuable bodily functions and impacting on gait (Heesen, et al., 2008) (Balantapu, Sosnoff, Pula, Sandroff, & Motl, 2014). Overall, one third of PwMS use an assistive mobility device like a cane, wheelchair, walker, or other (Larocca, 2011). Walking is a major problem in MS with 43% of the patients seeing this as a major problem that interferes in their life (Pike, Jones, Rajagopalan, Piercy, & Anderson, 2012). As a consequence, it is not surprising that persons with physical limitations are showing decreased walking mobility and physical activity (PA) in a daily life community setting, although part of reduced activity is also related to disuse (Motl, McAuley, & Snook, 2005) (Pearson, Busse, van Deursen, & Wiles, 2004) (Snook, Motl, & Gliottoni, 2009) (Stuifbergen, Blozis, Harrison, & Becker, 2006).

PA is defined as any bodily movement produced by skeletal muscles that requires energy expenditure. Physical *inactivity* has been identified as the fourth leading risk factor for global mortality in the general population. Also in PwMS, there is documented an increased risk for secondary cardiovascular diseases and the metabolic syndrome (Wens, Dalgas, Stenager, & Eijnde, 2013). Besides, it restricts participation in social life with an impact on travel behaviour, personal care, work and caring for children and family (Larocca, 2011) (Neven, et al.). In general, regular PA at moderate intensity – such as walking, cycling or participating in sports – has significant benefits for health. Healthy adults should make 10.000 steps per day according to the public health recommendations (Tudor-Locke, et al., 2011), whereas PwMS often do not reach this recommendation. Their average daily walking activity is overall 5.000-6.000 steps per day (Dlugonski, et al., 2013), with higher disability resulting in even fewer steps (Gijbels, et al., 2010). Many PwMS seem to reduce their physical activities when diagnosed, with even stopping all exercise in about one fifth of the population, despite the evidence that exercise is not leading to an increased relapse risk (Larocca, 2011) (Tallner, et al., 2012) and has been shown to potentially have a positive effect on fatigue, depression and quality of life (QoL) (Stroud & Minahan, 2009). Activity monitoring devices such as pedometers are increasingly applied to measure PA in daily living (Weikert, Motl, Suh, McAuley, & Wynn, 2010). Pedometers typically measure the daily number of steps taken (Gijbels, et al., 2010) (Cavanaugh, Gappmaier,

Dibble, & Gappmaier, 2011) (Sandroff, et al., 2014) and are thus a means to provide feedback to PwMS.

However, not only the number of steps per day is important for a healthy lifestyle, but also the intensity and duration of walking activity needs to be high enough to reach health benefits from self-directed PA. Guidelines for PA in healthy subjects recommend *30 minutes of moderate intensity* per day for 5 days per week, which may *also be performed in periods of at least 10 minutes* (Tudor-Locke, et al., 2011) (Tudor-Locke, 2010) (Haskell, et al., 2007). Recent guidelines on PA in MS advocate that to achieve important fitness benefits, PwMS with mild to moderate disability need *at least 30 minutes of moderate intensity aerobic activity 2 times per week* and strength training exercises for major muscle groups 2 times per week (Latimer-Cheung, et al., 2013). The average step-rate cut-off for moderate intensity PA is generally agreed as 100 steps per minute by researchers (Marshall, et al., 2009) (Tudor-Locke, Sisson, Collova, Lee, & Swan, 2005), which varies as a function of height, disease and disability (Tudor-Locke, et al., 2011). Recently, step-rate thresholds for PA intensity for ambulatory PwMS were developed (Agiouvasitis & Motl, 2014), by which for PwMS with minimal impairment and between a height of 158-190 cm, the predicted step-rate at moderate-intensity threshold was between 83-104 steps per minute; and between 83-101 steps per minute for PwMS with mild-moderate impairment.

Despite the wealth of papers on daily step count in MS, there is little information whether the guidelines of moderate intensity are being reached in a community setting. It was shown previously that only a small proportion of PwMS (20%) are achieving adequate amounts of daily moderate PA based on public health guidelines (30 minutes per day) (Klaren, Motl, Dlugonski, Sandroff, & Pilutti, 2013). However, there was no information on *the duration* of uninterrupted walking (or physical) activity at moderate intensity. Having knowledge about the duration when PwMS are making steps, is indispensable as PA guidelines recommend moderate intensity in periods of at least 10 uninterrupted minutes.

The objectives of the present study are to investigate PA in subgroups of PwMS with different degree of disability by providing (1) the number of steps; (2) the number of steps at low and moderate intensity during the day; and (3) the walking activity duration for 2, 3, 6, 10, 12 and 14 uninterrupted minutes, in total as well as at low and moderate intensity.

2. METHODS

2.1. Participants

The present study was part of a larger cross-sectional research project investigating changes in activity-related travel behaviour in PwMS, focussing on the relation between functional limitations, socio-economic and environmental factors (Neven, et al.). The study was approved by the ethical committees of Hasselt University, Rehabilitation and MS Center Overpelt, Antwerp University Hospital and National MS Centre Melsbroek. PwMS were recruited in the network of the REVAL Rehabilitation Research group (UHasselt), by neurologists of the rehabilitation centers, and after information sessions in an MS-specialized fitness center (Fit Up, Kontich) and support groups of the MS Society Flanders. All PwMS gave written informed consent and participated voluntarily.

Participants were included when they made minimal one outdoor trip weekly without using a wheelchair (Disease Steps, DS < 6). PwMS were excluded if they were bedridden, or had a relapse or related corticosteroid treatment within one month before the study. PwMS were divided in two subgroups, according to their Disease Steps (DS) describing ambulatory dysfunction (Hohol, Orav, & Weiner, 1995). The DS is a simple and brief clinical rating scale, based on a general physical examination by the researcher and the assistive devices needed to walk 25 feet. As patients were also recruited from the community, the DS was applied instead of the Expanded Disability Status Scale (EDSS) which is neurologist based, but there is however a strong correlation between both scales ($r=0.944$) (Hohol, Orav, & Weiner, 1999). Persons in the 'mild' subgroup with $DS \leq 2$ experienced no to mild limitations or might have a visible abnormal gait, but did not require ambulation aids to walk 25 feet. Persons in the 'moderate' subgroup with DS 3-5 required intermittent or continuous unilateral or bilateral support to walk.

2.2. Study design and outcome measures

The study design was similar as in the larger research project and preceding pilot study (Neven, et al.) (Neven, et al., 2013). At the first contact session at the persons' home or in a center, clinical measures were assessed, and the StepWatch Activity Monitor (SAM – see below) was thoroughly explained. During 7 consecutive days, walking activity was measured by wearing the SAM. In the second meeting after one week, the self-report indices and the SAM were returned. For the results on the activity-related travel behaviour, the reader is referred to previous publications (Neven, et al.).

2.2.1. Descriptive clinical measures

Clinical characteristics of PwMS by subgroup are shown in Table 1. The Multiple Sclerosis Functional Composite (MSFC) (National Multiple Sclerosis Society, 2001) measured the ambulation/leg function by the Timed 25-Foot Walk test (T25FW), the arm/hand function by the 9-Hole Peg test (9HPT) and cognition by the Paced Visual Serial Addition Test (PVSAT) (Nagels, et al., 2005). The Multiple Sclerosis Walking Scale (MSWS-12) measured the impact of MS on walking ability (Hobart, Riazi, Lamping, Fitzpatrick, & Thompson, 2003), while the impact of fatigue on daily functioning was measured by the Modified Fatigue Impact Scale (MFIS) (Kos, Nagels, D'Hooghe, Duportail, & Kerckhofs, 2006). The 36-item short-form health survey (SF-36) was used as self-assessment instrument for health related QoL with as well physical as mental health summary measures (Ware & Sherbourne, 1992).

2.2.2. Step count, walking intensity and walking activity duration

Walking activity was measured by the StepWatch Activity Monitor (SAM), a 2D accelerometer-based walking activity monitor that was shown to be highly accurate in persons with MS both at slow, comfortable and fastest speed (Sandroff, et al., 2014). The device is worn on the ankle, measures 75x50x20 mm and weighs approximately 38 grams. The SAM continuously records the number of strides per time interval (i.e. steps taken by the leg monitored) over extended monitoring periods. Total recorded single-sided strides were doubled in this study to represent both left and right steps. The time interval is adjustable, but one minute is encouraged for standardization and was also used in this study (Mudge & Stott, 2008). The SAM does not provide feedback to the subject and therefore minimizes impact on behaviour (performance behaviour) (Boone & Coleman, 2006). Main parameters of the SAM for the present study were:

1. Step count: Number of steps per day.

2. Walking intensity: Minutes and percentages of the day of inactivity, low and moderate intensity. The cut-point for moderate intensity is based on the recently developed step-rate threshold for PwMS which varies between 83-104 steps per minute (Agiovlasitis & Motl, 2014). Therefore, in our study we use cut-points 1-80 steps/min for low intensity and ≥ 82 steps/min for moderate intensity.

3. Walking activity duration: Number of times PwMS are making steps for 2, 3, 6, 10, 12 and 14 uninterrupted minutes. Minutes are based on different walking tests in MS (Gijbels, Eijnde, & Feys, 2011) (Kosak & Smith, 2005) as well as the PA guidelines recommending 30 minutes of moderate intensity per day, which may be performed in bouts of at least 10

(uninterrupted) minutes (Tudor-Locke, et al., 2011) (Tudor-Locke, 2010) (Latimer-Cheung, et al., 2013).

2.3. Data processing and statistical analysis

Of the 108 PwMS of the larger research project, step data from the SAM were collected from 72 PwMS. The other participants were wheelchair bound (n=13), did not receive a SAM due to operational (capacity) reasons (n=19), or were not willing to wear the SAM (n=4). Step data of 5 complete days were used in this study (4 days for n=4 PwMS), hereby exceeding the threshold of 3 days which is needed to reach a reliability of 0.80 (Motl, et al., 2007). 8 participants were excluded because they did not fulfil this quality control (by non-adherent wearing of the SAM), remaining 64 PwMS as participants in this study. The dataset included a combination of both weekdays and weekend days for each participant.

Data were analysed using SPSS Statistics ($p < 0.05$). Descriptive analyses were used for the descriptive clinical measures. Regarding the SAM data (step count, walking intensity and walking activity duration), means were calculated per day. The Shapiro-Wilk test indicated non-normal distributions of most clinical measures and therefore, non-parametric Mann-Whitney tests for independent samples and Chi-Square tests were used to examine differences between the mild and moderate subgroup.

3. RESULTS

3.1. Description of subgroups

Descriptive clinical measures of PwMS by subgroup (mild n=31, moderate n=33) are shown in Table 1. The overall significant disparity of physical outcome measures among subgroups justified the selected cut-off score 2 of the DS for differentiating between patients with various ambulatory dysfunction. On the other hand, there were no significant differences for the cognitive outcome measures (PVSAT, cognitive component of MFIS, mental subscore of SF-36). These findings suggest that the mild and moderate MS subgroup differ from each other on physical capacity, but cognition is not differently affected. Age and disease characteristics (MS type, duration since diagnosis) were significant different between MS subgroups.

3.2. Step count, walking intensity and walking activity duration

3.2.1. Step count

The average total number of steps per day is presented in Table 2. The data show that in general, persons with mild MS make significant more steps each day than the moderate MS subgroup. The number of daily steps is illustrated for each DS separately in Figure 1.

3.2.2. Walking intensity

The average number of steps at low and moderate intensity per day, as well as the average number of minutes (and percentage) at each intensity per day, is presented in Table 2. PwMS in the mild subgroup are overall significant more active during the day regarding number of steps, and walk significant more minutes at both low and moderate intensity.

3.2.3. Walking activity duration

In Table 2, the number of times that PwMS are making steps during an uninterrupted interval of n (2-14) minutes per day is shown. There is a significant difference between both subgroups for the number of times they are making steps during 2 and 3 uninterrupted minutes, but not for the other longer time periods. The data show that both subgroups do not often walk during more than 6 uninterrupted minutes.

3.3. Walking activity duration by intensity

Table 3 presents the number of PwMS by subgroup that are making steps at different intensities during an uninterrupted interval of n (2-14) minutes. The results at low intensity for 2,3 and 6 minutes show that there is almost no difference between both subgroups. About 60-70% of PwMS are making steps at low intensity during 10 uninterrupted minutes at least once a day; but only about 30% are making steps during 14 uninterrupted minutes. In relation to PA guidelines, there are only 6 PwMS in the mild subgroup (19%) and 9 in the moderate subgroup (27%) that are making steps 3 times per day for at least 10 uninterrupted minutes at low intensity (data not shown in the table).

Table 1: Clinical characteristics of PwMS by subgroup

Outcome measure	MS total (n=64) DS 1-5	Mild MS (n=31) DS 1-2	DS Moderate (n=33) DS 3-5	p-value comparison between subgroups
Disease Steps (DS)	2.8 ± 1.5 (1-5)	1.5 ± 0.5 (1-2)	4.1 ± 0.8 (3-5)	< 0.01
Type of MS (RR/SP/PP/unknown)	34/14/10/6	26/0/3/2	8/11/10/4	< 0.01
Disease duration (years)	13.6 ± 8.8 (2-38)	11.5 ± 8.4 (2-30)	15.6 ± 8.8 (2-38)	< 0.05
Age (Years)	49.5 ± 10.6 (25-73)	45.4 ± 9.8 (25-60)	53.3 ± 9.9 (34-73)	< 0.01
Gender (M/F)	26/38	9/22	17/16	ns
MS Functional Composite				
Timed 25 Foot Walk (s) ↓	10.3 ± 6.7 (4.1-29.6)	5.9 ± 1.2 (4.1-8.5)	14.5 ± 7.2 (6.1-29.6)	< 0.01
9 Hole Peg Test R (s) ↓	25.7 ± 7.4 (15.2-49.9)	22.9 ± 4.9 (15.2-38.1)	28.4 ± 8.5 (16.2-49.9)	< 0.01
9 Hole Peg Test L (s) ↓	28.6 ± 12.9 (14.8-86.8)	23.8 ± 4.9 (14.8-35.2)	33.3 ± 16.4 (17.5-86.8)	< 0.01
Paced Visual Serial Addition Test ↑	48.8 ± 12.2 (0-60)	51.2 ± 9.6 (26-60)	46.6 ± 13.9 (0-60)	ns
MS Walking Scale 12 ↓	39.4 ± 14.2 (13-60)	30.1 ± 11.2 (13-58)	48.2 ± 10.8 (21-60)	< 0.01
Modified Fatigue Impact Scale				
Total MFIS ↓	39.0 ± 15.8 (3-74)	34.1 ± 17.0 (3-74)	43.7 ± 13.7 (13-65)	< 0.05
Physical component ↓	19.7 ± 7.6 (1-32)	16.6 ± 8.0 (1-32)	22.6 ± 5.9 (5-32)	< 0.01
Cognitive component ↓	15.5 ± 8.4 (2-34)	14.3 ± 8.0 (2-34)	16.5 ± 8.8 (2-31)	ns
Psychosocial component ↓	4.1 ± 3.6 (0-28)	3.2 ± 2.1 (0-8)	4.8 ± 4.50 (-28)	< 0.05
Short Form (36) Health survey				
SF36 physical subscore ↑	31.7 ± 11.4 (9.1-53.8)	38.4 ± 9.1 (19.1-53.8)	25.5 ± 9.6 (9.1-43.0)	< 0.01
SF36 mental subscore ↑	49.6 ± 11.8 (20.2-66.4)	50.5 ± 10.0 (27.7-66.1)	48.8 ± 13.3 (20.2-66.4)	ns

Values are mean ± SD (range). Upward arrows indicate better performance with higher scores; downward arrows indicate worse performance with higher scores. Ns: not significant. P-value for Mann-Whitney & Chi-Square comparison between MS subgroups. PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis; RR, Relapsing-Remitting; SP, Secondary Progressive; PP, Primary Progressive.

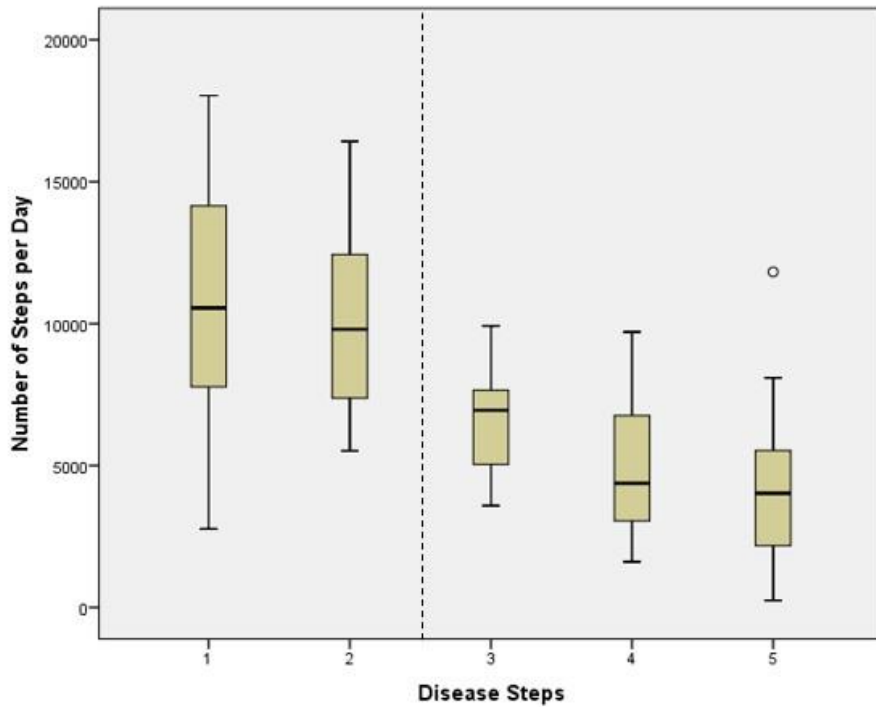


Figure 1: Relation between Disease Steps and number of steps per day

Regarding the moderate intensity level, fewer PwMS of the moderate subgroup are making steps during 2-3 minutes at moderate intensity than the mild subgroup. Only 42% in the mild subgroup makes steps at moderate intensity for 6 uninterrupted minutes, decreasing to 24% in the moderate subgroup. The majority of PwMS in the moderate subgroup (64%) never makes steps at moderate intensity, even not for short time periods. Only 13% and 3% of the mild and moderate subgroup, walk ≥ 10 minutes at moderate intensity, despite that the majority in the mild MS subgroup is able to walk at moderate intensity (≥ 82 steps/minute).

Table 2: Step count, walking intensity and walking activity duration of PwMS by subgroup

Outcome measure	MS total (n=64) DS 1-5	Mild MS (n=31) DS 1-2	Moderate MS (n=33) DS 3-5	p-value comparison between subgroups
1. STEP COUNT				
Number of steps per day	7636 ± 4202 (245 - 18031)	10243 ± 3817 (2767 - 18031)	5188 ± 2888 (245 - 11823)	< 0.01
2. WALKING INTENSITY				
Number of steps per day				
Low intensity	6251 ± 3133 (246 - 14434)	8013 ± 2996 (2766 - 14434)	4594 ± 2252 (246 - 8352)	< 0.01
Moderate intensity	1386 ± 1445 (0 - 5986)	2230 ± 1423 (0 - 5986)	592 ± 934 (0 - 3472)	< 0.01
Number of minutes per day				
Inactive	1137 ± 200 (816-2065)	1087 ± 212 (816-2065)	1184 ± 179 (985-1987)	< 0.01
Low intensity	324 ± 120 (57 - 645)	365 ± 105 (185 - 594)	285 ± 122 (57 - 645)	< 0.01
Moderate intensity	14 ± 14 (0 - 54)	22 ± 13 (0 - 54)	6 ± 9 (0 - 35)	< 0.01
Percentage of day				
Inactive	77% ± 8% (57%-96%)	73% ± 8% (57%-87%)	80% ± 7% (69%-96%)	< 0.01
Low intensity	22% ± 8% (4% - 41%)	25% ± 7% (13% - 41%)	19% ± 7% (4% - 32%)	< 0.01
Moderate intensity	1% ± 1% (0% - 4%)	2% ± 1% (0% - 4%)	0.4% ± 0.6% (0% - 3%)	< 0.01

Outcome measure	MS total (n=64) DS 1-5	Mild MS (n=31) DS 1-2	Moderate MS (n=33) DS 3-5	p-value comparison between subgroups
3. WALKING ACTIVITY DURATION Number of walking activity bouts per day lasting at least:				
2 minutes	71.2 ± 25.6 (11-136)	82.0 ± 24.9 (36-136)	61.1 ± 22.1 (11-91)	< 0.01
3 minutes	38.2 ± 14.5 (4-73)	42.8 ± 14.0 (20-73)	33.9 ± 13.9 (4-60)	< 0.05
6 minutes	9.3 ± 5.0 (0-29)	9.7 ± 4.0 (4-18)	8.9 ± 5.8 (0-29)	ns
10 minutes	2.3 ± 2.0 (0-11)	2.4 ± 1.5 (0-6)	2.3 ± 2.5 (0-11)	ns
12 minutes	1.4 ± 1.3 (0-7)	1.4 ± 1.0 (0-3)	1.3 ± 1.6 (0-7)	ns
14 minutes	0.8 ± 0.9 (0-5)	0.8 ± 0.6 (0-2)	0.8 ± 1.1 (0-5)	ns

Values are mean ± SD (range). Ns: not significant. P-value for Mann-Whitney comparison between MS subgroups. PwMS, Persons with Multiple Sclerosis; MS, Multiple Sclerosis. Low intensity 1-80 steps/min; Moderate intensity ≥82 steps/min.

Table 3: Walking activity duration by intensity: number of PwMS by subgroup

WALKING ACTIVITY DURATION BY INTENSITY	Low intensity (1-80 steps/min)		Moderate intensity (≥ 82 steps/min)	
	n	%	n	%
Mild MS subgroup (n=31)				
2 minutes	31	100%	29	94%
3 minutes	31	100%	26	84%
6 minutes	31	100%	13	42%
10 minutes	23	74%	4	13%
12 minutes	16	52%	2	6%
14 minutes	10	32%	1	3%
Moderate MS subgroup (n=33)				
2 minutes	33	100%	12	36%
3 minutes	33	100%	10	30%
6 minutes	31	94%	8	24%
10 minutes	20	61%	1	3%
12 minutes	13	39%	0	0%
14 minutes	9	27%	0	0%

4. DISCUSSION

The aim of this study was to investigate the actual daily walking activity of PwMS, disentangled by number, intensity and duration of steps, under real-world conditions in relation to the disability level. It was not only found that the number of steps was reduced, proportional to the disability level, but also that a considerable amount of PwMS are not walking for an uninterrupted duration of 10 minutes, and especially not at moderate intensity albeit capable. Results indicate a large non-compliance with PA recommendations advised for health promotion by both persons with mild and moderate MS.

The number of steps taken per day was previously shown to provide a reliable and valid outcome of free-living walking behavior in PwMS (Motl, Pilutti, Learmonth, Goldman, & Brown, 2013). The number found in this study was comparable to previous studies (Cavanaugh, Gappmaier, Dibble, & Gappmaier, 2011) (Gijbels, et al., 2010) (Shammas, et al., 2014) while, as expected, PwMS with mild ambulatory dysfunction made significant more steps than those with a higher disability degree (Filipovic, Matijaca, Lusic, & Capkun, 2011) (Gijbels, et al., 2010). The difference in daily step count can be partly explained by demographic factors as age (Dlugonski, et al.,

2013), however, the impact of the latter is considered to be small given only 8 years difference between subgroups in this study.

To achieve important cardiovascular health benefits from PA, not only the number of steps per day are important, but also the *intensity and duration of walking* needs to be high enough. The data demonstrate that PwMS of the mild disability subgroup clearly walk more minutes at moderate intensity than persons with moderate MS. Guidelines on PA advocate to have at least 30 minutes of moderate intensity activity, which may be performed in bouts of minimal 10 minutes. Therefore, in the present study, the number of *uninterrupted* minutes that PwMS make steps at low and moderate intensities were analyzed as well. The results show that both MS subgroups, on average, do not often make steps during 10 uninterrupted minutes or more, and certainly not at moderate intensity levels. About 60-70% of PwMS are making steps during 10 uninterrupted minutes at least once a day, but at low intensity. Only 6 PwMS in the mild subgroup (19%) and 9 PwMS in the moderate subgroup (27%) made steps 3 times per day for 10 uninterrupted minutes at low intensity. Regarding the moderate intensity level, only 13% of PwMS in the mild MS subgroup made steps for an uninterrupted duration of 10 minutes at moderate intensity at least once a day, and only 3% of PwMS in the moderate MS subgroup. There was no single participant (of 64 PwMS) that made steps 3 times per day for 10 uninterrupted minutes at moderate intensity level.

The low frequency of PwMS walking for at least 10 minutes at moderate intensity, is not related to an incapacity to walk at moderate intensity in the mild MS subgroup, as 94% of PwMS in the mild MS subgroup were able to make steps at moderate intensity for 2 consecutive minutes. This implies that the majority of participants with mild ambulatory dysfunction of the present study are able to make steps for at moderate intensity, but they simply don't do this for a longer period, needed to achieve the PA recommendations. It can be hypothesized that part of the patient sample may experience walking-related motor fatigue, leading to a slowing down of walking speed over time especially in the more disabled patient group. However, the latter cannot account for the large number of insufficiently active PwMS, and especially not in the mild MS subgroup where motor fatigue seems less prevalent. For future studies, one may include a long walking capacity test as the 6MWT or 12MWT to be able to document the walking intensity capacity during prolonged uninterrupted walking.

Educational and motivational strategies are needed to encourage PwMS with mild ambulatory dysfunction to make steps at a higher intensity and during

at least 10 uninterrupted minutes to improve their PA behaviour (Cavanaugh, Gappmaier, Dibble, & Gappmaier, 2011) (Tudor-Locke, 2010). There should be a paradigm shift towards "PA for health", by which a more physically active lifestyle is promoted through behavioral and self-management interventions to adapt their lifestyle incorporating a high level of PA, by increasing ambulatory activity (Motl, 2014). Hereby, pedometers and activity trackers can not only serve as an outcome measure for interventions but also as a direct information tool for patients, demonstrating the real type and intensity of daily physical activities performed by PwMS, including for example also outcomes of walking speed and duration besides the number of steps (Shammas, et al., 2014). Besides, educational programs are needed to make patients 'exercise-ready' and enable the belief that an active healthy lifestyle can be achieved (Feys, et al., 2013) (Smith, Olson, Hale, Baxter, & Schneiders, 2011).

Overall, behavioral (e.g. internet-delivered) interventions can be effective for increasing and sustaining PA in PwMS (Shammas, et al., 2014) (Motl & Dlugonski, 2011) (Dlugonski, Motl, Mohr, & Sandroff, 2012), and sometimes even leading to benefits in symptomatic outcomes like fatigue severity, depression and anxiety (Pilutti, Dlugonski, Sandroff, Klaren, & Motl, 2014). For other patients, conventional physical rehabilitation interventions like focusing on increasing leg muscle strength, dynamic balance or improving gait parameters may improve the walking activity in PwMS as well because of decreasing energy expenditure during walking (Motl, Sandroff, Suh, & Sosnoff, 2012). On a higher ICF level, improving the walking speed of PwMS appears to have important effects on the ability to participate in daily life by PwMS, as it had a significant impact on health-related QoL and (assistance in) activities of daily living (ADL) (Yildiz, 2012) (Goldman, et al., 2013).

There are also limitations in the present study related to the measurement technology. The approach on walking activity duration needs to be interpreted carefully. As the SAM uses time intervals of 1 minute for analysis in the StepWatch program, a minute is counted as active if a person makes minimal 1 (single-sided) step during this interval. Even if the person takes only a few steps in that 1 minute interval, the SAM analysis counts this as *walking* for one minute at low intensity. Therefore, the activity at low intensity may be overrated. A more correct designation of the parameter would therefore be 'step activity' instead of 'walking activity'. However, our findings of walking/step activity duration at moderate intensity are considered as valid in the context of achieving health benefits from PA, as this implies that a person with MS is making steps (and thus performing PA)

during several consecutive minutes without taking rest breaks between these minutes. Walking activity is an important part of PA, but there are also activities requiring a lot of body movements that are very intensive without foot displacement (e.g. gardening), and thus not measured by the SAM. Questionnaires such as the International PA questionnaires could be applied for this reason, however, have the drawback of potentially impaired recall to accurately quantify PA.

5. CONCLUSIONS

The results of the present study show that most PwMS are not active enough to benefit from the positive health outcome effects of PA; both in terms of daily number of steps, intensity of walking and walking activity duration. Since the majority of PwMS with mild ambulatory dysfunction are able to make steps at moderate intensity for several consecutive minutes, these persons have to be stimulated to increase their uninterrupted walking activity in their community setting.

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CHAPTER 5

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Methodology to optimize resource requirements of a Demand Responsive Transport system for persons with disabilities: case study of Flanders.

An Neven¹

Kris Braekers^{2,3}

Katrien Declercq¹

Tom Bellemans¹

Davy Janssens¹

Geert Wets¹

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² Hasselt University, Research Group Logistics, Diepenbeek, Belgium.

³ Research Foundation Flanders (FWO), Brussels, Belgium.

ABSTRACT

Demand Responsive Transport (DRT) services are frequently offered in the context of door-to-door transportation of elderly and persons with disabilities. The present study describes an optimization methodology to analyze the minimal resource requirements of a DRT system in terms of vehicles and drivers required and total distance traveled, by means of a vehicle routing plan, taking into account heterogeneous users (persons with different severity and type of disabilities), heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots (locations where vehicles are stored). The implementation of a geographically covered DRT system for the transportation of persons with disabilities in Flanders in the prediction years 2015, 2020 and 2030, was applied. A microscopic simulation of the demand of persons with disabilities for transportation, spatial and temporal effects taken into account, was applied over the whole service area, in order to obtain a detailed overview of all transportation requests that need to be processed by each individual service provider. Specific travel data of persons with disabilities (with specific disability-related attributes) were collected by means of a survey that was distributed among 344 persons with disabilities. Next, a separate vehicle routing plan was created for each service provider for both a weekday and weekend day, resulting in the required number of vehicles and vehicle kilometers. The results of the Flemish application show that the new DRT system seems unaffordable for the society, despite the applied optimization methodology.

Key words

Aged, Demand responsive transportation, Optimization, Physically handicapped persons, Routing, Simulation, Travel demand, Trip length.

1. INTRODUCTION

Demand responsive transport (DRT) services may be considered as transport on demand from passengers, using fleets of vehicles scheduled to pick up and drop off people in accordance with their needs (Grosso, Higgins, Mageean, & Nelson, 2002). In order to reduce operating costs, passengers may be grouped together in a vehicle (Chevier, Liefoghe, Jourdan, & Dhaenens, 2012). Hence, DRT is an intermediate form of transport, between fixed-route fixed-schedule public transportation and personal taxi services. Several variants of DRT exist, both in literature and practice. The concept is also denominated as demand responsive transit, dial-a-ride services, or paratransit, among others.

Two main types of applications of DRT may be distinguished. On the one hand, these kinds of services are offered in rural areas with low demand for public transport. Offering traditional fixed-route fixed-schedule services in these areas would be too costly, while flexible on-demand transport systems provide a more cost-efficient alternative. On the other hand, DRT services are frequently offered in the context of door-to-door transportation of elderly and persons with disabilities (PWD). This paper focuses on the second application. PWD often cannot make use of general public transportation services because these are not adapted to their needs. Age, walking difficulties and employment status are considered as important factors in the decision to make trips with DRT (Ben-Akiva, Benjamin, Lauprete, & Polydoropoulou, 1996). Besides lower employment levels and associating lower income levels, disabled persons are less likely to live in areas with easy access to social services (Maunder, Venter, Rickert, & Sentinella, 2004) and might have an increased level of car dependence (Davison, Enoch, Ryley, Quddus, & Wang, 2012). As an alternative to costly taxi services, authorities might introduce (subsidized) on-demand transportation systems to provide PWD with an affordable means of transportation. This should allow PWD to participate in social life, as individuals have a personal need to perform activities, requiring travelling to the destinations of these specific activities. Such DRT projects, offering transport for PWD, have been reported in many large cities around the world already. These type of services are expected to become even more widely spread in the future due to the ageing population in many western countries (Paquette, Cordeau, & Laporte, 2013) (Markovic, Milinkovic, Schonfeld, & Drobnjak, 2013), with associated potential to develop physical limitations in large numbers.

Given its increasing importance for mobility impaired people, DRT has received more research attention as well (Nguyen-Hoang & Yeung, 2010). Stated preference studies revealed that DRT would be considered as the most preferred travel mode above all by seniors with physical limitations. As PWD most likely have very few transport alternatives, DRT is extremely price-inelastic with a strong willingness to pay of its users. However, DRT services for PWD are expensive to provide, which makes it imperative to maximize its efficiency (Nuworsoo, 2009). Although a substantial proportion

of the costs of DRT might be paid by society rather than by the individual consumer in some regions, this does not reduce the costs, but merely shifts the incidence of payment (Oxley & Richards, 1995).

The present study describes an optimization methodology to analyze the minimal resource requirements of a DRT system in terms of vehicles and drivers required and total distance traveled, by means of a vehicle routing plan, taking into account heterogeneous users (persons with different severity and type of disabilities), heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots. An application in the region of Flanders is presented. A microscopic simulation of the demand of PWD for transportation is applied over the whole service area of Flanders, in order to obtain a detailed overview of all transportation requests that need to be performed by each specific service provider.

This paper is structured as follows: in the Problem statement, the context of the problem and the Flemish case study are discussed. Next, the creation of all transportation requests of PWD, and the methodology to calculate the associating resource requirements of the different types of service providers, are described. The following section describes the results of the study, while the paper concludes with discussing future research opportunities and major conclusions.

2. PROBLEM STATEMENT

Given the increasing importance of DRT, with social participation enhancement of PWD as ultimate goal, some governments have committed to a more coherent approach regarding the organization of DRT services, in order to offer affordable adapted transport. Since DRT are expensive to provide, there is a need to organize them in a cost effective way in order to be able to meet this commitment. The present study describes a methodology to optimize the resource requirements to offer round the clock DRT services in a region, using a large number of individual service providers.

Previous studies on calculating the resource requirements of DRT systems have mainly focused on the required fleet size (number of vehicles) (Markovic, Milinkovic, Schonfeld, & Drobnyak, 2013) (Fu, 2003) (Diana, Dessouky, & Xia, 2006) (Luo & Schonfeld, 2012). For an overview of literature on this topic, the reader is referred to (Markovic, Milinkovic, Schonfeld, & Drobnyak, 2013) and (Diana, Dessouky, & Xia, 2006). The majority of research has focused on estimating resource requirements based on a limited set of parameters which are assumed to be constant and applicable to all users (service area size, demand density, time window length, maximum ride time, average ride length, and others). Hence, spatial and temporal dependencies between user requests are mostly not taken into account, i.e. requests are distributed uniformly over space and time. Recently, Markovic et al. have proposed a model which takes into account

peak and non-peak demand periods (Markovic, Milinkovic, Schonfeld, & Drobnjak, 2013). Their results demonstrate the need to model DRT operations of an entire day instead of only during a peak period, due to the existence of route duration limits in practice. To the best of our knowledge, only Deflorio (Deflorio, 2011) and Kuo et al. (Kuo, Shen, & Quadrifoglio, 2013) consider both spatial and temporal effects of demand for DRT services. Finally, Luo et al. (Luo & Schonfeld, 2012) indicate that existing models often suffer from the limitation of using manual or very simple vehicle routing algorithms (e.g. insertion algorithms) and neglecting user time constraints.

In this paper, resource requirements are measured in terms of vehicles and drivers required and total distance traveled. Distance traveled is taken into account since it has a large impact on the operating costs of the service providers. Estimation of minimal requirements is based on a model which optimizes the transportation planning of each individual service provider. In contrast to other papers, this vehicle routing and scheduling step for each service provider is optimized using a state-of-the-art meta-heuristic algorithm instead of using a simple insertion algorithm. This way, better solutions are obtained. In order to solve the vehicle routing problem, detailed data about the demand and supply of DRT services are necessary. Spatial and temporal effects of demand are of importance, as these effects greatly influence the ability to combine requests of several users into a single route, which clearly has a large impact on the required resources and the service cost-efficiency (Deflorio, 2011) (Kuo, Shen, & Quadrifoglio, 2013). As well, specific personal disability-related data (e.g. type and severity of disability of each PWD, probability of making trips) need to be taken into account, as the activity system and the weekly rhythms of PWD are different from those of the general population (Desharnais & Chapleau, 2012), and the disability-related characteristics can influence the mode choice of each individual trip. Therefore, a microscopic simulation of the demand of PWD for transportation is applied. The input of this vehicle routing problem is a detailed list of all transportation requests that need to be performed by each specific service provider, containing for each request the specific pick-up and drop off location, desired timing, capacity requirements (wheelchair, accompanying person), and others. Using aggregated data would not reveal such detailed data, causing that the spatial, temporal and disability-related effects would not be taken into account.

This paper describes the application of the optimization methodology to analyze the minimal resource requirements of a new DRT system for PWD in the region of Flanders (the northern, Dutch speaking part of Belgium). Flanders is characterized by an area of 13.521 km², a population of six million inhabitants and a population density of 470 inhabitants per km². The need for a more coherent approach was recognized by the Flemish government, and a new Decree about DRT services was issued: the 'Decree to compensate the public service obligation of the transport of persons with a disability or seriously limited mobility' (Flemish Parliament, 2012),

approved in December 2012. The idea behind this Decree is that a mobility system will be developed by which subsidized adapted transport will be offered, geographically covering the whole of Flanders. Hereby, on the one hand, PWD can make use of voluntary organizations, denoted as 'Less Mobile Services' (LMS), relying on volunteers who use their own passenger car to offer transportation services in their neighborhood. This type of service is only available for persons in low income classes (income constraint of 2x the current living wage), and persons in a wheelchair cannot be accommodated. On the other hand, if PWD do not meet these conditions, they can rely on a limited set of geographically dispersed 'Adapted Transport Services' (ATS) that are compensated by the Flemish government. These ATS services generally use a heterogeneous fleet of vehicles with at least one adapted vehicle, and are suitable for persons in a wheelchair. The (predetermined selection of) 'compensated' service providers may apply for a compensation of the government for their driven kilometers with a wheelchair user or person with seriously limited mobility, and therefore they can offer payable adapted transport to PWD.

Disaggregated data are used to simulate the transportation requests of PWD in Flanders. Disability-related data (e.g. type and severity of disability of each PWD) and travel behaviour data of PWD (e.g. probability of using adapted transport) are collected, as these characteristics influence the use of a specific transportation service. Figure 1 shows the specific conditions of both types of transportation services (LMS and ATS), and their relation to the disability-related characteristics of PWD. The objective of this study is to determine the minimal resource requirements to offer round the clock on-demand transportation services in the whole region, using a large number of individual, local, voluntary service providers as well as selected compensated service providers of this Decree. These resource requirements are calculated for the start-up year 2015, as well as for the medium term (2020) and for the long term (2030).

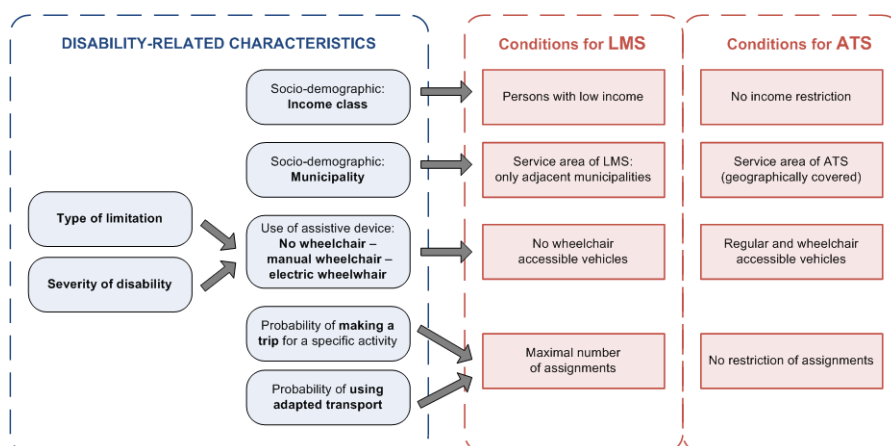


Figure 1: Conditions of using LMS and ATS services, and their relation to disability-related characteristics of PWD.

3. METHODOLOGY

3.1. Overview of procedure

To determine the minimal resource requirements of this geographically covered DRT system, a detailed overview of all transportation requests that need to be performed by each specific service provider, is necessary. Figure 2 shows the procedure to determine the minimal resource requirements. The first step consists of creating a synthetic population of all PWD in Flanders (3.2), representing individual actors (so-called 'agents') which are statistically equivalent to the real population of PWD in Flanders. Next, the transportation requests of these PWD are generated with specific travel-related characteristics (3.3). Each simulated transportation request is first assigned to a specific service provider (3.4), after which a separate vehicle routing plan is created for each provider (3.5) for both a weekday and weekend day. This plan results in the minimal required number of vehicles and vehicle kilometers in order to perform all transportation requests assigned to this specific provider.

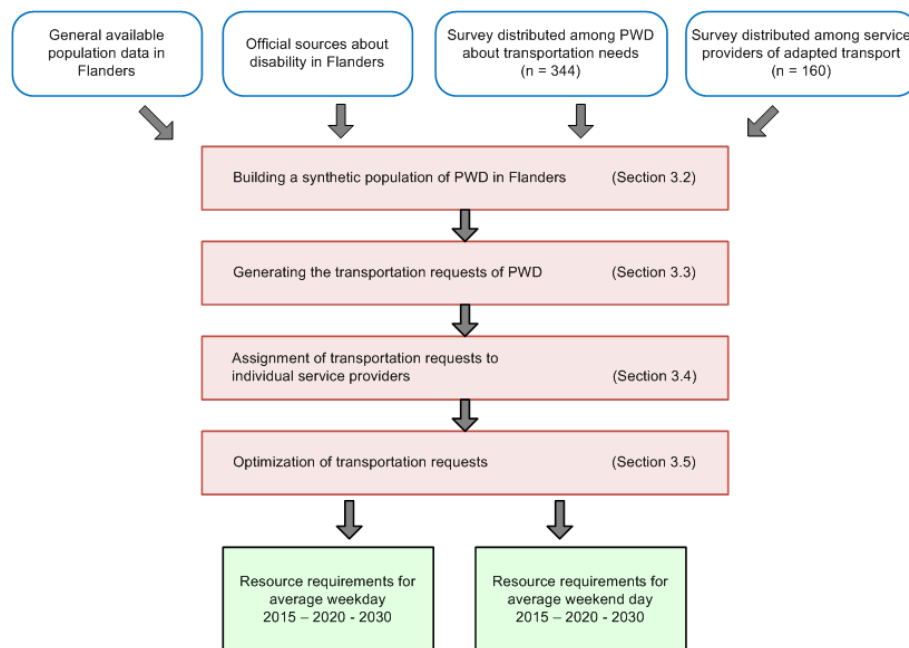


Figure 2: Flowchart of the procedure to determine the minimal resource requirements of the DRT system.

3.2. Building a synthetic population of PWD in Flanders

Aggregate data at population level in Flanders are available by means of the 'General socio-economic survey 2001', where the full Flemish population (about 6 million) was obligatory surveyed on several socio-demographic

variables (age, gender, etc.) (Algemene Directie Statistiek en Economische Informatie, 2006). Official sources about disability are consulted, such as the Flemish Agency for Disabled Persons and the Federal Public Service of Social Security. As well, a survey is distributed among PWD in Flanders between June and July 2012. A total of 344 internet-based questionnaires are completely filled out by persons with various types and severity of disability, e.g. persons with physical limitations, intellectual limitations, visual limitations, and others.

The distribution of allowances of PWD in Flanders offers detailed information about the number of PWD in each municipality, by age group and gender. Information about the *type of limitation* (or combination of types) is needed as this influences the assignment to a specific service provider (and associating fleet of vehicles). For example, persons with severe motor impairments likely need a wheelchair accessible vehicle, while the vehicle type to transport individuals with an intellectual impairment is less relevant. The *severity of the disability* is based on information about the level of independence of PWD in Flanders, which is generally determined by a medical assessment in order to calculate the amount of allowance the disabled person may claim. Based on the previous variables, the *probability of using an assistive (ambulatory) device* is determined, influencing the decision whether not wheelchair accessible vehicles could be used or not. Persons with a high level of independence are less likely to use a manual or electric wheelchair, while this probability increases in persons with a lower level of independence. For an overview of the influencing factors of the assignment to a specific service provider, the reader is referred to Figure 1.

Based on this information, the synthetic population of all PWD in Flanders is created, which aims at reproducing the human behaviour of PWD at the individual level (e.g. *how many activities and trips are made by PWD or which transport mode do they use?*). The population is created by means of the Iterative Proportional Fitting (IPF) technique (Ye, Konduri, Pendyala, Sana, & Waddell, 2009). Population projections from the Federal Planning Bureau (Bryon, Duyck, Lambrecht, & Paul, 2011) are used as marginals to generate the population data for the prediction years 2015, 2020 and 2030 respectively. As a result, each person of the synthetic population is simulated on a microscopic scale, with specific socio-demographic and disability-related characteristics: municipality, gender, age, income class, type of limitation, severity of disability, and use of an assistive device (e.g. walking cane, manual or electric wheelchair, electric scooter). For the future prediction years (2020 and 2030), the percentage of persons with disabilities in each age category, the severity of disability and all other socio-demographic and disability-related characteristics are supposed to be constant. As well, the activity and travel patterns are assumed unaltered.

3.3. Generating the transportation requests of PWD

All individuals of the synthetic population are also simulated with a number of travel-related characteristics, using probability distributions of the characteristics based on the results of the survey that was distributed among PWD. The conditional probability of making a (specific) activity-related trip is based on the queried number of performed trips (for each type of activity). Based on the frequency of the use of different transport modes, the conditional probability of using adapted transport for a specific type of activity is estimated for each individual. As well, the acceptable maximum user ride time of trips with adapted transport (i.e. the maximum time a person would accept to spend in the vehicle) is obtained by means of this survey. The study area is divided in 2386 transportation analysis zones (TAZ), of which attractiveness measures are available via the General socio-economic survey 2001 (3.2), resulting in the conditional probability of going to a specific TAZ while making a trip with adapted transport.

All individuals' personal and travel-related attributes are used as inputs to generate the list of transportation requests (i.e. the demand of transport) of PWD in Flanders, for an average weekday and weekend day. Table 1 shows the (generated) number of PWD in the synthetic population and their trips made by DRT.

Table 1: Number of PWD, and trips by DRT by PWD in Flanders of 1 weekday, by assistive device

	No wheelchair	Manual wheelchair	Electric wheelchair	Total
Number of PWD in Flanders				
2015	154,094	23,032	7,792	184,918
2020	164,320	24,398	8,159	196,877
2030	185,589	27,644	9,122	222,355
Number of trips by DRT by PWD in Flanders				
2015	27,718	4,044	1,376	33,138
2020	29,628	4,274	1,396	35,298
2030	33,126	5,038	1,670	39,834

3.4. Assignment of transportation requests to service providers

The objective of the Decree about DRT services, which was recently issued by the Flemish government, is to provide affordable adapted transport in

the whole of Flanders. On the one hand, services will be provided by LMS (voluntary organizations) for those who are eligible, and on the other hand by a selected set of compensated ATS service providers. However, the practical implementation process of the Decree, and the actual selection of compensated service providers, is still being evaluated at the moment.

A (second) survey was distributed among current individual service providers of adapted transport in Flanders, which provided information about the demand (e.g. timing of the trips, travel times) and supply of transport (e.g. service area, capacity and number of vehicles) in their specific organization. Since the average radius of the service area of an individual service provider in Flanders currently is 20-25 kilometers, we assume service areas of similar size in this paper for the compensated service providers. This approach leads to 26 compensated ATS service providers in Flanders. Another assumption is that the amount of volunteers, offering inexpensive transport by LMS, will increase in the future, as the proportion of young retirees will increase the coming years (due to the ageing population). Since these people are still (physically) active, no longer work and as a consequence have more time available, it may be expected that a portion of them is willing to sign up as a volunteer for these services. Therefore, we assess that a doubling of the current number of volunteers is realistic, and consequently a doubling of the current supply of transport by LMS will occur.

To estimate the minimal resource requirements for this system of DRT services, a vehicle routing problem is solved for each of the service providers individually (3.5). To do so, each transportation request as simulated in 3.3 should first be assigned to a specific service provider. Therefore, for each service provider the following attributes are estimated based on the survey that was distributed among the individual service providers of adapted transport in Flanders:

- Average number of seats in regular vehicles;
- Average number of seats in adapted vehicles (if there are any);
- Average number of wheelchair places in adapted vehicles (if there are any);
- Number and locations of vehicle depots;
- Service area.

Each transportation request is assigned to a specific service provider as follows. It is analyzed whether the user that initiated the transportation request is allowed to make use of a LMS service. This is the case when the user is not in a wheelchair, his income is below a certain threshold, the transportation request takes place within the service area of a LMS service provider and the maximum number of assignments to LMS's is not reached (Figure 1). The maximum number of assignments is imposed because the number of volunteers is limited to twice the current level. When one of the conditions is not met, the request is assigned to the closest of the 26 compensated ATS service providers. The distribution of trips during the day

is derived from the survey among the service providers. Both types of service providers are providing shared-ride trips, and are therefore different from commercial taxi services.

3.5. Optimization of transportation requests

For each service provider, a separate vehicle routing plan is created, both for a weekday and for a weekend day. A vehicle routing plan is a schedule that determines which transportation requests are performed by which vehicle and, for each vehicle, the respective order in which the requests are performed. This plan gives an indication on how many vehicles and vehicle kilometers are required on an average weekday or weekend day in order to perform all transportation requests assigned to this specific provider. The detailed input list of transportation requests is derived from the microscopic simulated synthetic population, with associated travel characteristics, taking into account the spatial and temporal effects of demand. In order to take into account the variability of travel times during a day, each weekday is divided into five time intervals: morning peak (6-9am), day (9am-4pm), afternoon peak (4-7pm), evening (7-22pm) and night (10pm-6am). Transportation requests are assigned to the appropriate interval, based on the desired timing. A separate planning is made for each interval, using appropriate travel times. A similar approach is used for weekend days, but only a day (6am-22pm) and a night period (22pm-6am) are assumed.

To obtain an efficient vehicle routing plan for a given service provider and time interval, a dial-a-ride problem (DARP) is solved. Dial-a-ride problems are a generalization of the classical capacitated vehicle routing problem (VRP). They are closely related to the Vehicle Routing Problem with Pickup and Delivery (VRPPD), in which goods have to be transported from a specific pick-up to a specific delivery location (Cordeau, Laporte, Potvin, & Savelsbergh, 2007). A major distinction is the fact that dial-a-ride problems deal with transporting people rather than goods. Hence, user inconvenience should be accounted for. This is generally done by imposing additional constraints to restrict user inconvenience or by introducing some quality of service aspects in the objective function of the problem. In this paper, the first approach is followed.

Most research on DARP considers a homogeneous set of users and a homogeneous fleet of vehicles located at a single depot (Braekers, Caris, & Janssens, 2013) (Braekers, Caris, & Janssens, 2013). However, in the application described in this paper, two types of users are considered (non-wheelchair and wheelchair). Besides, service providers may operate both regular and adapted vehicles, located at several depots in the service area. For an overview of research on DARP taking into account such heterogeneous aspects of users and vehicles, the reader is referred to (Braekers, Caris, & Janssens, 2013) and (Parragh, 2011). General overviews of literature on DARP are provided by Cordeau et al. (25-26), and Parragh et al. (Parragh, Doerner, & Hartl, 2008).

To the authors' knowledge, the Multi-Depot Heterogeneous Dial-A-Ride Problem (MD-H-DARP) introduced by Braekers et al. (Braekers, Caris, & Janssens, 2013) (Braekers, Caris, & Janssens, 2013) is the only problem that simultaneously deals with heterogeneous users, heterogeneous vehicles and multiple depots. Hence, in this paper this problem definition is adopted. The MD-H-DARP is defined as follows. Users specify a set of transportations requests between specific pick-up and drop off locations. With each request a time window at the pick-up location (inbound requests) or at the drop off location (outbound requests) is associated (see 3.4). This time window indicates the time interval between which service (picking up or dropping off the user) should start. Furthermore, each request has a service time (time needed to pick-up/drop off the user) and a capacity requirement for regular vehicle seats and for wheelchair places. Finally, a maximum user ride time is defined, indicating the maximum time the user may spend in the vehicle. Transportation is performed by a set of vehicles with limited capacity for both vehicles seats and wheelchair places. Each vehicle is assigned to a depot where it should start and end its route. To take into account maximum shift durations of drivers, a maximum route duration is imposed. The objective is to minimize total distance traveled, while satisfying all transportation requests without violating time window, ride time and maximum route duration constraints.

A slight adaptation to this problem definition is made in this paper. The number of vehicles to be used is an objective rather than a constraint. Hence, an unlimited fleet of vehicles is assumed, together with a hierarchical objective function which first minimizes the number of vehicles used and second total distance traveled.

Braekers et al. (Braekers, Caris, & Janssens, 2013) propose two algorithms to solve the MD-H-DARP: an exact branch-and-cut algorithm and a deterministic annealing meta-heuristic. The exact algorithm can only be used to solve relatively small problems in terms of number of transportation requests, while the meta-heuristic approach provides near-optimal solutions within a couple of minutes even for large problems (≥ 100 requests). Experimental results on several sets of benchmark instances have indicated that the meta-heuristic algorithm outperforms other state-of-the-art solutions methods on homogeneous and heterogeneous dial-a-ride problems. Therefore, in this paper the meta-heuristic approach is used to solve the routing problem of each service provider. The algorithm is implemented in C++.

4. RESULTS

The model described in Section 3 is applied for three prediction years (2015, 2020, 2030). Results for an average weekday and weekend day are reported in Table 2. Next to total results, results for both types of service providers (LMS and ATS) are shown separately. The number of vehicles required for a service provider is calculated by taking the maximum number of vehicles used over all time intervals of the day.

The results show that a large number of resources are required to offer DRT services, given the fact that e.g. a fleet of 3285 vehicles is needed to perform all transportation requests on an average weekday (Table 2). This resource requirement is expected to increase considerably in the coming years, as indicated by the results for 2020 and 2030. For all service providers together, the number of transportation requests is expected to increase by 20% from 2015 to 2030. This increase is solely an effect of the ageing population and the associated probability of developing physical limitations. As a result, minimal resource requirements in terms of vehicle and kilometers increase almost proportionally by respectively 19% and 20%.

Transportation requests and hence resource requirements are considerably higher during weekdays than during weekend days in our model. This can be explained by the fact that recurrent trips to the fitness, physiotherapist or rehabilitation center, trips for day care, or trips to the doctor or hospital, of which the frequencies are based on the self-collected data of PWD of the survey, are mostly performed on weekdays. This pattern is similar to persons without disabilities, as they also make significantly fewer trips on Sunday compared to weekdays (Declercq, Janssens, & Wets, 2012), but the specific activity types of PWD in our model are different compared to persons without disabilities.

Finally, from Table 2 it is clear that for this case study, most transportation requests will be performed by the ATS service providers. Only about 11% of all requests are carried out by LMS service providers, due to their strict acceptance rules and limited number of volunteers.

More detailed information on the number of requests per service provider and on route characteristics for the year 2015 is shown in Table 3. While LMS operate on a local scale with few requests per day (given on average 16 requests per provider per day, Table 3), the 26 compensated ATS service providers operate on a larger area with a huge number of requests per day (1128 requests per provider). Furthermore, results indicate that average route length is considerably smaller for LMS. The reason is that the maximum route duration is generally much lower for these services (e.g. 4h instead of 8h) since they rely on volunteers which are often only available for a couple of hours per day. Average trip length is on average 17 kilometers (almost similar for LMS and ATS during weekdays), and on average about 1.2 passengers are present in a vehicle at a given time.

Table 2: Results for an average weekday and average weekend day, by type of service providers

		LMS Less Mobile Services		ATS Adapted Transport Services		Total	
			%		%		%
Results for an average weekday							
Total number of requests	2015	3,806	-	29,332	-	33,138	-
	2020	4,068	+ 6.9	31,230	+ 6.5	35,298	+ 6.5
	2030	4,572	+ 20.1	35,262	+ 20.2	39,834	+ 20.2
Total number of vehicles required	2015	690	-	2,595	-	3,285	-
	2020	722	+ 4.6	2,730	+ 5.2	3,452	+ 5.1
	2030	797	+ 15.5	3,114	+ 20.0	3,911	+ 19.1
Total number of kilometers traveled	2015	128,987	-	869,574	-	998,561	-
	2020	129,947	+ 0.7	928,086	+ 6.7	1,058,034	+ 6.0
	2030	155,281	+ 20.4	1,040,911	+ 19.7	1,196,192	+ 19.8
Results for an average weekend day							
Total number of requests	2015	2,206	-	18,118	-	20,324	-
	2020	2,512	+ 13.9	19,126	+ 5.6	21,638	+ 6.5
	2030	2,804	+ 27.1	21,584	+ 19.1	24,388	+ 20.0
Total number of vehicles required	2015	441	-	1,592	-	2,033	-
	2020	472	+ 7.0	1,742	+ 9.4	2,214	+ 8.9
	2030	556	+ 26.1	1,968	+ 23.6	2,524	+ 24.2
Total number of kilometers traveled	2015	68,789	-	525,014	-	593,803	-
	2020	86,189	+ 25.3	555,980	+ 5.9	642,169	+ 8.1
	2030	100,857	+ 46.6	630,391	+ 20.1	731,248	+ 23.2

5. DISCUSSION

From the results of the Flemish application, it is clear that an enormous amount of resources are required to implement a region-wide system of transportation services adapted to PWD in Flanders, e.g. a necessary number of 3285 vehicles and a total of almost 1 million kilometers for an average weekday (Table 2). Solely relying on volunteers and a limited number of compensated ATS service providers seems not feasible. In the future, these requirements will even be much larger as the demand for adapted transport will increase because of the ageing population, making the proposed results completely unaffordable for the Flemish government, given that the necessary number of vehicles will even increase to 3911 in 2030. Furthermore, implementing such a system would exclude all current

commercial service providers, as a geographically covered DRT system of compensated service providers is assumed. Clearly, this would be a sensitive policy measure.

Table 3: Detailed results for prediction year 2015

	Weekday			Weekend day		
	LMS	ATS	Total	LMS	ATS	Total
Number of service providers	240	26	266	240	26	266
Average number of requests per provider per day	15.9	1128.2	124.6	9.2	696.9	76.4
Average number of kilometers per route	78.5	121.5	113.4	71.7	130.6	119.3
Average number of kilometers per request	17.0	17.4	17.3	14.6	16.9	16.6
Average number of requests per route	2.3	4.1	3.8	2.3	4.5	4.1
Average number of passengers in vehicle	1.2	1.2	1.2	1.2	1.2	1.2

To overcome these problems, the idea has emerged to only offer compensated DRT services for a realistic, limited number of transportation requests, based on e.g. the traveler's mobility restriction, the availability of accessible public transport, the type of activity, and the financial possibilities. All other requests could then be performed by commercial service providers in Flanders. Our model can easily be applied to calculate the effect of such a combined system on the minimal resource requirements. In the assignment step, only those transportation requests passing the objective selection criteria should be assigned to a specific compensated service provider. All other transportation requests may either be removed from the model, or may be used to model the service requirements of the commercial service providers.

In the present study, disaggregated data are used to simulate the transportation requests of PWD on a microscopic scale, taken into account spatial, temporal and disability-related characteristics of the transport demand. This is an important advantage compared to formerly used four step models, based on aggregate data and neglecting these detailed behavioral information. Additional improvements could be made by using activity-related travel diaries, instead of surveys about the frequencies of making trips for each activity type in this study, in order to gather exact information of the individual activity patterns of PWD.

Regarding the destination choice of the trips by adapted transport, our model is an improvement over similar models, as other models mostly assume a uniform distribution of origin and destination locations, instead of taking into account the availability and attractiveness of zones for specific activity types (Luo & Schonfeld, 2012). In the present study the destination choice of the trips by adapted transport was determined by the attractiveness of the different TAZ for each activity type, based on the General socio-economic survey (3.2). Future research may take into account the attractiveness of specific care related facilities mostly used by PWD.

In this study, it was assumed that geographically covered transport in Flanders was provided by 26 individual ATS service providers (with an average service area of 20-25 km), and that the number of volunteers would double (with consequently a doubling of the current supply of transport by LMS). These assumptions are input parameters of the model, and can easily be modified to analyze the effects of changes of these parameters. For example, the model can also be calculated if assuming a smaller or larger service area and consequently a smaller or larger number of service providers; or if the number of volunteers would decrease. Modifying the size of the service areas could lead to additional optimization, as economies of scale (e.g. higher occupancy rates of the vehicles) influence the minimal resource requirements.

Future research may also focus on analyzing the effects of changing the service attributes of the vehicle route planning (e.g. longer maximum user ride times), causing that more passengers could be grouped together in a vehicle per route. Because of budget constraints, it is important to establish what service attributes would have the greatest impact for PWD as well as for the society as a whole, and what tradeoffs can be made among them (Ben-Akiva, Benjamin, Lauprete, & Polydoropoulou, 1996). A social cost-benefit analysis could facilitate the weighing up of all social advantages and disadvantages of the various service attributes changes, not only in monetary terms (vehicles and drivers required, total compensated distance), but also in terms of participation enhancement, quality of life of PWD, and others. Our model can be applied to calculate the impact of changed service attributes.

6. CONCLUSION

- The present study shows that the proposed optimization methodology can easily be applied to determine the minimal resource requirements of a specific DRT system, while taking into account heterogeneous users, heterogeneous vehicles and multiple depots.
- The microscopic simulation of demand of PWD offers various advantages: a high spatial and temporal resolution of the transport demand (which allows to combine requests of several PWD into a single route), knowledge about specific disability-related characteristics

(influencing the mode choice of individual trips), and knowledge about specific travel behaviour patterns of PWD.

- The results of the Flemish application show that the new Decree about DRT services, by which affordable adapted transport will be offered for PWD, geographically covering the whole of Flanders, seems unaffordable for the society as a whole, despite the applied optimization methodology.

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CHAPTER 6

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Assessing the impact of different policy decisions on the resource requirements of a Demand Responsive Transport system for persons with disabilities.

An Neven¹

Kris Braekers^{2,3}

Katrien Declercq¹

Geert Wets¹

Davy Janssens¹

Tom Bellemans¹

¹ Transportation Research Institute (IMOB), Hasselt University, Diepenbeek, Belgium.

² Hasselt University, Research Group Logistics, Diepenbeek, Belgium.

³ Research Foundation Flanders (FWO), Brussels, Belgium.

ABSTRACT

Demand Responsive Transport (DRT) services are frequently offered in the context of door-to-door transportation of elderly and persons with disabilities (PWD), but are expensive to provide. Therefore, the present study aims to determine the impact of different policy decisions on the resource requirements of a DRT system, in terms of vehicles and drivers required and kilometers traveled. A number of policy scenarios are analyzed in the case study of Flanders for the prediction years 2015, 2020 and 2030: a base scenario assuming a geographically covering subsidized DRT system; a more economical scenario limiting the subsidized DRT services; a more accessible public transport; more flexibility of the users of the DRT system; an increase in the service area of the DRT service providers; and a doubling of the current supply of transport by volunteers.

A microscopic simulation of the demand of elderly and PWD for transportation was performed in order to obtain a detailed overview of all transportation requests that need to be processed. Next, each simulated transportation request was assigned to a specific service provider and a separate vehicle routing plan was created, taking into account heterogeneous users (persons with different severity and type of disabilities), heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots. Resource requirements were calculated for each of the considered scenarios.

The results show that changing the modal split (the mix between the different DRT providers), as well as the realization of adequate public transport and an improved flexibility, seem to be key elements in Flanders to minimize the resource requirements of a DRT system. Our applied methodology can easily be transferred to other regions or areas, as the flexibility of the model allows to easily modify the input criteria based on the specific context. This information can be used by governments for the optimization of their DRT system.

Key words

Demand Responsive Transport, Paratransit.

1. INTRODUCTION

Demand responsive transport (DRT) services may be considered as transport on demand from passengers, using fleets of vehicles scheduled to pick up and drop off people in accordance with their needs (Grosso, Higgins, Mageean, & Nelson, 2002). In order to reduce operating costs, passengers may be grouped together in a vehicle (Chevrier, Liefoghe, Jourdan, & Dhaenens, 2012). Hence, DRT is an intermediate form of transport, between fixed-route fixed-schedule public transportation and personal taxi services. Several variants of DRT exist, both in literature and practice, and the concept is also denominated as demand responsive transit, dial-a-ride services, or paratransit, among others.

Two main types of applications of DRT may be distinguished. On the one hand, these kinds of services are offered in rural areas with low demand for public transport (PT). On the other hand, DRT services are frequently offered in the context of door-to-door transportation of elderly and persons with disabilities (PWD). This paper focuses on the second application. PWD often cannot make use of general PT services because these are not adapted to their needs. Age, walking difficulties and employment status are considered as important factors in the decision to make trips with DRT (Ben-Akiva, Benjamin, Lauprete, & Polydoropoulou, 1996). Besides lower employment levels and associated lower income levels, disabled persons are less likely to live in areas with easy access to services (Maunder, Venter, Rickert, & Sentinella, 2004) and might have an increased level of car dependence (Davison L. , Enoch, Ryley, Quddus, & Wang, 2014). As an alternative to costly taxi services, authorities might introduce (subsidized) on-demand transportation systems to provide PWD with an affordable means of transportation. This should allow PWD to participate in social life, as individuals have a personal need to perform activities, requiring travelling to the destinations of these specific activities. Such DRT projects, offering transport for PWD, have been reported in many large cities around the world already. These types of services are expected to become even more widely spread in the future due to the ageing population in many western countries (Nguyen-Hoang & Yeung, 2010) (Nuworsoo, 2009), with associated potential to develop physical limitations in large numbers.

Originally, the application of the DRT concept in the context of transportation for PWD grew in the 1970s and 1980s, when countries started to develop legislation for transport authorities to provide transport to PWD (e.g. Sweden, the UK, the USA) (Nelson, Wright, Masson, Ambrosino, & Naniopoulos, 2010). Some countries have been successful at integrating elderly and PWD into the mainstream PT by implementing accessible PT (e.g. Sweden), but in other countries conventional fixed route PT was often not sufficiently designed for use by PWD. Therefore, this disability discrimination legislation has led to many DRT services being

developed to meet this transport challenge (Mulley, Nelson, Teal, Wright, & Daniels, 2012). Most DRT in systems in Europe were created and maintained locally, evolving from a local need for transportation, without strong involvement of higher levels of government (Nelson, Wright, Masson, Ambrosino, & Naniopoulos, 2010). Since two decades, there is a growing interest of governments to coordinate the organization of DRT from a higher level, but the impact of legal barriers, the position of the DRT system in the PT network, and its rules and arrangements, still vary greatly from country to country.

Mainland European schemes typically benefit from a commitment to funding at a national level and a robust planning framework at a regional or sub-regional level (e.g. by a small number of call centers that take bookings from passengers anywhere in the country); and have been implemented within the context of an integrated network of PT. The types of DRT schemes operating in for example the Netherlands and Switzerland typically use a fleet of small vehicles, providing shared transport to passengers who pre-book. In the UK, the licensing of taxi operators is locally regulated and operated. DRT services in the UK tend to be small-scale, door-to-door, and only for a defined region or specific community of people. UK schemes have historically focused on providing access to local shops and health care for rural residents who do not have a car, so integration with wider PT is limited or absent. Many UK schemes were implemented using 'Bus Challenge' funding streams (funding of the government to subsidize services falling outside the commercial network) with a finite end-date (Ambrosino, Nelson, & Romanazzo, 2004), and therefore often seen as transitory experiments (Commission for Integrated Transport, 2008). In recent years, since the deregulation of public transport services, a greater range of local stakeholders appeared to be involved in planning DRT services, and the focus has shifted more towards rural locations in order to fill the gap caused by the withdrawal of conventional bus services (Davison, Enoch, Ryley, Quddus, & Wang, 2014), whilst the voluntary sector continued to address the need for more specialized travel (Brake & Nelson, 2007). In Australia, conventional bus services are typically provided by private operators under contract to the State government. Local governments are funding flexible transport but these are typically for a restricted user group, while innovative services developed by bus operators which are open to the public, are difficult to develop. In the USA, the primary funding for (public) transport originates at the local level and decisions about the type of service are generally within the purview of the local PT authority and its local political overseers (Mulley, Nelson, Teal, Wright, & Daniels, 2012).

Recently, countries are expanding their view on the potential users of the system, and there have been considerable moves towards a more coordinated model in some countries (e.g. Netherlands, Denmark), in which

the DRT for PWD (so-called 'target market' users with special eligibility permits to travel) is combined with the open DRT for the general public (e.g. intermediate or complementary PT service in (sub)urban areas or rural transport, or for groups of school children or work transport). This coordinated model shares resources by a more efficient coordination and planning of different types of transportation (each trip with its specific needs, requirements and (lack of) flexibility) from many different authorities, and matching different user groups in the same vehicles, leading to a more efficient use of vehicles and a variety of economies of scale (e.g. costs associated with the purchase and maintenance of the vehicles). However, institutional barriers may be a major obstacle on these new developments in Europe, the USA and Australia, e.g. because of difficulties with integrating vehicle fleets when different operators use vehicles with different vehicles standards and specifications, or a fragmented nature of both political authority and funding source (Davison L. , Enoch, Ryley, Quddus, & Wang, 2014) (Mulley, Nelson, Teal, Wright, & Daniels, 2012). Population density and fineness of the geographic boundaries of municipalities may also play a role, as administrative fragmentation does not promote the coordination necessary to achieve economies of scale (Darbera, Westerlund, & Cazemier, 2012).

Given its increasing importance for mobility impaired people, DRT has received more research attention as well (Nguyen-Hoang & Yeung, 2010). Stated preference studies revealed that DRT would be considered as the most preferred travel mode above all by seniors with physical limitations (Nuworsoo, 2009). However, DRT services for PWD are expensive to provide, which makes it imperative to maximize its efficiency. A recently published study about the current provision of DRT in Great Britain showed that long term financial sustainability of such DRT schemes continues to be questioned, with a limited number of schemes recognized as commercially sustainable (Davison, Enoch, Ryley, Quddus, & Wang, 2014). Another recent review paper about (barriers to implement) DRT confirmed that in most countries and regions, the adoption of DRT is challenged by the financial performance of this form of transport, which is invariably less cost-effective than higher volume fixed route services (Mulley, Nelson, Teal, Wright, & Daniels, 2012). Given the increasing importance of DRT, with social participation enhancement of PWD as ultimate goal, a substantial proportion of the costs of DRT might be paid by society rather than by the individual consumer in a some regions.

The aim of this paper is to determine the impact of policy decisions (e.g. improving the accessibility of the PT, changing the service area of the service providers) on the resource requirements of a DRT system, in terms of vehicles and drivers required and kilometers traveled. The results of the analysis of these different policy decisions can be used by governments for

the optimization of their DRT system, in order to guarantee its financial sustainability. While this paper focusses on a DRT system specifically for PWD; partly similar policy decisions can be calculated for other DRT applications (e.g. employment- or age-related, rural areas with a low demand for PT) to determine their impact on the resource requirements.

2. CASE STUDY OF FLANDERS

In this paper, a number of policy scenarios are analyzed in the case study of Flanders (the northern, Dutch-speaking part of Belgium). Flanders is characterized by an area of 13.521 km², a population of six million inhabitants and a population density of 470 inhabitants per km². The region of Flanders is an ideal test case for this analysis, since the need for a more coherent approach on DRT services was recently recognized by the Flemish government. In the past, the supply of accessible transport in Flanders has been very fragmented, not geographically covered and existing of different types of transport providers (voluntary organizations, subsidized adapted transport services and commercial services). The Flemish Fund for the Social Integration of Disabled Persons started already in the mid-nineties to give subsidies to a limited number of adapted transport services. In 2000, the Flemish government decided to transfer these subsidies to the Equal Opportunities policy domain, by which a broader system of adapted transport services was built. However, these services were grown spontaneously in response to ad hoc problems in certain locations and in specific situations, with consequently a considerable diversity in terms of vehicles, cost, service, timetable, assistance and dispatching. Moreover, these services were still not geographically covering Flanders and had no decree basis, as a general approach about the transport of PWD was missing. Subsequently, the Flemish government decided to transfer the subsidizing of the adapted transport services to the Mobility policy domain starting from 2011. This policy domain has been taking steps for several years already in the development of an area wide, inclusive accessible mobility system in Flanders. Hereby, the intention is to make the PT network more accessible so that more PWD could make use of it, while additional transport services should be organized only for PWD who are still not able to make use of this conventional PT. In order to realize these permanently available, area wide and affordable adapted transport services, a new Decree about DRT services was issued by the policy domain Mobility: the 'Decree to compensate the public service obligation of the transport of persons with a disability or seriously limited mobility', approved in December 2012. The idea behind this Decree is that a mobility system will be developed by which subsidized adapted transport will be offered, geographically covering the whole of Flanders.

Hereby, on the one hand, PWD can make use of voluntary organizations, denoted as 'Less Mobile Services' (LMS), relying on (a limited number of) volunteers who use their own passenger car to offer transportation services in their neighborhood. This type of service has as eligibility requirements that it is only available to persons that are both in low income classes (income constraint of 2x the current living wage) and not travelling in a wheelchair. LMS services are typically organized by municipalities or health insurances. However, since LMS services are not subsidized by the Flemish government, the user is dependent on the number of available volunteers in his region to fulfill his transportation requests. In some regions, these LMS services are subsidized by local governments. On the other hand, if PWD do not meet both conditions, they can rely on a limited set of geographically dispersed 'Adapted Transport Services' (ATS) that are subsidized by the Flemish government in the context of the new Decree. These ATS services generally use a heterogeneous fleet of vehicles with at least one adapted vehicle, and are suitable for persons in a wheelchair. The (predetermined selection of) subsidized ATS service providers may apply for a compensation of the government for their driven kilometers with a wheelchair user or person with seriously limited mobility, and therefore they can offer payable adapted transport to PWD. This preferred assignment priority of transport modes (first LMS, next ATS) is predetermined by the regulation of the Decree, so users cannot freely choose their preferred transport mode. Besides, PWD can also rely on commercial service providers, but these are not eligible for subsidy by the government and therefore are quite expensive for the users.

However, the practical implementation process of the Decree in Flanders is still being elaborated at the moment. Through the application of the different policy scenarios in this paper, it is investigated whether the proposed Decree is feasible regarding the resource requirements, and which policy measures should be taken to meet the transport demand of PWD in a cost effective way. To assess how resource requirements will change over time due to demographic evolutions, the analysis is performed on three prediction years: 2015, 2020 and 2030. This study is motivated by concerns about the future demand for transportation by PWD. The number of PWD and hence demand for transportation by PWD will increase in the near future due to the ageing society. As a part of these PWD will not be able to make use of conventional PT, demand for DRT services will increase. As a result, concerns about the resource requirements, and associated cost implications, of the Decree were raised. These resource requirements can be influenced by a number of factors including the size of the target group (number of PWD), the modal split (number/share of trips by DRT), the distances of the trips, the costs involved per travel mode (e.g. assign subsidies to specific transport modes), among others.

Although the policy scenarios in this study are applied in the context of Flanders, the proposed methodology allows to easily modify the context-sensitive input criteria of the model (e.g. population of PWD, modal split, eligibility requirements) so that the model can be transferred to other regions as well.

The paper starts with a discussion of the proposed methodology to estimate the minimal resource requirements of a DRT system (Section 3). Section 4 describes a number of policy scenarios to analyze which input parameters (e.g. changing the available number of volunteers, the share of accessible PT) and service attributes (e.g. changing the maximum user ride times) can contribute to meet the transport demand of PWD in a cost effective way, in order to guarantee the financial sustainability of the DRT system. Section 5 provides the simulation results and a discussion of the calculations of these different scenarios, which can be used by the Flemish government as a decision support tool in the implementation of the DRT system. Finally, conclusions are drawn and the transferability to other regions is discussed in Section 6.

3. METHODOLOGY

3.1. Overview of procedure

An overview of the methodology that is used to determine the resource requirements of a DRT system is shown in Figure 1. A first version of this methodology, along with some preliminary results, is described in Neven et al. (Neven, et al., 2014). This methodology consists of three main steps, which are explained in the following sections in detail. First, a microscopic simulation of the demand of PWD for transportation was performed in order to obtain a detailed overview of all transportation requests that need to be processed (Section 3.2). For this purpose, a synthetic population of all PWD was created, representing individual actors which were statistically equivalent to the real population of PWD; and their corresponding transportation requests with specific travel-related characteristics were generated. Second, each simulated transportation request was assigned to a specific service provider (Section 3.3). This assignment might change, depending on the (policy) scenario that is considered. Third, a separate vehicle routing plan was created for each provider for both a weekday and weekend day (Section 3.4). This vehicle routing plan indicates the minimal resource requirements, in terms of vehicles, drivers and kilometers that are required to perform all transportation requests assigned to this specific provider. This step took into account heterogeneous users (persons with different severity and type of disabilities), heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots (locations where vehicles are stationed).

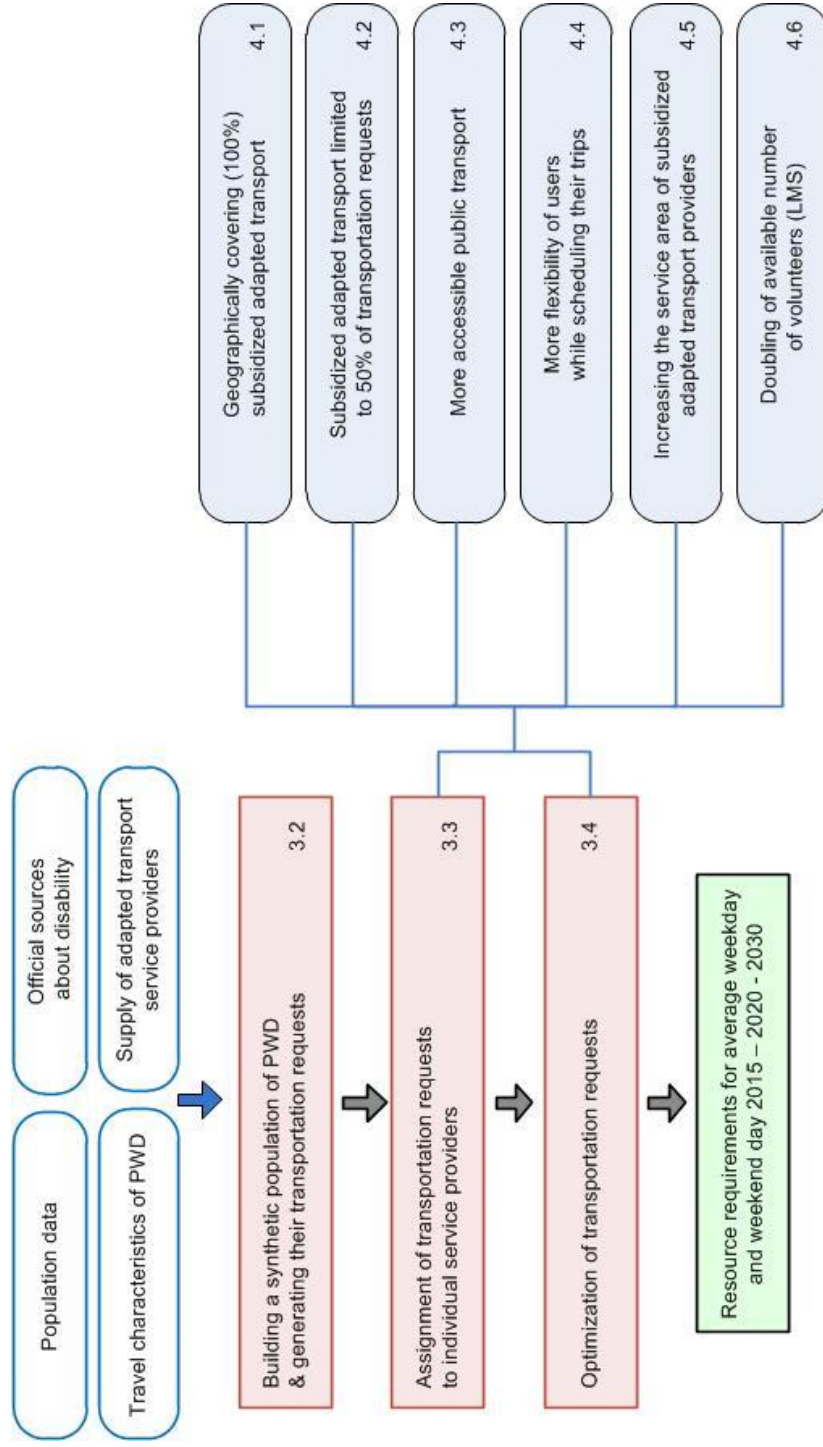


Figure 1: Overview of procedure (left) and considered policy scenarios (right) to determine the resource requirements of a DRT system

The majority of existing research on resource requirements for DRT services has mainly focused on finding the required number of vehicles and are based on a limited set of parameters which are assumed to be constant and applicable to all users (service area size, demand density, time window length, maximum ride time, average ride length, and others). Hence, spatial and temporal dependencies between user requests are mostly not taken into account, i.e. requests are distributed uniformly over space and time. For an overview of literature on this topic, the reader is referred to (Markovic, Milinkovic, Schonfeld, & Drobnyak, 2013) and (Diana, Dessouky, & Xia, 2006). Recently, Markovic et al. have proposed a model which takes into account peak and non-peak demand periods (Markovic, Milinkovic, Schonfeld, & Drobnyak, 2013). Their results demonstrate the need to model DRT operations of an entire day instead of only during a peak period, due to the existence of route duration limits in practice. To the best of our knowledge, only Deflorio (Deflorio, 2011) and Kuo et al. (Kuo, Shen, & Quadrioglio, 2013) consider both spatial and temporal effects of demand for DRT services. Finally, Luo et al. (Luo & Schonfeld, 2012) indicate that existing models often suffer from the limitation of using manual or very simple vehicle routing algorithms (e.g. insertion algorithms) and neglecting user time constraints.

In this paper, a microscopic simulation of demand for DRT is performed, allowing for taking both spatial and temporal effects into account. Resource requirements are measured in terms of the number of vehicles, drivers and vehicle kilometers required. In addition, instead of using a simple insertion heuristic to generate vehicle routes, a state-of-the-art meta-heuristic is applied, considering heterogeneous vehicles and users, and taking into account relevant time constraints such as time windows and maximum user ride times.

3.2. Synthetic population of PWD and transportation requests in Flanders

In order to determine the transportation requests for DRT services in a region, a synthetic population of all PWD in this region was created. Based on this population, the human behaviour at the individual level was modelled (e.g. how many activities are made by PWD in this region and which transport mode do they use?).

In Flanders, aggregate data at population level are available by means of the 'General socio-economic survey 2001', where the full Flemish population was compulsorily surveyed on several socio-demographic variables (Algemene Directie Statistiek en Economische Informatie, 2006). The distribution of allowances of PWD in Flanders offered detailed information about the number of PWD in each municipality, by age group and gender. Official sources about disability were consulted, such as the Flemish Agency

for Disabled Persons and the Federal Public Service of Social Security, to gather information about the type of limitation (or combination of types), severity of disability (based on the level of independence), and associated probability of using an assistive (ambulatory) device. The previous variables are important as they influenced the assignment to a specific service provider and associated vehicle (wheelchair accessible vehicle or not). As well, a survey was distributed among PWD in Flanders (Neven, et al., 2014), by which a total of 344 internet-based questionnaires were completely filled out by persons with various types and severity of disability, e.g. persons with physical limitations, intellectual limitations, visual limitations, and others. Based on this information, the synthetic population of all PWD in Flanders was created. Population projections from the Federal Planning Bureau (Bryon, Duyck, Lambrecht, & Paul, 2011) were used to generate the population data for the prediction years 2015, 2020 and 2030 respectively. As a result, each person of the synthetic population was simulated on a microscopic scale, with specific socio-demographic and disability-related characteristics: municipality, gender, age, income class, type of limitation, severity of disability, and use of an assistive device (e.g. walking cane, manual or electric wheelchair, electric scooter).

In addition, all individuals of the synthetic population were simulated with a number of travel-related characteristics, based on the results of the survey: the probability of making a trip for a specific type of activity, and the probability of using adapted transport for this specific activity type. The study area was divided in 2386 transportation analysis zones (TAZ, with an average area of 5km²), for which attractiveness measures (e.g. number of inhabitants or available facilities) were available via the General socio-economic survey 2001, resulting in the probability of going to a specific TAZ (location) while making a trip with adapted transport.

All individuals' personal and travel-related attributes were used as inputs to generate the list of transportation requests of PWD in Flanders, for an average weekday and weekend day. The percentage of persons with disabilities in each age category, the severity of disability and all other socio-demographic, disability-related and travel-related characteristics were supposed to be constant for the prediction years. Based on the previous travel-related sources, the share of adapted transport use by PWD in Flanders in the modal split equaled to 7.4%, and the share of PT 11.2%. The remaining 81% of the trips were conducted as a car driver, as car passenger, on foot, by bicycle, or by other travel modes.

For each transportation request by DRT the following data were generated: the origin and destination TAZ, the type of vehicle required (wheelchair accessible or not), whether an accompanying person need to be present, a time window within which the pickup or delivery should take place (denoting

the desired timing and a maximum deviation from this timing expressed by the user), and a maximum ride time (the maximum additional time a user may spend in the vehicle due to combination of trips of different users). The parameters related to distribution of trips over the day, time window length and maximum ride times, were derived from a survey conducted among Flemish service providers (see Section 3.3).

3.3. Assignment of transportation requests to service providers

In the specific situation of Flanders, services will be provided on the one hand by LMS (voluntary organizations) for those who are eligible, and on the other hand by a selected set of subsidized ATS service providers, as defined in the Decree about the new DRT system. However, the practical implementation process of this Decree, and the actual selection of subsidized service providers, is still being evaluated at the moment.

Therefore, we rely on the current situation regarding the service providers. A second survey was distributed among current individual service providers of adapted transport in Flanders (completed by 160 different service providers) (Neven, et al., 2014), which provided information about the supply of transport in their specific organization: service area, capacity and number of regular vehicles, capacity and number of adapted (wheelchair accessible) vehicles. Since the average radius of the service area of an individual service provider in Flanders currently is 20-25 kilometers, service areas of similar size were assumed in this paper for the subsidized service providers. Only considering locations of existing service providers, this approach led to (approximately) 26 subsidized service providers (ATS) in Flanders, as shown in Figure 2.

Each transportation request (generated as discussed in Section 3.2) was assigned to a specific service provider, based on the relevant parameters of the policy scenario under consideration (see description of the different scenarios in Section 4). Hereby, the specific eligibility requirements of each transport mode, as well as the priority of the assignment to the different transport modes (first LMS, next ATS – as described in the introduction) predetermined by the regulation of the Decree, were taken into account.

3.4. Optimization of transportation requests

For the base scenario and each of the policy scenarios, a separate vehicle routing plan was created for each service provider, both for a weekday and for a weekend day. A vehicle routing plan is a schedule that determines which transportation requests are performed by which vehicle and, for each vehicle, the respective order in which the requests are performed. This plan gives an indication on how many vehicles, drivers and vehicle kilometers are required on an average weekday or weekend day in order to perform

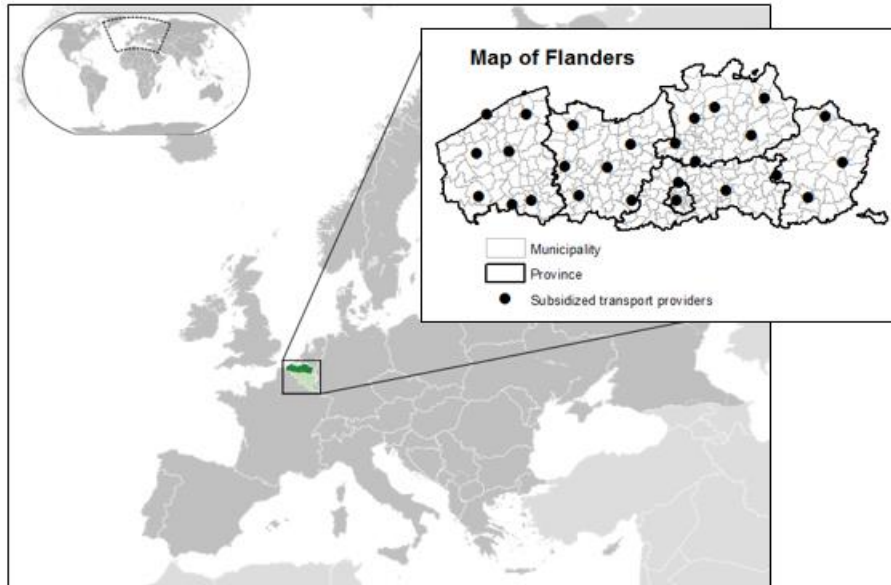


Figure 2: Overview of subsidized transport providers (ATS) in Flanders.

all transportation requests assigned to this specific provider. The detailed input list of transportation requests was derived from the microscopically simulated synthetic population, with associated travel characteristics, taking into account the spatial and temporal effects of demand. In order to take into account the variability of travel times during a day, each weekday was divided into five time intervals: morning peak (6-9am), day (9am-4pm), afternoon peak (4-7pm), evening (7-22pm) and night (10pm-6am). Transportation requests were assigned to the appropriate interval, based on the desired timing. A separate planning was made for each interval, using appropriate congestion dependent travel times. A similar approach was used for weekend days, but only a day (6am-22pm) and a night period (22pm-6am) were considered.

To obtain an efficient vehicle routing plan for a given service provider and time interval, a Multi-Depot Heterogeneous Dial-A-Ride Problem (MD-H-DARP) was solved using the state-of-the-art deterministic annealing meta-heuristic approach presented in (Braekers, Caris, & Janssens, 2014). This MD-H-DARP simultaneously considers heterogeneous users (non-wheelchair and wheelchair), heterogeneous vehicles (regular and adapted) and multiple geographically distributed vehicle depots in the service area (since service providers may have several locations where vehicles are stationed and some drivers even take their vehicles home after their shift). To ensure user convenience, both time windows and maximum ride time

constraints were imposed. Transportation is performed by a set of vehicles with limited capacity for both passenger seats and wheelchair places. Each vehicle was assigned to a depot where it should start and end its route. To take into account maximum shift durations of drivers, a maximal route duration was imposed. As the rationale behind the new Decree is that the DRT system should be covering Flanders with as few refusals as possible, it is assumed that service providers are not allowed to refuse transportation requests assigned to them. Instead, no upper bound on the number of available vehicles at a service provider is assumed in order to find the actual resources required to satisfy all requests in Flanders. The objective of the vehicle routing model was to minimize first the number of vehicles required and second the total distance traveled, while satisfying all transportation requests without violating time window, ride time and maximum route duration constraints. The meta-heuristic method works as follows. In a first phase, an initial solution to the MD-H-DARP is generated using a simple insertion heuristic. Starting from a set of empty vehicle routes, transportation requests are inserted in random order at their best possible position. In a second phase, this initial solution is improved on by applying a deterministic annealing algorithm for a predefined number of iterations. In each iteration, five local search operators are applied. These operators try to improve the solution by making slight changes, e.g. by relocating a single transportation request from the route of one vehicle to that of another vehicle. To escape from local optima, solutions which have a larger distance than the current best solution are accepted as well, as long as the increase in distance is below a certain threshold value which is dynamically adapted during the search. For more details on the meta-heuristic approach, the reader is referred to (Braekers, Caris, & Janssens2014).

4. POLICY SCENARIOS

The overall aim of the paper is to determine the impact of different policy scenarios on the resource requirements of a DRT system, in order to assess its financial sustainability. The base scenario, assuming a geographically covering subsidized DRT system, is discussed in Section 4.1. Next, the influence of changing some input parameters or service attributes is assessed by considering the following five policy scenarios: a more economical scenario by limiting the number of transportation requests that can be handled by subsidized DRT services (Section 4.2); a more accessible PT causing the number of PWD needing adapted transport services to decrease (Section 4.3); more flexibility of the users of the DRT system while scheduling their trips (Section 4.4); and an increase in the service area of the service providers allowing more passengers to be grouped together (Section 4.5). As there are also voluntary organizations (LMS) offering transport for PWD in the Flemish context, the last scenario considers a doubling of the current supply of transport by LMS because of more

available volunteers (Section 4.6). The following sections describe how the policy scenarios were applied to the Flemish situation. It would also be possible to combine some of the scenarios, as this would increase the number of policy options available to the decision-maker. For example, it would be possible to analyze a scenario in which both the PT would become more accessible, and the service area of the service providers would increase. However, in this study, all scenarios were analyzed separately, in order to identify the specific impact of each policy option.

4.1. Geographically covering (100%) subsidized adapted transport

The scenario of the geographically covering DRT system, by which 100% of all trips by adapted transport are executed by either LMS or ATS, is considered as the base scenario. Services are provided by LMS (voluntary organizations) for those who are eligible, and by a selected set of subsidized ATS service providers for those who are not eligible. Each transportation request was assigned to a specific service provider as follows. It was analyzed whether the user that initiated the transportation request is allowed to make use of a LMS service. This is the case when the user is not in a wheelchair, his income is below a certain threshold, the transportation request takes place within the service area of a LMS service provider and the maximum number of assignments to LMS's is not reached. The maximum number of assignments was imposed because the number of volunteers was limited to the current level. When one of the conditions was not met, the request was assigned to the closest of the 26 subsidized ATS service providers. All transportation requests of adapted transport (7.4% of the modal split) are thus executed by either LMS or by ATS.

4.2. Subsidized adapted transport limited to 50% of transportation requests

In this first policy scenario, the principal assignment to LMS (if eligible) remains unaltered. Regarding the other trips, it is assumed that not all other trips can be subsidized by the Flemish government (ATS) because of the limited budgets. Therefore, only 50% of the non-LMS trips are assumed to be subsidized in this scenario (and thus executed by ATS), while the other trips need to be executed by non-subsidized transport providers (e.g. commercial service providers). The subsidized trips are now only offered to a limited number of transportation requests (e.g. based on the traveler's disability severity).

4.3. More accessible PT

The second policy scenario assumes that the accessibility of the PT (e.g. physical accessibility) will gradually improve over the coming years. Indeed, European legislation imposes guidelines for more accessible PT, which also

have to be realized by Belgium (and Flanders). As a result, in this scenario, more PWD who are currently using adapted transport, would be able to use PT for their trips. More specifically, for PWD who can travel independently to the PT stop (based on their disability severity), it is assumed that each year 2.5% more people will be able to use PT (instead of using adapted transport). Therefore, the resulting share of adapted transport in the modal split of PWD would decrease to 6.7% in 2020 and 5.2% in 2030. The rules for assignment of adapted transport requests to a specific service provider are similar to the base scenario (assigned to LMS if eligible and all other trips to subsidized ATS if not), but one of the input parameters (i.e. the share of trips by adapted transport and the corresponding number of trips that needs to be executed by DRT) is different.

4.4. More flexibility of users while scheduling their trips

In the third policy scenario, it is assumed that users are somewhat more flexible while scheduling their trips. For transportation requests to activities with a fixed start time (e.g. working or a doctor's appointment), a time window of 30 minutes is assumed, compared to an average time window length of 10 minutes in the base scenario, which means that users may be subject to longer waiting times. Similarly, for activities with a variable start time (e.g. shopping or visiting someone) a time window of 60 minutes is assumed, instead of an average time window of 30 minutes in the base scenario. Hence, more flexibility regarding the start time of these activities is expected from the users. Furthermore, it is assumed that the maximum additional user ride time (i.e. the additional time that users have to sit in the vehicle because of the combination of trips of other users) is 20 minutes instead of 15 minutes. The assignment of adapted transport requests to a specific service provider is the same as in the base scenario, by which all trips by ATS are subsidized. However, because of these changes in service parameters, more flexibility in the scheduling of the trips is available and requests of users can be combined more often, resulting in an increase of the vehicle utilization and a reduction in the required number of trips and kilometers.

4.5. Increasing the service area of subsidized adapted transport providers

The next policy scenario assumes that the size of the service area of the subsidized service providers (ATS) is increased, resulting in only 13 subsidized service providers in Flanders (instead of the proposed 26 providers in the base and other policy scenarios). Because of these increased service area size, different users can be combined more often compared to the previous policy scenario.

4.6. Doubling of available number of volunteers (LMS)

In the final policy scenario, the amount of volunteers, offering inexpensive transport by LMS, is assumed to increase in the future. A doubling of the current number of volunteers, and consequently a doubling of the current supply of transport by LMS, is assumed in this scenario. In the assignment process, the maximum number of assignments to LMS's is observed to double, as the available number of volunteers is also doubled. Again, all other (non-LMS) trips were assigned to subsidized ATS service providers.

5. RESULTS AND DISCUSSION

The vehicle routing plan (described in 3.4) was applied for three prediction years (2015, 2020 and 2030), for the base scenario as well as for the five policy scenarios. Table 1 shows the results for an average weekday in absolute numbers. Next to total results, results for both types of services providers (LMS and ATS) are shown separately. Relative differences with respect to the base scenario are shown in Table 2. The number of vehicles required for a service provider is calculated by taking the maximum number of vehicles used over all time intervals of the day.

The results from the base scenario show that a large number of resources are required to offer geographically covering DRT services, given the fact that a fleet of 2,295 vehicles and a total of more than 900,000 kilometers is needed to perform all transportation requests on an average weekday. In the future, these requirements will even be larger as the demand for adapted transport will increase because of the ageing population, expected to make the proposed results completely unaffordable for the Flemish government (Enter, IMOB (UHasselt), Ernst & Young, 2013), given that the necessary number of vehicles will even increase to 2,773 in 2030. This increase is solely an effect of the ageing population and the associated probability of developing physical limitations. As a result, minimal resource requirements in terms of vehicle and kilometers increase almost proportionally. Most transportation requests are performed by ATS service providers: only about 5.9% of all requests are carried out by LMS service providers, due to their strict acceptance rules and limited number of volunteers. However, if service providers would be able to relax their eligibility requirements (e.g. a relaxation of the income constraint by LMS providers), the results would be affected.

Table 1: Absolute number of requests, vehicles and kilometers on an average weekday

RESULTS FOR AN AVERAGE WEEKDAY	LMS			ATS			Total		
	2015	2020	2030	2015	2020	2030	2015	2020	2030
Absolute numbers									
Base scenario (4.1)									
- Number of requests	1,962	2,000	2,312	31,166	33,298	37,522	33,138	35,298	39,834
- Number of vehicles	322	332	398	1,973	2,095	2,375	2,295	2,427	2,773
- Number of vehicle km	65,154	66,879	77,452	839,244	894,951	1,007,182	904,398	961,830	1,084,634
50% subsidized ATS (4.2)									
- Number of requests	1,962	2,000	2,312	15,486	16,570	18,722	17,448	18,570	21,034
- Number of vehicles	322	332	398	1,061	1,143	1,249	1,383	1,475	1,647
- Number of vehicle km	65,154	66,879	77,452	452,299	478,151	535,338	517,453	545,030	612,790
More accessible PT (4.3)									
- Number of requests	1,962	2,008	2,310	31,166	29,700	25,358	33,138	31,708	27,668
- Number of vehicles	322	333	383	1,973	1,882	1,652	2,295	2,215	2,035
- Number of vehicle km	65,154	64,320	78,942	839,244	811,151	692,518	904,398	875,471	771,460
More flexibility of users (4.4)									
- Number of requests	1,962	2,000	2,312	31,166	33,298	37,522	33,138	35,298	39,834
- Number of vehicles	265	276	305	1,421	1,514	1,714	1,686	1,790	2,019
- Number of vehicle km	62,582	65,113	73,813	718,805	764,608	852,037	781,387	829,722	925,850
Larger service area ATS (4.5)									
- Number of requests	1,962	2,000	2,312	31,166	33,298	37,522	33,138	35,298	39,834
- Number of vehicles	322	332	398	1,944	2,068	2,358	2,266	2,400	2,756
- Number of vehicle km	65,154	66,879	77,452	853,486	910,937	1,025,362	918,640	977,816	1,102,814
Doubling of volunteers (4.6)									
- Number of requests	3,822	4,068	4,572	29,316	31,230	35,262	33,138	35,298	39,834
- Number of vehicles	557	576	639	1,917	1,975	2,250	2,474	2,551	2,889
- Number of vehicle km	125,577	125,259	150,539	791,698	849,369	947,523	917,274	974,628	1,098,062

Table 2: Relative differences of policy scenarios with respect to the base scenario for an average weekday

RESULTS FOR AN AVERAGE WEEKDAY	LMS			ATS			Total		
	2015	2020	2030	2015	2020	2030	2015	2020	2030
% with respect to base scenario									
50% subsidized ATS (4.2)									
- Number of requests	+ 0 %	0 %	0 %	- 50 %	- 50 %	- 50 %	- 47 %	- 47 %	- 47 %
- Number of vehicles	+ 0 %	0 %	0 %	- 46 %	- 45 %	- 47 %	- 40 %	- 39 %	- 41 %
- Number of vehicle km	+ 0 %	0 %	0 %	- 46 %	- 47 %	- 47 %	- 43 %	- 43 %	- 44 %
More accessible PT (4.3)									
- Number of requests	0 %	0 %	0 %	0 %	- 11 %	- 32 %	0 %	- 10 %	- 31 %
- Number of vehicles	0 %	0 %	- 4 %	0 %	- 10 %	- 30 %	0 %	- 9 %	- 27 %
- Number of vehicle km	0 %	- 4 %	+ 2 %	0 %	- 9 %	- 31 %	0 %	- 9 %	- 29 %
More flexibility of users (4.4)									
- Number of requests	0 %	0 %	0 %	0 %	0 %	0 %	0 %	0 %	0 %
- Number of vehicles	- 18 %	- 17 %	- 23 %	- 28 %	- 28 %	- 28 %	- 27 %	- 26 %	- 27 %
- Number of vehicle km	- 4 %	- 3 %	- 5 %	- 14 %	- 15 %	- 15 %	- 14 %	- 14 %	- 15 %
Larger service area ATS (4.5)									
- Number of requests	0 %	0 %	0 %	0 %	0 %	0 %	0 %	0 %	0 %
- Number of vehicles	0 %	0 %	0 %	- 1 %	- 1 %	- 1 %	- 1 %	- 1 %	- 1 %
- Number of vehicle km	0 %	0 %	0 %	+ 2 %	+ 2 %	+ 2 %	+ 2 %	+ 2 %	+ 2 %
Doubling of volunteers (4.6)									
- Number of requests	+ 95 %	+ 103 %	+ 98 %	- 6 %	- 6 %	- 6 %	0 %	0 %	0 %
- Number of vehicles	+ 73 %	+ 73 %	+ 61 %	- 3 %	- 6 %	- 5 %	+ 8 %	+ 5 %	+ 4 %
- Number of vehicle km	+ 93 %	+ 87 %	+ 94 %	- 6 %	- 5 %	- 6 %	+ 1 %	+ 1 %	+ 1 %

In the '50% subsidized ATS' scenario, the number of requests that could be handled by ATS was halved, as the subsidized trips were only offered to a limited (50%) number of transportation requests that could not be executed by LMS. As a result, the required number of vehicles and the traveled kilometers for LMS and ATS combined decreased with 40% and 43% respectively in 2015. The resulting decrease in number of vehicles was slightly less, as a more efficient vehicle routing plan might be obtained in case of more transportation requests. The assumption of only offering subsidized DRT services for a limited number of non-LMS transportation requests (50%), means that other trips have to be executed by alternative service providers. Likely, the only transport solution would be to make use of commercial service providers, resulting in a very high cost price for its users (especially compared to LMS or ATS).

The results of the 'more accessible PT' demonstrate that the relative distribution between the different types of service providers remained unaltered, but the total proportion of adapted transport requests decreased (in favor of the use of PT) with 10% with respect to the base scenario in 2020 and 31% in 2030. Hereby, the total required number of vehicles decreased considerably as well by 9% in 2020 and 27% in 2030 respectively. However, the assumption of more accessible PT means that additional investments in both the rolling stock (which is legally imposed in management agreements between the Flemish government and the PT companies) and the stop infrastructure (which is the responsibility of the local road authorities) are necessary, of which the costs were not taken into account in this study. While PT accessibility improvements could increase the number of PWD that can make use of the conventional PT (which was the intention of the Flemish government, as described in the introduction), not all PWD would benefit from this policy measure. Indeed, there would be still a group of PWD who cannot make use of the PT, because the distance to the bus stop is too far, or simply because PT is lacking in their living environment.

In the 'more flexibility of the users' scenario, both the relative distribution between the different types of service providers and the absolute number of requests remained unaltered. However, the traveled kilometers and required number of vehicles were reduced considerably (with 27% and 14% on average respectively) by a more efficient route planning. Contrary, the scenario with the larger service area sizes appeared to have only limited impact on the optimization of the route planning. The required number of vehicles only decreased with 1% on average, while the total number of kilometers even increased with 2%. This can be explained by the fact that most of the trips were local, causing only little additional grouping possibilities with other users.

Finally, the scenario with the 'doubling of volunteers' caused the number of transportation requests that could be handled by LMS to double. Similarly, the number of vehicles and kilometers by LMS also increased by 73% and 93% respectively in 2015 (the increase of the number of vehicles was smaller because trips of different users could be combined more often in a vehicle). As a result, the number of requests and associated required number of vehicles and traveled

kilometers by ATS decreased by 6% on average. While the total number of vehicles and kilometers increased, the reduction in vehicles of ATS (the most important cost driver) caused cost savings for the DRT system. One may argue that a doubling of the available number of volunteers is not realistic. However, the proportion of young retirees will increase in Flanders in the coming years due to the ageing population. Since these people are still (physically) active, no longer work and as a consequence have more time available, it may be expected that a portion of them is willing to sign up as a volunteer for these services. Therefore, we assess that a doubling of the current number of volunteers is realistic. While such a 'young retired' population may be realistic in some countries or regions (e.g. Flanders and some others parts of western Europe), a volunteer based service provision may be questionable in other countries given the implications of the financial crisis for retirement incomes and pensions. However, this input parameter can easily be modified in the proposed model to analyze the effects of different situations such as e.g. a decrease in the number of volunteers.

A similar analysis was performed for an average weekend day, as the probability of making a trip for a specific type of activity is different compared to weekdays, resulting in a different number of transportation requests. The vehicle routing plan showed a similar impact of each of the policy scenarios (in relative terms), while the absolute number of requests, vehicles and kilometers was less. An overview of the results for an average weekend day can be found on the website <http://alpha.uhasselt.be/kris.braekers>.

6. CONCLUSION

In this paper, the effect of several policy scenarios with respect to resource requirements of a DRT system was studied. The applied methodology to calculate resource requirements was discussed and results of a case study on Flanders were presented. The comparison of the different policy scenarios showed that the '50% subsidized ATS' scenario is the most economically efficient, as it causes the number of transportation requests by ATS to be reduced greatly, which is the most important cost driver of the model. However, as a consequence many trips would have to be executed by other (commercial) service providers with a higher price for its users. This could cause PWD to decide not to perform their trip(s) anymore, which is not a desirable outcome in the context of the social enhancement goal. The selection of which transportation requests would be allowed to make use of the (subsidized) services, should be made very carefully by the government. Therefore, a selection or scaling method should be created, based on a combination of objective personal as well as situational criteria, e.g. (the severity of) the traveler's mobility restriction, the availability of accessible PT and public space (in his/her neighborhood and on the destination), the type of activity (e.g. work, social activities), the availability of family and friends, and the financial possibilities.

Cost savings can also be achieved by a more flexible approach of the users themselves, so that more trips can be combined. Because of their limitations, it is argumentative to assume that PWD should be transported directly, while in the

proposed policy scenario (4.4) they would not be able to leave on exactly the desired time and would have a (limited) additional user ride time. However, since flexibility of trips in regular PT trips is limited in time (timetable) and space (stop locations), we consider limited concessions of the users of the DRT system as acceptable since this has a major impact on the affordability of the DRT system. However, if the regular PT were more accessible, fewer trips would be needed by DRT, causing the number of requests, vehicles and kilometers to decrease.

The projected demand in this study is based only on demographic data (both regarding the number of PWD and the number of volunteers), but does not take into account other developments which could affect the travel behaviour of PWD. It needs to be considered for follow-up research that developments in digital technologies, influencing the access to shops, banking or economic participation (e.g. by means of teleshopping or teleworking); as well as social media; may reduce the need for travel for economic, social or other purposes. However, the face-to-face interaction, and associated need for making trips, may not be substituted completely, certainly not in the context of PWD who may make many recurrent trips for rehabilitation or for medical reasons.

In this study, both the input criteria of the model (i.e. the projected population of PWD in Flanders and their generated transportation requests), and the supply of service providers and their specific eligibility requirements (based on the implementation of the Decree) were based on the specific context of Flanders. However, any other specific situation or region can easily be modelled using our methodology by simply modifying the context-sensitive input criteria of the model (e.g. population of PWD, modal split, supply of service providers, eligibility requirements, among others). Once the specific input data are imported, the proposed methodology is widely applicable and can therefore be generalized to other areas or regions. The methodology can be used for other DRT applications as well, e.g. based on employment or for rural areas, simply by modifying its input criteria.

A number of scenarios in this study are concerned with policy options, which may be generalized to other areas, as e.g. more flexibility of the users is not a context-sensitive policy option but may lead to more efficient grouping possibilities in other areas as well. On the other hand, a number of scenarios may have limited transferability to other countries or regions, as they are particularly based on context-sensitive input data of the Flemish context. The funding of the DRT scheme in Flanders is at a high level (Flemish level) while the planning framework is at a sub-regional level (i.e. small service areas with an average size of 20-25 km); which is comparable to other areas in mainland Europe but different with the policy framework in e.g. the USA and Australia. A comparison of the population density, another important key variable of the organization of DRT, shows that the population density in Flanders is similar to neighboring countries like the Netherlands, but much more densely populated compared to countries in Southern Europe or Scandinavian countries. Unlike countries such as the Netherlands or Denmark, DRT services in Flanders are (nowadays) only for PWD,

so economies of scale might be obtained when these DRT services would be combined with services open for the general public. Another difference is that while in some other countries in mainland Europe the DRT services are integrated with the PT network, in this study it is assumed that the entire trip is made either completely by DRT, or completely by PT, so the planning is not restricted to narrow time intervals based on PT timetables or narrow geographic areas based on PT stops.

Therefore, to determine whether a particular scenario is applicable to a specific region or not, the assumptions of each scenario should be compared with the context of that specific region.

To conclude, in the Flemish landscape, changing the modal split (or the optimal mix between the different transport providers), as well as the realization of adequate public transport and an increasing flexibility, seem to be key elements to minimize the resource requirements of a DRT system for PWD. Based on these requirements, the corresponding financial implications of each of the (basis and policy) scenarios can be calculated. This information can be used by the Flemish government to decide on the actual implementation parameters of the system. Other areas or governments can transfer the model to their specific context as well, as the flexibility of the model allows to easily modify the input criteria based on the specific situation. Because of budget constraints, it is important to establish what service attributes would have the greatest impact for the resource requirements of the DRT system as well as for the PWD themselves (Ben-Akiva, Benjamin, Lauprete, & Polydoropoulou, 1996). A social cost-benefit analysis could facilitate the weighing up of all social advantages and disadvantages of the various service attribute changes, not only in monetary terms (vehicles and drivers required, total subsidized distance), but also in terms of participation enhancement, quality of life of PWD, and others.

Highlights

- Resource requirements of a Demand Responsive Transport (DRT) system were calculated
- Different policy scenarios were applied to assess their impact on these requirements
- The applied methodology and results for a case study on Flanders are presented
- Modal split, accessible public transport and user flexibility are key elements
- Methodology provides insights for governments on assessing the financial sustainability of a DRT system

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FINAL CONCLUSIONS

The performed studies in this doctoral thesis lead to more insights in the activity-related travel behaviour of persons with disabilities (PWD).

This final chapter summarizes some major conclusions and implications, discusses the room for improvement and gives an outlook on further research possibilities. In the first section, the main findings of each of the performed studies are summarized. Secondly, some clinical and policy implications are provided. The next section critically discusses the limitations of this doctoral thesis, while the last section ends with some recommended directions for future research, and the role of activity-related travel behaviour in the field of rehabilitation.

1. MAIN FINDINGS OF DOCTORAL THESIS

The main findings of each of the performed studies are summarized below.

Firstly, the activity-related travel behaviour of the patient group of PwMS, with different overall disability severity, is investigated in detail.

An exploratory pilot study was performed to document the number of activities and trips, the activity type and the transport mode of the related trips that are daily made by persons with Multiple Sclerosis (PwMS). It was shown that persons with **mild ambulatory dysfunction showed similar travel characteristics as healthy controls** regarding their number of trips (4.2 daily trips on average), travel mode (most trips as car driver, 15% of trips by non-motorized travel modes) and company (most trips performed alone). However persons with mild MS are still physical active and able to walk and/or drive independently, they **self-limited their trips** as car driver, as they appealed to others for trips with longer distances and drove less in bad weather conditions or on unfamiliar roads. It was also shown that the activity-related travel behaviour was **changed in PwMS with moderate to severe disability**: driving independently became less frequent, significant more trips were made with company and the duration of performed activities had increased. A number of persons with severe MS who were living in adapted houses (with assistance in their activities of daily living, ADL) nearby a specialized MS rehabilitation center, made a high number of independent trips by use of their ambulatory device.

Next, a large-scale study of 108 PwMS with various disability level was performed, in order to assess the specific impact of health condition (physical, cognitive and psychosocial functioning) and contextual (personal and environmental) factors on the activity-related travel behaviour in MS. The activity-related travel behaviour in MS decreased significantly in persons with higher disability severity regarding travel modes, number, type and planning of activities; confirming previous results of the pilot study. The overall significant associations with physical functioning measures (measured on different levels of the ICF-framework) indicated that the **number of trips decreased with increasing ambulatory dysfunction**, while

the relation between cognitive function was less obvious. Personal factors like the household size, educational level and age, among others, correlated (however only poor to low) with the number of trips; of which similar results were found previously in studies with healthy persons. The large-scale study demonstrated that **contextual environmental factors may influence** activity-related travel behaviour, as in the mild MS subgroup the number of trips was dependent on the distance to friends or the nearest shops, while in the severe MS subgroup persons living farther away from rehabilitation services had a lower probability of going to these services. Multiple regression analyses confirmed that, to measure or predict the activity-related travel behaviour in MS, it is important to take into account not only the health condition (mostly physical functioning), but as well contextual factors.

As the accuracy of self-report data collection methods in travel behaviour may be influenced by disease-related dysfunctions (e.g. because of memory problems), we analyzed in detail whether physical, cognitive or psychosocial impairments contributed to the reporting rate of the subjective self-report travel diaries and objective GPS tracking devices in 108 PwMS with various disability severity during a seven days data collection period. The study demonstrated that there was **only limited influence of clinical variables on the reporting rate** (and associating data quality) of subjective travel diaries and objective GPS tracking devices, as well as limited significant differences between subgroups with various disability severity. Confirming previous studies in healthy persons, socio-demographic and trip-related factors influenced the reporting rate: PwMS with a higher educational level and persons who are working seem to better report their trips in the diary; while persons who performed more trips, reported their trips worse. 66% of the trips were reported in both data collection methods, while overall more than one fifth of all trips were forgotten to be registered by GPS (and even 29% by persons with severe disability), and 11% were forgotten to be reported in the diary. It was shown that **self-report travel diaries** seemed to be better suitable for persons with a higher disability severity, as these persons had to think about a number of organizational issues when making a trip and hereby forgot to take their GPS with them more often.

Physical (walking) activity (PA) in MS is most commonly measured as number of strides or steps, while also walking intensity and walking activity duration are keys for a healthy lifestyle. Therefore, we investigated the number of steps PwMS take, the number of steps they take at low and moderate intensity, and their walking activity duration for 2, 3, 6, 10, 12 and 14 uninterrupted minutes; all related to the degree of disability. The study demonstrated that **step count in MS was lower than PA recommendations**, and negatively influenced by a higher disability degree. As well, PwMS are 77% of the day inactive, and making steps for 22% at low and **only 1% at moderate intensity**. Both PwMS with mild and moderate disability rarely walk for more than 6 uninterrupted minutes, especially not at moderate intensity level. It was shown that PwMS need to be motivated to

make steps at moderate intensity, but as well to make steps for longer periods of time at moderate intensity level in their community setting, in order to comply with PA guidelines.

After these in depth studies in PwMS, supporting measures for the larger population of PWD (with all types and severities of disability) are developed. While the travel patterns and/or experienced problems may be different between different patient groups (and are thus investigated in detail only in MS as research population), supporting measures to optimize their travel behaviour should be developed for the full population of PWD, as this will lead to a higher cost-efficiency because of economies of scale.

In order to enable PWD to fully participate in society, many Demand Responsive Transport (DRT) systems were developed as conventional fixed route public transport (PT) was not sufficiently designed for use by PWD. We determined the minimal resource requirements, in terms of vehicles and drivers required and total distance traveled, to offer round the clock DRT by individual service providers for a case study in Flanders. Disaggregated data were used **to simulate the transportation requests of PWD on a microscopic scale**, which showed to offer advantages, as hereby a high **spatial and temporal resolution of the transport demand** was taken into account, and we got knowledge about both specific disability-related factors (influencing the transportation demand) and travel behaviour patterns. As well, regarding the service providers, heterogeneous vehicles (regular and wheelchair adapted vehicles) and multiple geographically distributed depots (locations where vehicles are stored) were taken into account, in order to obtain knowledge which transportation requests could be processed by each individual service provider. The results of the Flemish case study showed that the new DRT system was unaffordable for the society, despite the optimization methodology that was applied.

Because of budget constraints, it was important to establish which investments in (attributes of) the DRT system, among others, would have the greatest impact for the participation enhancement and quality of life of PWD. The impact of different policy decisions on the resource requirements of this DRT system was determined for the prediction years 2015, 2020 and 2030 for the case study of Flanders: a base scenario assuming a geographically covering subsidized DRT system; a more economical scenario limiting the subsidized DRT services; a more accessible PT; more flexibility of the users of the DRT system; an increase in the service area of the DRT service providers; and a doubling of the current supply of transport by volunteers. The results show that changing the modal split (the mix between the different DRT providers), as well as the **realization of adequate PT and an improved flexibility**, seem to be key elements in Flanders to minimize the resource requirements of a DRT system. Our applied methodology can easily be transferred to other regions or areas, as the flexibility of the model allows to **easily modify the input criteria** based on the specific context.

2. CLINICAL AND POLICY IMPLICATIONS

The findings of the studies about the activity-related travel behaviour in MS recommend the development of behavioral strategies in order to encourage PwMS to make trips and participate (more) in society. It was shown that persons with mild disability level, however they were able to walk and drive independently, self-limited their driving behaviour because of uncertainty feelings about their physical and cognitive functioning. Anxiety was demonstrated to not only affect driving behaviour (in terms of number of trips as car driver and performed distances, among others) in our study, but was shown to affect divided attention during driving (measured by a test in a driving simulator) in MS as well (Devos, Brijs, Alders, Wets, & Feys, 2013). In this context, behavioural therapy could help to develop better coping and problem-solving skills to **overcome anxiety** in the making of trips by persons with mild MS, especially in the making of trips as car driver.

Based on our findings, it is also suggested to develop motivational and educational strategies to encourage PwMS to make steps at higher intensity levels and for longer uninterrupted time intervals, in order to improve their PA behaviour. The intensity and duration of walking needs to be high enough to achieve important cardiovascular health benefits from PA, but the majority of PwMS in our study don't make steps at moderate intensity for a longer time period, albeit capable. A more physically active lifestyle needs to be promoted through **behavioral and self-management** interventions to adapt their lifestyle incorporating a high level of PA (paradigm shift towards "PA for health"), by increasing ambulatory activity (Motl, 2014), e.g. by means of internet-delivered interventions. Activity trackers can serve as an outcome measure for interventions, but may also be used as a direct information tool for patients, demonstrating the real type and intensity of daily PA performed by PwMS, including for example also outcomes of walking speed and duration besides the number of steps (Shammas, et al., 2014). If physically capable, individuals may in this way be encouraged to make (short) trips by active travel modes like walking or cycling, instead of making the trip by car. Besides, educational programs are recommended as well, to make patients exercise-ready and enable the belief that an active healthy lifestyle can be achieved (Feys, et al., 2013). For other patients, conventional physical rehabilitation interventions, like focusing on increasing leg muscle strength or improving gait parameters, remain necessary as well to improve the walking activity, and in a broader view the activity-related travel behaviour, in MS.

Another interesting finding of this doctoral thesis is that, besides disability related to the health condition and personal factors, contextual environmental factors are predictive for activity-related travel behaviour in MS as well. In order to enhance social participation, it is recommended to acknowledge the important influence of residential location choice and other environmental factors in the development of rehabilitation strategies. Based on our findings, it is suggested that multi-

disciplinary teams should include **counselling on living situation** and on advice regarding environmental factors, for example advising patients to consider moving to a housing location closer to medical and rehabilitation services for optimal use. Policy makers should be recommended to integrate **medical and other services in community**, instead of locate them remotely and relatively isolated from other social services (like shops, social or sport facilities, among others) in community. When looking closer to the results, to obtain an increased use of regular PT by PwMS, the results motivated to improve the accessibility of and to the stops, e.g. by providing accessible stops closer to the residence of physically impaired persons.

In the studies about supporting measures for all PWD, it was shown that DRT systems were developed in several countries to enable PWD to participate in society, as conventional fixed route PT was not sufficiently designed for use by PWD. Our findings about the requirements of a region-wide DRT system calculated for the region of Flanders, show that an enormous amount of resources are required, which will even become larger in future years and seems unfeasible because of budget constraints. If (policy) measures are taken to make the mobility system more inclusive, it is recommended to perform a **sensitivity analysis on beforehand**, to establish which investments in (attributes of) the mobility system would have the greatest impact. This analysis should take into account the various social advantages and disadvantages of the service attributes changes, not only in monetary terms (vehicles and drivers required, total compensated distance), but also in terms of participation enhancement and quality of life of PWD, among others. For example, when only offering subsidized services for a limited number of transportation requests, the cost for the government would be reduced greatly, but PWD should execute their other trips by other commercial service providers with a higher price, probably leading to a decline in societal participation. If the government should decide which transportation requests would be allowed to make use of subsidized services, we recommend to make this selection very carefully, based on a combination of objective personal and situational criteria, like (the severity of) the traveler's mobility restriction, the availability of accessible PT and public space (in his/her neighborhood and on the destination), the type of activity, the availability of family and friends, and the financial possibilities, among others. Based on our findings, we already started another subsequent study about the development of such a 'mobility scaling method', commissioned by the Flemish Ministry of Mobility and Public Works (study not reported in this doctoral thesis). Besides, in order to make the DRT system more affordable, we recommend to combine the DRT services with services open for the general public (like countries such as the Netherlands or Denmark), in order to achieve economies of scale.

3. LIMITATIONS AND METHODOLOGICAL CONSIDERATIONS

3.1. Activity-related travel behaviour in MS

In this doctoral thesis, we performed four cross-sectional studies in PwMS. As MS is however a degenerative disease, with a life-long progression which can be very various between and within PwMS themselves, changes are expected in the activity-related travel behaviour of these individuals over time. Both changes in health condition (e.g. decreased functioning due to exacerbations of symptoms or a gradual increase of worsening symptoms) or changes in contextual factors (e.g. change of living environment or household situation) may determine activity-related travel behaviour and quality of life. It can be expected that negative evolutions of the disease over time, or a change of the physical or social environment, may in most cases lead to a decreased participation; while on the other hand an increase in the number of trips can also happen by some persons (e.g. stop working and have more time available for other activities, acceptance of the disease after initial uncertain and negative future expectations, an improved supply of adapted transport, among others). For future studies, one may therefore include a **longitudinal study** to be able to identify possible influencing factors causing changes in activity-related travel behaviour over time, which can be used to further improve rehabilitation strategies. Results on relationships between changes would provide stronger statistical evidence of underlying factors of activity-related travel behaviour than the current associations found in the cross-sectional studies. Besides, we did not perform any intervention study in this doctoral thesis, targeting the specific factors that showed to influence the activity-related travel behaviour.

In order to get a complete overview of the health condition of participants, and to identify influencing factors on both the level of the body, the level of the individual and the level of the individual as a member of the society, outcome measures of health condition were applied on different levels of the ICF-framework in the large-scale study in MS. As health is defined as the complete physical, mental and social functioning of a person (WHO, 2001), we applied outcome measures of each of these functioning levels (see General Introduction chapter Table 4). Despite our extensive test battery, there may still be **functioning problems in other neurological domains** as well (Kister, et al., 2013), that may cause that PwMS have changes in their activity-related travel behaviour. For example, it is possible that some PwMS are physical active and can make their trips independently, but are not making trips anymore, or only short trips, because of bladder or vision problems. As MS is characterized by so-called *good and bad days*, performance-based outcome measures by which the functional capacity is assessed by the researcher at a specific moment in time for only a relatively short task, may be affected. We therefore also applied self-reported outcome measures, by which the impact of certain functioning problems for a longer period of time was reported, to overcome this phenomenon.

A number of contextual personal and environmental factors were applied, which were selected because their relationship with activity-related travel behaviour was already demonstrated in previous studies in healthy populations. Similarly, there may be **other contextual factors** causing changes in activity-related travel behaviour, as for example bad weather conditions or inaccessible doorsteps in the neighborhood could influence the making of trips, the modal split, the company or the use of an assistive device, among others. In this context, we already started to investigate the specific impact of environmental factors (like sidewalk quality or obstacles on the route) on the walking behaviour in MS, by analyzing each of the performed walking trips of the participants in detail.

To analyse the travel behaviour and influencing factors of different patient profiles, a representative sample of PwMS was tested, ranging from persons who are still physical active and can drive a car themselves, over persons with a decreased walking capacity and driving ability, to persons who are (almost) completely wheelchair-bound and dependent on others for making trips. It was an inclusion criterion that PwMS had to make minimal one outdoor trip weekly – in order to examine the specific impact of influencing factors on their activity-related travel behaviour, so **home-bound PwMS were excluded** from our studies. These persons could however as well provide useful information about the specific reasons why there were not making trips (anymore).

A combination of both subjective self-report travel diaries and objective GPS tracking devices was used. While these instruments provided detailed information about activity-related travel behaviour in MS, they could be considered as a burden for the respondents: PwMS were required to fill out the travel diaries for 7 consecutive days with detailed information about each outdoor trip, including activity type, start time, location, travel mode used, company, use of assistive device, among others; leading to **incompleteness and inaccuracies of reported trips** (Bricka, Sen, Paleti, & Bhat, 2012). The required detailed information not only involved a large amount of time to report all trips in detail, but also required persons not to have cognitive deficits to remember all trips. As well, it was a time-consuming task for the researcher to manually import all the reported trips in a database. Besides, participants had to carry out the GPS logger for each outdoor trip (in order to verify or supplement the reported trips), which could cause on the one hand user errors like **forgetting carrying the device** when they started the trip, and on the other hand **device limitations** such as signal drops insides building or low battery life. Current innovations in GPS technology and mobile positioning data, by which trips and stops can be automatically extracted from GPS traces and presented on a map to the traveler soon after their accomplishment in order to supplement or correct this information (prompted recall) (Cich, Knapen, Bellemans, Janssens, & Wets, 2015), may lower the respondent burden. Other technological innovations, like visual life-logging technologies capturing every day activities and trips by digital cameras, may potentially make self-report diaries or surveys redundant, hereby lowering the

respondent burden as well. These innovative technologies were not yet available at the start of (the data collection of) this doctoral project. Especially in studies in PWD, the (disease-related) capabilities of the participants should however be taken into account in order to make a substantiated choice of data collection instrument.

With the relatively small and unequal sample size in the different subgroups (n=51-27-30 for the mild, moderate and severe MS subgroup, respectively), the results of the **statistical analyses** should be interpreted with caution. We used a significance level of $p=0.05$, by which there is 5% chance that a difference would be wrongly considered as significant. However, we made use of non-parametric statistics in our analyses, which are less dependent on outliers. As well, in our results, we also showed the significance level of $p=0.01$, by which it was shown that a large number of differences were still significant, even within this more conservative confidence interval. We decided to apply the correlation analyses at detailed subgroup level, as the magnitude of significant correlations was dissimilar among subgroups. For example, the distance to friends and shops (mild subgroup), and the distance to rehabilitation centers (severe subgroup) seemed to correlate significantly with the number of trips; but this important relationship would not be manifest if we should only show the correlation scores of the total MS sample.

3.2. Walking/step activity in MS

There are some methodological aspects related to the measurement technology used in the study about walking activity in MS. The StepWatch Activity Monitor (SAM) uses time intervals of 1 minute for analysis, likely causing an **overestimation of walking activity at low intensity** as even one step a minute is counted as *walking* (even if the person only takes one or a few steps and then sits down). While it would be more correct to designate this parameter as 'step activity' for the low intensity levels, the findings of walking activity at moderate intensity are considered as valid and provide new insights into walking behaviour in MS.

There is large variability in **step-rate thresholds for activity intensity** (Agiovlasitis & Motl, 2014). The average step-rate cut-off for moderate-intensity PA is agreed as 100 steps per minute in several studies (Tudor-Locke, Sisson, Collova, Lee, & Swan, 2005) (Marshall, et al., 2009) (Harrington, Dowd, Tudor-Locke, & Donnelly, 2012), varying as a function of height, disease and disability (Tudor-Locke, et al., 2011). A recent study in MS developed step-rate thresholds for PA intensity for ambulatory people (Agiovlasitis & Motl, 2014). Hereby, it was shown that for PwMS with minimal impairment, and between a height of 158-190 cm, the predicted step-rate at moderate-intensity threshold was between 83-104 steps per minute; and 83-101 steps per minute for PwMS with mild-moderate impairment. As these thresholds are not exactly equal to the thresholds that we

used in our study (i.e., 1-80 steps/min for low intensity and ≥ 82 steps/min for moderate intensity), our results should be interpreted with caution.

3.3. Resource requirements of a DRT system for PWD

In the studies about the DRT system, we did not collect detailed information about the actual performed trips of participants during a specific time period, but we surveyed them about their frequency of the use of travel modes, and the making of trips for each activity type. Hereby, we were able to **indirectly deduce the modal split of PWD**. Additional improvements could be made by using activity-related travel diaries in order to gather exact information of the *individual activity patterns* of PWD, instead of only using frequencies of travel modes and activities.

The destination choice of trips was determined by the attractiveness of transport analysis zones (TAZ) for each activity type, based on the General socio-economic survey in Flanders. In this context, future research may as well take into account the **attractiveness of care related facilities** mostly used by PWD. However, using disaggregated data in our studies is already an important advantage compared to formerly used four step transport models, neglecting detailed behavioral information about spatial, temporal and disability-related characteristics of the transport demand.

4. TRANSFERABILITY AND FUTURE RESEARCH POSSIBILITIES

In the studies about the in depth investigation of the activity-related travel behaviour, the patient group MS was chosen in this doctoral thesis because of the occurrence of multi-dimensional symptoms and functioning problems with different severity, involving both young and older persons, and (work) active and less active persons. The performed studies showed that **MS served as a useful model** to investigate the possible effects of different symptoms on activity-related travel behaviour. The methodology and results of this research can therefore likely be transferred to persons with other diseases with (partly) similar personal characteristics or life categories (e.g. brain injury or stroke). The disability distribution of PwMS was in line with that of disease severity in Flanders (Kobelt, et al., 2006), by which the impact of health condition can be generalized to the whole MS population (at least in Flanders). The convenience sample of MS that we used in this doctoral thesis is considered as a sufficient geographical representation of PwMS in Flanders, as respondents were recruited in both rural and urban areas in various provinces, and living in both residential and community settings. One may however be careful to generalize the findings of the present study to the overall MS population worldwide, given different prevalence of MS, as well as availability of public transport, population densities and traffic congestion.

PwMS were divided in subgroups based on their overall disability level, taking important ambulatory dysfunction into account (EDSS, DS). It was also possible

to **classify the subgroups** based on other functioning domains, for example the cognitive status, or based on contextual factors like the living environment, employment status or household situation; which would have influenced the results of the subgroups. We have chosen to divide subgroups based on ambulatory dysfunction, as walking is a key component for independence during activities of daily life (ADL) (Goldman, et al., 2013) with an important influence on societal participation. Other studies in MS that used a division in subgroups, were as well usually based on ambulatory functioning level, measured by the EDSS (Pfenning, et al., 1999) (Lobentanz, et al., 2004) (Grasso, Troisi, Rizzi, Morelli, & Paolucci, 2005) (Guarnaccia, et al., 2006) (Kitis, Altug, Cavlak, & Akdag, 2008) (Grasso, Pace, Troisi, Tonini, & Paolucci, 2009).

While the impact of contextual factors on the activity-related travel behaviour in MS in general was investigated in this doctoral thesis, there are some interesting future research possibilities regarding the impact on walking activity in MS. Environmental factors, like degree of urbanization, obstacles or sidewalk quality, may influence walking behaviour, of which the impact was already demonstrated in previous studies: Doerksen et al. indicated that in MS, the presence of shops, stores, markets or other places within walking distance (measured by self-reported questionnaires) was related to pedometer measured PA (Doerksen, Motl, & McAuley, 2007), while a recent study in Flanders qualitatively showed that a neighborhood should have well-maintained walking facilities in order to promote walking for transportation among older adults (Van Cauwenberg, et al., 2012). As a subset of 72 PwMS from our study carried both the SAM (measuring step data) and the GPS logger (measuring travel behaviour) during the data collection period, we are able to **quantitatively investigate if changes in environmental factors are related to changes in walking activity** in MS. We already started to investigate the specific impact of various environmental factors in MS, by analyzing each of the performed (segments of) walking trips in detail. Hereby, we objectively investigate if, for example, the presence of obstacles on the road, the absence of sidewalks, or busy crossings, will lead to a temporary decline in walking speed.

Besides, the collected data in this doctoral thesis enables us to objectively measure the **impact of neighborhood profiles** on the habitual walking performance of PwMS. By geocoding the postal address of participants (i.e., converting the location with geographical coordinates), it can be enriched with spatial reference data like land use, population density, PT stops, location of care facilities, among others. Instead of using only self-reported information about distances to shops, stores or other places, we can perform spatial analyses (e.g. by GIS-software) in order to determine more accurately the impact of specific environmental factors on the number of steps in different residential settings.

Despite PwMS often experience changes in subjective fatigue during the day, it was shown previously that testing of walking capacity, by means of the 6 Minute

Walk Test, was unaffected by time of day (Feys, et al., 2012). It would be valuable to further investigate if the actual walking activity, in terms of number of steps and intensity, is different across the time of the day. Our dataset not only enables to analyze the number of steps PwMS make in **different time intervals**, but may as well clarify the step count as we have also detailed information about the outdoor activities that participants made at that specific time. It is hypothesized that PwMS with different living situations (e.g. employment status, marital status) or in different living environments (e.g. urban versus rural environment) not only have a dissimilar number of steps per day (of which the differences for some socio-demographic characteristics were examined by Motl and colleagues previously (Motl, Pilutti, Learmonth, Goldman, & Brown, 2013) (Dlugonski, et al., 2013), but that the variation may also be different according to the time of the day. We already started to investigate the differences in step count *variation* across the day for some socio-demographic characteristics in MS, by which preliminary results show that living in a family with more household members leads to more steps in the morning and in the evening; while PwMS who are fulltime working perform more steps during the day but are less active in the evening (study not reported in this doctoral thesis).

In the studies about supporting measures for PWD, about determining the resource requirements of a DRT system, both the input criteria of the model (projected population of PWD in Flanders and their generated transportation requests), and the supply of service providers and their specific eligibility requirements, were based on the specific context of Flanders. However, any other specific situation or region can easily be modelled using our methodology by **simply modifying the context-sensitive input criteria of the model** (e.g. population of PWD, modal split, supply of service providers, eligibility requirements, among others). Once the specific input data are imported, the proposed methodology is widely applicable and can therefore be generalized to other areas or regions. The methodology can be used for other DRT applications as well, e.g. based on age or employment or for rural areas with low demand for PT, simply by modifying its input criteria.

5. ACTIVITY-RELATED TRAVEL BEHAVIOUR IN REHABILITATION

This doctoral project showed the importance of measuring activity-related travel behaviour in PWD. Research into the body functions/structures and activity level of the ICF framework is well elaborated in scientific literature, but knowledge about (enabling or disabling determinants of) activity-related travel behaviour is relatively sparse, however it may serve as an ecological valid measurement of a person's functioning in daily life within the community. While body level or impairment interventions (at the lowest level of ICF-framework) are primarily medical or rehabilitative, they attempt to prevent or ameliorate limitations in person (activity level) or societal level functioning (participation level) by correcting or modifying intrinsic functions or structures of the body. Other

rehabilitative treatment strategies are designed to increase capacity levels, or focus on the actual performance by either capacity-improvement or environmental modification (WHO, 2001). Hence, the **ultimate goal of rehabilitation strategies is to enhance societal participation**, likely influencing quality of life (Kwok, Pan, Lo, & Song, 2011). International concern about health care outcomes has shifted to the assessment of functioning at the level of the whole human being, in day-to-day life (WHO, 2001).

Outcome measurement is essential to evaluate the impact or results of a specific rehabilitation intervention. While conventional outcome measures are based on self-administered questionnaires, or performance-based measures carried out in clinical settings and under controlled conditions, it is important to **understand the full impact of the intervention** by obtaining data in real-life conditions (Barzilay, et al., 2011). Therefore, measuring activity-related travel behaviour may serve as a promising outcome measure to provide objective data about an individual's improvement or recovery (or lack of it) following a rehabilitation intervention. Measures of activity-related travel behaviour may also be used as benchmarks in patients with different type and severity of disability, to detect whether patients are approximately making trips as expected.

As well, it may be more sensitive to **detect dysfunction** or unfavorable changes at functioning level due to deterioration. For example, if spatial patterns suggestive of psychosocial problems (like staying all day at home, or avoiding crowded areas) are identified, these data will provide the treating physician or physiotherapist more information about the patients' specific problems, that will allow for more targeted treatment and counseling (as kind of a 'personalized medicine'). On the other hand, enhancement in societal participation following an intervention may also be detected more sensitively. For example, a reduction in the walking distance or walking performance after a few weeks may reflect an increase in motor vehicle trips or more sedentary tasks, due to the patient's return to work (Barzilay, et al., 2011). Without this relevant information about the activity-related travel behaviour, one may wrongly interpret this data as if the individual is functioning worse (activity level), although the decrease in number of steps, in this example, actually means an improvement in terms of participation. Information about activity-related travel behaviour does not only offer important knowledge to the treating physician or physiotherapist, but may also be used as a **direct self-management** information tool for patients themselves, as described earlier in this chapter.

Regarding rehabilitation strategies focusing on environmental modification, it is important to have knowledge about the **contextual key factors** influencing changes in activity-related travel behaviour, in order to identify environmental facilitators and barriers and to make the social and built environment more accessible for all persons, those with and without disabilities (WHO, 2001).

Nevertheless, activity-related travel behaviour is not a single, well-defined outcome measure as compared to standardized tests and questionnaires of health condition, but covers an entire **range of different transport-related dimensions**: frequency of trips, modal split, traveled distances, trips made at time of the day, among others, which can all be combined together. Conventionally used measures in travel behaviour studies with PWD have been trip generation (as indication of out-of-home activity engagement) or distance traveled during the course of the day (as proxy for the range of opportunities potentially available to individuals) (Páez, Mercado, Farber, Morency, & Roorda, 2009). As there is recently growing attention to the out-of-home mobility of PWD and elderly, a variety of outcome measures is nowadays reported in literature, varying from engagement in both utilitarian (maintaining independence and fulfilling basic needs) and discretionary (important for the individual existing in relation to the surroundings) outdoor activities (Siren, Hjorthol, & Levin, 2015); available travel opportunities in terms of household car availability, number of trips, distances traveled by mode, or minimum travel time to reach the nearest key services (Mackett, 2014); health-related outcome measures providing exercise like active transport modes like walking or cycling, in terms of number of walking events per day, maximal walking distance or the amount of time spent outdoors (O'Hern & Oxley, 2015); among other transport-related variables like valuations of overall travel during a specific day, valuation of possibilities to travel by different modes of transport, or dependence on PT, by car as a passenger and/or by special transport service (Stjernborg, Emilsson, & Ståhl, 2014).

Selecting appropriate outcome measures of activity-related travel behaviour in the field of rehabilitation should therefore be based on the **expected, or desirable, outcomes of the specific intervention** at participation level. As well, the outcomes should be targeted towards the specific patient group, taking into account the type and severity of disability. For example, increasing the use of active travel modes and reducing the reliance on motorized transport may offer an opportunity to address physical inactivity (Arnott, et al., 2014) and may therefore be beneficial for a patient group with mild disability level. On the other hand, for persons with severe ambulatory dysfunction, the ultimate goal of a rehabilitation strategy may be the prolongation of the safe active driving period (e.g. by training through driving simulator tasks or home computer tasks). Similarly, while an increase in the making of trips would be an anticipated outcome for the majority of patients, other patients may prefer to make fewer trips, if for example, they are making trips by bike almost daily for shopping, but would prefer to do this less frequently if they would be able to make these trips by PT.

Hence, in order to define (interventions for) activity-related travel behaviour outcome measures, the appropriateness for the specific target group, as well as the needs or expectations of the patients themselves, should be included.

It should however be taken into account that the expectations of the patients themselves may be influenced by **limited travel horizons**, which means that PWD or individuals with transportation limitations, tend to lower their expectations of travel, and as a consequence, of out-of-home activities (Lucas, Maia, Marinho, & Santos, 2013) (Paéz & Farber, 2012). Due to lowered expectations, transport problems or a desire for more activities or trips, may be under-reported by respondents; leading that their problems or desires are even more present than indicated by the data. In our survey that we distributed among 344 PWD in Flanders with various types and severity of disability (chapter 5-6), we asked the respondents if they would be willing to make more trips, if their travel possibilities would allow this. Hereby, around 70% of the respondents stated that they would be willing to make more trips, especially for social activities (data not shown in this doctoral thesis). Since the reported latent demand for more trips is already very high, it may be expected that there are few under-reporting problems, due to limited horizons. As the majority of PWD in our study (of chapter 5-6) is willing to make more trips, we may as well state that they are rather dissatisfied with their current participation levels, and the reduction in travel behaviour therefore thus (partly) results in social exclusion.

A complex interaction of factors may contribute if the **experience of mobility loss by PWD results in dissatisfaction with participation frequency**, and in turn, in social exclusion. For example, it was previously shown in PwMS that the reality of having the disease (e.g. physical problems, the day-to-day variability), mobility needs (sense of control about the mobility and the ability to participate in valued activities), and contextual factors (e.g. the availability of social support, availability and accessibility of transportation) all contributed to persons' mobility experiences; and the consequences of their experiences (Finlayson & Denend, 2003). While some PWD may have a great difficulty dealing with mobility losses, probably resulting in feelings of social exclusion, others may be able to make modifications to their lives (e.g. through the use of social supports, mobility aids or digital technology), in order to fulfill their mobility and/or participation needs.

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ABOUT THE AUTHOR

° 09/12/1986, Tongeren, Belgium
Mobile: +32 (0)497 04 49 61
Work E-mail: an.neven@uhasselt.be

An Neven graduated in Latin-Mathematics at the Heilig Graf Instituut in Bilzen in 2004. Afterwards, she started her studies in Transportation Sciences at Hasselt University. An obtained her degree of bachelor in 2007, and subsequently her master degree with a specialization in Mobility Management in 2009 (magna cum laude).

In October 2009, An was granted a doctoral fund by the Special Research fund (BOF) of Hasselt University, under the supervision of Prof. dr. Geert Wets (promoter) and Prof. dr. Peter Feys and Prof. dr. Davy Janssens (co-promoters) – as a collaboration between the Transportation Research Institute IMOB and the REVAL Rehabilitation Research Institute. She is employed at IMOB in the research group Transportation.

During these past years, An was involved in several projects in the domain of mobility (e.g. Mobility plan Flanders, Accessibility study of the Pukkelpop festival, Sustainable mobility to the campus - Pendelfonds) and autonomy (e.g. projects with BlueAssist, Supporting safe mobility of elderly in traffic – CareVille Limburg). As well, she was involved in some projects about the development of an accessible transport system in Flanders. Besides, An was enrolled in some educational activities of the Transportation Sciences program at Hasselt University.

Journal publications

- Voets T, **Neven A**, Thewys T, Kuppens T (2013). GIS-based location optimization of a biomass conversion plant on contaminated willow in the Campine region (Belgium). *Biomass & bioenergy*, 55, 339-349. (IF=3.411)
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- Enter, IMOB (UHasselt), Ernst & Young. (2012-2013). *Business plan for an area covering, complementary and integrated accessible transportation system in Flanders*. Commissioned by the Flemish Ministry of Mobility and Public Works, Department Mobility and Public Works.
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- BlueAssist, IMOB (UHasselt). (2013-2014). *Co-creation of BlueAssist spaces*. With support of EWI – Social Innovation.
- Enter, IMOB (UHasselt), PXL, Toegankelijkheidsbureau (2014). *Mobility indication*. Commissioned by the Flemish Ministry of Mobility and Public Works, Department Mobility and Public Works.
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- IMOB (UHasselt). (2014-2015). *Moveable transport devices on vehicles of VVM De Lijn and/or vehicles that are used for the public service obligation to transport persons with disabilities or with severe limited mobility*. Commissioned by the Flemish Ministry of Mobility and Public Works, Department Mobility and Public Works.
- Jessa hospital, BVBA Dr. Lutin, IMOB (UHasselt), Enter. (2014-2017) *CareVille Moving Care - A multidisciplinary approach of evaluation and support of safe mobility of seniors*. With support of the Flemish Government.

Supervision of PhD-students

- Emilie Couwenberg (09/2014 - now): *Supporting persons with dementia in maintaining their out-of-home mobility*.
- Lucy Joseph (01/2015 – now): *Role of informal public transport and Bus Rapid Transit (BRT) on poverty reduction among users of the system, Dar es Salaam city, Tanzania*.

Supervision of master theses

- Thomas Vranckx (2012): *Investigating the travel behavior of individuals with MS, and its relationship to physical, cognitive and neuropsychological characteristics.*
- Ine De Schutter (2013): *An analysis of disease-related personal, socio-demographic and trip-related characteristics influencing the reporting rate of data collection methods during a travel survey.*
- Maria Van Damme (2014): *Measuring walkability in a study area of Flanders*
- Annelien Vanderstraeten (2014): *Understanding walking activity in people with Multiple Sclerosis*
- Wouter Leysen (2015): *De invloed van omgevingskarakteristieken op het dagelijks functioneren van personen met een beperking*
- Ben Ceyssens (2015): *Optimalisatie van het leerlingenvervoer in het buitengewoon onderwijs*

Teaching activities

- Master of Business Engineering, course Transport Geography: work sessions of GIS (academic years 2009/2010 - 2013/2014)
- Bachelor of Transportation Sciences, course Geographic Information Systems: work sessions of GIS (academic years 2010/2011 - 2014/2015)
- Bachelor after bachelor in Coaching the Elderly (Thomas More, before KHK), course Mobility (academic year 2011-2012)
- Bachelor of Transportation Sciences, course Sustainable Mobility and General Environmental Science: lectures/sessions about sustainable mobility (academic years 2012/2013 - 2014/2015)
- Bachelor of Transportation Sciences, course Transportation Research 1/2: guest lectures/sessions about qualitative research (academic years 2011/2012 - 2014/2015)
- Bachelor of Transportation Sciences, course Integrated Project: supervision of students (academic years 2010/2011 - 2014/2015)
- Master of Transportation Sciences, course Internship: supervision of students (academic years 2012/2013 - 2013/2014)

***"Success is the ability to go from one failure
to another with no loss of enthusiasm."***

Winston Churchill

