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PARTICIPATION IN EVERYDAY OCCUPATIONS AND SITUATIONS OUTSIDE HOME FOR OLDER ADULTS LIVING WITH AND WITHOUT DEMENTIA:

PLACES, FAMILIARITY AND RISKS.

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Participation in everyday occupations and situations outside home for older adults living with and without dementia: places, familiarity and risks

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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I dedicate this book to my family:

*To my husband Pierre, for always supporting me in saying "*no, I won't quit*" whenever I felt like abandoning this endeavour, at least a hundred thousand times.*

To my first son Simon Henri, who was a child when I started, went through his teenage years, and now is a fine young man. I was not there for you as much as I wanted. I am so proud of who you have become and of the discussions we can now hold as you become an adult.

To my second son Kritsana William, who has only ever known his mother working on her PhD. I was not always available for you as much as I wanted, because of the doctorate. You understood it as if I had a disease… I promise you it is not an illness.

This book would not have existed if not for these extraordinary people.

ABSTRACT

Participation in occupations and places outside the home has been related to health and social benefits as well as offering challenging and risks for older adults living with and without dementia, yet little is known about how this participation is experienced, also considering the places visited and the occupations performed. Places are central in a transactional and occupational perspective to understand how visiting, maintaining and abandoning them affects their participation outside the home. *Acknowledging the complexity and interrelatedness properties of participation, with the embodiment of places by the occupation while it is embedded in the place, provides a new way of examining participation*. Thus, the overarching aim of the fours studies was to explore and provide new knowledge on participation in places outside the home for older adults with mild-to-moderate dementia as compared with older adults without dementia, as well as developing an understanding of the transactions between the persons and the places, and how places outside home are associated with perceived participation.

To attain this aim, the Participation in Activities and Places Outside Home (ACT-OUT) questionnaire was developed in Study I, as no tool existed that combined occupations and places. ACT-OUT was revised and aligned using cognitive interviews with 26 older adults living without dementia and five older adults living with dementia. ACT-OUT was then used in Study II, together with the occupational gap questionnaire OGQ, to evaluate stability and change in places visited outside home, and associations between number of places currently visited and perceived occupational gaps, and in Study III to consider factors, e.g. perceived risks, that potentially affected perceived participation outside the home with 35 older adults living with dementia, in comparison with 35 older adults living without dementia. Study IV used qualitative, mobile interviews to explore familiarity outside home as experienced by nine older adults living with dementia.

Findings (Study II) showed that participants living with dementia visited places to a lesser extent than the comparison group. Social and cultural places as well as places for recreation and physical activity tended to be abandoned, in contrast to places for medical care. Overall, they maintained less places and abandoned more places than the group of comparison, and participation in places was associated with occupational gaps for those living without dementia. In Study III, number of places visited, were associated with the perception of participation outside home, but only for the group of persons living without dementia, while risks of falling and for getting lost were associated for those living with dementia. Findings in Study IV showed that familiarity was experienced in a continuous way, as a whole and in repeated occurrences in personal territories that encompassed diverse places and occupations.

This thesis contributed new knowledge about how visiting places contributed to our understanding of the conception of participation outside the home of older adults living with and without dementia, including how perceived risks would influence participation. Familiarity was seen as an overarching concept that links place with participation outside the home, as personal territories including places support participation outside the home for older adults living with dementia.

Keywords: dementia, places, occupations, participation outside home, occupational therapy, occupational science, environment.

LIST OF SCIENTIFIC PAPERS

I. Margot-Cattin, I., Kühne, N., Kottorp, A., Cutchin, M., Öhman, A., & Nygård, L. (2019). Development of a Questionnaire to Evaluate Out-of-Home Participation for People With Dementia. *American Journal of Occupational Therapy, 73(1),* 1-10. https://doi.org/10.5014/ajot.2019.027144

II. Margot-Cattin, I., Ludwig, C., Kühne, N., Eriksson, G., Berchtold, A., Nygård, L., & Kottorp, A. (2021). Visiting out-of-home places when living with dementia: a cross-sectional observational study. *Canadian Journal of Occupational Therapy, 0(0)*. https://doi.org/10.1177/00084174211000595

III. Margot-Cattin, I. Berchtold, A., Gaber, S., Kühne, N., Nygård, L., & Malinowksky, C. (n.d.). Associations between perceived participation outside home and types of places visited among persons living with and without dementia: risks perception and socio-demographic aspects [Manuscript not submitted]. Department of Neurobiology, Care Sciences and Society, Karolinska Institutet.

IV. Margot-Cattin, I., Kühne, N., Öhman, A., Brorsson, A., & Nygård, L. (2021). Familiarity and participation outside home for persons living with dementia. *Dementia, 0(0)*. https://doi.org/10.1177/14713012211002030

CONTENTS

LIST OF ABBREVIATIONS

ACT-OUT	The Participation in ACTivities and Places OUTside home for older adults
ADI	Alzheimer Disease International
AMPS	Assessment of Motor and Process Skills
CRPD	Convention on the Rights of Persons with Disabilities
DAD	Disability Assessment for Dementia
ETUQ	Everyday Technology Use Questionnaire
FCCS	Functional Capacity Card Sort
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICF	International Classification of Functioning, Disability and Health
META	Management of Everyday Technology Assessment
MoCA	Montreal Cognitive Assessment
OFSP	Office Fédéral de la Santé Publique / Federal Office of Public Health
OGQ	Occupational Gaps Questionnaire
QoL	Quality of Life
WHO	World Health Organisation

PERSONAL INTRODUCTION

This research project originated in my own inquiries and interests about the environment we live in. How, as human beings, we interact with our environment, how we perceive it and use its characteristics for supporting our experiences in this world, has always fascinated me. Mostly, I have been interested in understanding how human beings relate to the forever changing environment and how the environment changes us. This dynamic relationship is central to my perspective on life in general and social participation in particular.

It made sense for me to invest time and emotional energy in asking questions about that relationship. As I have been working with older adults living with dementia both in the community in their own homes or in nursing homes and in specialised locked units, focusing on the person-environment relationship of this population group in my PhD studies was related to my personal interests. So when about ten years ago, I started taking about my ideas and wanting to transform them into a PhD project, most people I discussed with thought there wasn't a problem or a research question in my project. There was an assumed inability for older adults living with dementia participate outside the home. And if there was participation, it was supposed older adults living with dementia would not be going out alone and were dependent on significant others. The picture of older adults living with dementia given in this thesis hopes to destroy this assumption. From the many publications that have appeared these last two to five years and the requests I have received for using ACT-OUT in research project, I dare to say that there were and still are issues to be considered in relation to participation outside the home.

This journey that took me almost a decade was filled with good moments, when realisation and understanding hit me, but also with struggles and difficulties, when I wanted to quit. How many times did I tell myself: “no I will not quit!”. Probably a few hundred thousand times!

One difficulty I remember and will share here is the struggle to gain access to older adults diagnosed with a dementia, living in the community. Access to the memory clinic in the biggest French-speaking canton (Vaud) was denied by the physician in charge, because I was an occupational therapist and researcher from a university of applied sciences (UAS) and because he prioritised research from his department at the faculty of medicine. Hopefully the memory clinics of the other cantons agreed to refer participants to the studies in this thesis.

Finally, I have acquired not only new scientific knowledge about participation outside home and scientific methods during this incredible journey, but I also learned about myself and others. I am thankful for all the support I received from the extraordinary people I was fortunate enough to meet and work with.

INTRODUCTION

Structure of the thesis

This thesis is organised with three reprints and one manuscript of the studies presented at the end. They are preceded by seven sections: (a) introduction, to help orientate the reader, set the scene, and delineate the scope of the thesis; (b) background, to present the state of the art on the subject, elaborate on the theoretical resources used, and identify the knowledge gaps; (c) rationale for the thesis and the research aims; (d) methodology and methods, to explain the methodological research approaches in each of the studies, and clarify why they were chosen; (e) presentation of findings for each sub-study, and a synthesis to summarise the new knowledge derived; (f) critical discussion of the synthesis, methodological, and ethical considerations; and finally, (g) conclusion and implications, and future ideas for research.

Setting the scene and scope of this thesis

The focus of this thesis is on participation outside the home for older adults living with dementia. To make the focus explicit, older adults living without dementia are included in order to provide comparison in two studies, and to contribute to the development of the Participation in Activities and Places Outside Home Questionnaire (ACT-OUT). Participation is a broad term that has been defined and explored in different ways, depending on disciplines and worldviews. Since its introduction in the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001), the term participation has been used to refer to performance in a list of tasks, activities, and domains of life, as an engagement in occupations, and as an outcome for good practice in health care. Furthermore, the recognition that, depending on viewpoints, the context has varying influences on participation, and has broadened and complexified the use of the concept of participation (Magasi et al., 2009). Moving from a linear and deductive reasoning perspective, the concept of participation gains in complexity through the application of an eco-systemic view.

The background provided in this thesis endeavours to define the scope of participation happening outside the home for older adults living with dementia, using a transactional and occupational perspective which will be detailed in the sub-section about theoretical resources. Research has shown that older adults living with dementia benefit from being able to go out of their homes (Bantry White & Montgomery, 2016; Ward Thompson & Travlou, 2007), to navigate the environment and to reach places where they may perform occupations such as grocery shopping, meeting friends, or going for a walk along the lake. Identified benefits are social connectedness, self-awareness and continuity of self, and increased autonomy (de Bruin et al., 2017; Pollock, 2012), but less is known about their participation outside the home as such. Older adults living with dementia also face difficulties, challenges and risks when going outside the home, such as getting lost or feeling embarrassed (Bailey et al., 2013; Sandberg et al., 2017), and these issues are also not well understood. Hence, there is a knowledge gap about participation in places outside the home as perceived by older adults living with dementia, compared with older adults living without dementia.

To understand participation outside the home, there is a need to briefly explain how the concept of “home” can contribute to being able to go outside of it (Johansson et al., 2020). There is no “outside” if there is not an “inside”. Hence, there is a need to also understand the environment outside the home which is part of the background supporting this thesis and the studies. “Outside the home” has been described in various ways depending on the discipline. For instance, it has been called public space (urban planning) (Madanipour, 2010), life-space (mobility) (Marottoli et al., 2000) or neighbourhood (environmental gerontology) (Blackman, 2006), depending on the focus used. It could be seen as a container for activities, performance and landmarks, and it could also be an agglomerate of places linked together by the patterns of participation in activities. Based on the transactional and occupational perspective, places are instead seen here to represent the delimited spaces in which the occupation being performed by the person is embedded and situated, creating occurrences that are experienced and repeated such as going to the grocery store every Wednesday and Friday, meeting friends in the café at 10 in the morning every Thursday, or joining a daughter for a walk along the lake every two weeks. Thus, place is a central topic in this thesis. Familiarity of both the place and the occupation play a major role in transforming spaces into places, but familiarity has not yet been precisely described as of now. There is also a knowledge gap in understanding places and the role they play, as well as the role of familiarity and risks, in supporting participation outside the home for persons living with dementia.

Increased understanding about participation outside the home for older adults living with dementia will provide new knowledge of the types of places currently visited, visited in the past, and anticipated to be visited in the future. At the same time, increased insights into the places, as older adults living with dementia interact in them, will provides new knowledge on participation outside the home. This new knowledge is based on the relationship between the person and the places they visit, in transaction through the occupations performed (Cutchin & Dickie, 2013). Based on the view of participation introduced here, other aspects that might support participation in life outside the home are of interest, as well as how familiarity and risks are experienced by older adults living with dementia. Again, this is because of the way participation outside home is experienced as situated and embedded in places, based on transactional relationships supported by the occupations being performed.

To capture older adults’ perceptions of the aspects that support participation in life outside the home, there was a need to develop a questionnaire focusing on places inspired by transactional perspective, to include the performance of occupations and types of places, at the same time. This was made clear after screening for tools to gather data on participation outside the home, of which the closest were questionnaires developed in the SenTra Study (Oswald et al., 2010; Wettstein et al., 2012). These existing tools collected information on important places and activities separately, but did not connect them. For this reason, we developed a new questionnaire, the ACT-OUT, grounded in a transactional and occupational perspective; it will be further elaborated on in all parts of the thesis.

As said in the beginning, older adults living without dementia were included in the research process of this thesis to help with developing the new ACT-OUT questionnaire and to provide a comparison group, from which to establish statistical differences from the older adults living with dementia. As such, the topic in focus in this thesis is older adults living with dementia, and their participation outside their home.

BACKGROUND

In this section, I present a review of the state of the state-of-the-art knowledge related to this thesis and identify the knowledge gaps that my studies seek to address. First, I describe the main theoretical resources underpinning this thesis, and the way in which these contribute to my theoretical framework. Although a transactional and occupational perspective is preeminent here, theories issued from environmental geography, gerontology and psychology have also been included as frames of reference. Then I present the population with whom the thesis was conducted and how they are considered in society, both statistically and conceptually. The specific focus is on Switzerland as the data collection took place in the French-speaking region of Switzerland. Older adults living with dementia are recognised in this thesis as living in a situation of disability (Shakespeare et al., 2019); that perspective is in line with recognition of the environment as having a strong influence on participation, and the difficulties they face may resemble situations of disability. Participation outside the home is considered within a transactional and occupational perspective in which places play a central role.

THEORETICAL RESOURCES

This thesis is theoretically grounded in occupational therapy and occupational science, and in a wider context it also draws upon environmental geography, gerontology and psychology. This framework will be used for defining participation outside the home among older adults living with and without dementia.

A new conceptual framework using those concepts and theories is used here to construct an understanding of the space "outside the home" in which older adults living with dementia are participating. Since the 19702 the context or environment has been recognised as being highly important in influencing participation – notably with the publication of Bronfenbrenner's eco-systemic model (Bronfenbrenner, 1979) – theories about participation have been included from the disciplines of environmental geography, gerontology, and psychology. Environmental human geography focuses on the spatial aspects, organisations, and interactions between humans and the natural world (Boyle, 2015). Environmental gerontology focuses on the environments in which people live out their later lives (Rowles & Bernard, 2013), and the link with identity, health, and well-being (Blackman, 2006). Environmental psychology focuses on studying the relationship between the person and the environment (Bechtel & Churchman, 2002).

Intertwining of an occupational with a transactional perspective

Nevertheless, not all of these theories focus on humans as occupational beings, not whether they actively engage in occupations wherever they happen to be and live (Wilcock & Hocking, 2015). Although activities are sometimes present, and are incorporated in environmental gerontology and psychology theories used in the background of this thesis;

however, they do not encompass occupations as the ordinary and extraordinary activities of daily living, specifically situated and contextualised, offering a sense of belonging, giving purpose, meaning and continuity in life, and sharing a sense of control and power over one's life (Bontje, 2018; Hammell, 2014; Hasselkus, 2011; Hocking, 2009). These specific attributes enrich the theoretical framework used in this thesis according to an occupational perspective of participation outside the home among older adults living with dementia (Njelesani et al., 2014). In their review of the idea of an occupational perspective, Njelesani and colleagues (2014) propose a definition that is quite broad: a "way of looking or thinking about human doing". Common elements of an occupational perspective have been identified as including contextual factors, being connected to health and well-being, all types of occupational forms, functions, and meaning, and contributing to doing, being, becoming and belonging (Njelesani et al., 2014). An occupational perspective also includes the experience of doing and meaning, autonomy and self-determination (Hemmingsson & Jonsson, 2005). Others stress the importance of relating the occupational perspective to the societal context underpinning occupational justice (Whiteford & Hocking, 2012). Applying a perspective is to stress the idea of having a point of view on a subject or situation. Here, using an occupational perspective means, for example, that the occupations performed by older adults living with dementia while participating outside their homes enables them to experience belonging and autonomy.

Furthermore, there is a need to add a transactional perspective to the theoretical framework, as the concept of place as relational and embodied is central to this thesis. Transactional theory was elaborated based on Dewey's philosophy (Cutchin, 2004; Dewey & Bentley, 1949) and on theory in occupational therapy and occupational science (Farias & Laliberte Rudman, 2016; Ikiugu & Pollard, 2015; Kuo, 2011; Madsen & Josephsson, 2017; Whiteford & Hocking, 2012). The transactional perspective highlights and strengthens the parts of theory that address how components interact, or rather transact, such as the relationship between the person and the environment. The transactional perspective contends that the experience of participation is always situated and embedded in the context or places where it happens (Cutchin, 2004; M. P. Cutchin & Dickie, 2013). The occupation performed becomes the bridge of the transaction between the person and the visited place (Fritz & Cutchin, 2017). The transactional perspective allows for linking places and persons to occupations performed outside the home. As such, these links and relationships create a transactional pattern of participation in occupations and places outside the home, which can then be explored through research designs like a cross-sectional study for example. Being immersed in activity in places – being in place – is an ongoing life process that generates important meaning (Rowles, 2009). It is closely related to the process of place integration – the continual adjustment of person-place relationships to enhance well-being (Cutchin, 2004). Participation in activities and places outside the home is seen here as fundamental to the functional coordination of person and place in response to problematic situations, also called disharmonised situations (Cutchin & Dickie, 2013; Dickie et al., 2006). Situations are viewed as the togetherness of the individual embedded in places while engaging in occupations.

Situations cannot be separated into components and are the construct that provide familiar experience and meaning. Situations are both familiar in the way they might repeatedly occur and unique to that specific happening. When an individual faces a challenge or a risk, the situation becomes problematic or disharmonised, and requires intelligence to modify the occupation, for example, the way the person transacts with the environment. As such, the interdependency of places and occupations can facilitate or hinder participation. Examples of this interdependency include the distances and layout of commodities, availability of transportation and support, and the meaning of activities, risk perception, and familiarity.

An intertwining of both transactional and occupational perspectives into a singular perspective enriches the view on occupations. Occupations are seen as transactions in the transformation of spaces into places that hold meaning and identity (Cutchin & Dickie, 2013; Fritz & Cutchin, 2017; Rosenberg & Johansson, 2013). This is also supported by the theory on place from environmental gerontology (Cresswell, 2015). Experiencing continuity and familiarity in everyday life is especially important for people living with dementia, and this perspective allows for highlighting continuity and familiarity. This perspective, transactional and occupational together, will increase the understanding of older adults living with and without dementia going outside their homes and participating in places and occupations.

OLDER ADULTS LIVING WITH DEMENTIA

Dementia is a chronic condition, identified by the progressive deterioration of cognitive functions, including memory loss, language impairment, disorientation, planning, attention, motivation, and executive functioning, and by changes in personality and identity (Livingston et al., 2017). Abstract reasoning, space and time orientation, and understanding of the environment are also affected. As a syndrome, dementia includes multiple forms and diverse symptoms; the most common type is Alzheimer's disease. As the brain tissue atrophies, so the cognitive functions will slowly diminish, eventually resulting in difficulties in all activities of everyday life, affecting participation possibilities both inside and outside the home (Classon et al., 2016; Kuosa et al., 2014).

The World Health Organisation (WHO) has expressed that dementia is a global health priority (World Health Organisation (WHO), 2012). The number of older adults living with cognitive impairment is increasing in in European countries and elsewhere around the world (Alzheimer Disease International & Patterson, 2018; Winblad et al., 2016). As age is a leading risk factor for dementia (Livingston et al., 2020), this increase might be more specifically attributed to the life expectancy of those over 85 (Alzheimer Disease International & Patterson, 2018). This issue is also visible in Switzerland, as more than 155,000 people were recorded in 2019 with a form of dementia, with a majority living at home (Association Alzheimer Suisse, 2018). Importantly, the response to this problem is being organised at the cantonal level due to Switzerland's internal political organization, in which cantons can be viewed as autonomous political units with different health contexts

(Monsch et al., 2008); thus the place of residence has an influence on the type and way services are structured and provided to the population.

Older adults living with dementia seen as being in a situation of disability

There is an emerging discourse that pictures dementia as a disability (Shakespeare et al., 2019). Several recent interventions from the Alzheimer Disease International (ADI) have proposed adopting a social model approach to dementia (Thomas & Milligan, 2018). Dementia, like disability, is a multi-dimensional phenomenon, suggesting the need for widening the focus on various aspects, such as the relationship with the environment, clinical aspects, and social and political viewpoints. Although older adults with dementia do not necessarily think of themselves as being disabled, regarding dementia as a disability could be beneficial for them; the design of the built environment for dementia is lacking compared with the advances obtained by the disability movement (Alzheimer Disease International et al., 2020).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD)'s first article includes those who have "*…long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*" Article 9, "*…to enable persons with disabilities to live independently and participate in all aspects of life…*" stresses the importance of participation for all, both inside and outside the home (United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2007). The social model of disability distinguishes the health condition with the social experiences of exclusion, stigmatization and loss of participation. Earlier research has shown an increased understanding of environmental influences on quality of life and participation in those living with dementia (Thomas & Milligan, 2018). "Age-friendly" cities (World Health Organization, 2007) or "dementia-friendly" communities (Buckner et al., 2019; Shannon et al., 2019), aim at recognising the older adults living with and without dementia as an actor in society and making them feel understood, respected and supported. Based on the social model of disability of removing environmental barriers in the society, they tend to focus on physical as well as attitudinal barriers, by raising accessibility to diverse locations and awareness of the experience of living with a dementia, as well as decrease stigmatisation of having to live with a dementia. A review of "dementia-friendly" communities in the UK showed that this label was attributed to very diverse locations such as a university, churches, airports, banks, supermarkets, a fire department, and senior associations (Buckner et al., 2019). In another review, having access to a natural landscape was shown to be part of the features needed to uphold a "dementia-friendly" community, decreasing agitation and apathy, and increasing engagement of older adults living with dementia (Motealleh et al., 2019). As the term "disability-friendly" was criticised so has the term "dementia-friendly" for advocating a charitable kindness due to negative social representations towards people with a disability or dementia alike (Oliver, 2013; Shakespeare et al., 2019). However, initiatives based on the social model, like the "dementia-friendly" communities, by focusing mainly on removing environmental barriers, only partially support participation outside the home (Alzheimer Disease International et al., 2020). Thus, a more inclusive and relational approach might highlight the relationship that the older adult living with dementia constantly experiences with their environment (Clark et al., 2020; Meijering et al., 2019; Motealleh et al., 2019), and may help support participation outside the home. If an environment is rendered accessible, and discrimination is effectively countered, then people using wheelchairs are enabled to participate with equal opportunity. For older adults living with cognitive impairments, that additionally diminish over time, the challenge of enabling participation outside the home becomes much more complex.

As advocated by a relational social model of disability, the opportunity to make choices about which places to visit outside the home and which occupations to perform there, is supported by an occupational perspective (Shakespeare et al., 2019). Occupations performed outside the home happen in relation to the places visited by the older adults living with dementia as they make use of those opportunities that society has offered them. Considering older adults living with dementia as living with a disability allows for using the knowledge developed about environmental design to promote participation and recognising participation as a human right.

Supporting community-dwelling older adults living with dementia

In Switzerland, limited public home-health services are available everywhere in the country in a limited way. The professionals hired might include disciplines other than nursing and auxiliaries, like occupational therapists, social workers, or psychologists; in cities and some densely populated areas, there might be private home-health services. Civil society such as the Alzheimer's Association also offers services, including respite, social or legal counselling, and discussion groups for significant others. Memory clinics provide specialist assessments for diagnosis and some support. In 2019, only half of persons living with dementia obtained a diagnosis (Office fédéral de la santé publique (OFSP), 2019).

For some time now, countries in Europe and others around the world have adopted policies to maintain older adults at home as long as possible and support age-and-dementia-friendly environment initiatives (World Health Organization, 2007). Switzerland only recently deployed the first national Alzheimer plan in 2016 (Office Fédéral de la Santé Publique (OFSP), 2016), primarily focusing on maintaining older adults at home as long as possible, relaying on care from significant others. So, as persons living with dementia remaining at home becomes the norm in European countries and elsewhere, the immediate outdoor environment becomes of interest in dementia studies (Alzheimer Disease International et al., 2020). This highlights a need to better understand how dementia may impact participation outside the home, and how to better enable older adults living with dementia to go out of their homes and to participate in the society, not solely focusing on the built environment.

PARTICIPATION OUTSIDE THE HOME FOR PERSONS LIVING WITH AND WITHOUT DEMENTIA

Literature reviews on participation and dementia show the importance of activities for older adults living with dementia and for members of their family (Egan et al., 2006; Kuosa et al., 2014). They strive to maintain their preferred patterns of participation as long as possible, including keeping the same routines and habits (Hart & Heatwole Shank, 2016). While their ability and independence in performing complex activities gradually deteriorate (Livingston et al., 2020), the need for engagement and participation in occupations continues for people with dementia (Hasselkus & Murray, 2007).

Defining and evaluating participation

Participation is an often-used concept in health and social research, although it is complex, seldom well-defined, and often taken for granted by authors (Cornwall, 2008; Larsson-Lund & Nyman, 2017; Shakespeare, 2020). Participation has first been a subject of discussion in the field of disability as the end-goal of intervention (health care) (Hammel et al., 2008) or as a basic human right (social science) (Shakespeare, 2006). The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) stems from those perspectives, defining participation as “involvement in life situations” and creating a single taxonomy for both “activities” and “participation”. The ICF taxonomy restricts the concept of participation to a list of tasks, skills, abilities, and large areas of daily life expressed as a level of performance by sharing the list with the concept of activity; and has been widely criticized (Brown, 2010; Sugarhood et al., 2017; Whiteneck & Dijkers, 2009). Participation seen only as a level of performance, like how the ICF might be used in health care, lacks a more in-depth understanding of other aspects such as engagement, purpose, meaning, risks perception, and satisfaction (Brown et al., 2004; Hemmingsson & Jonsson, 2005). Furthermore, the construct of the environment in the ICF is limited to physical, attitudinal and systems elements and is only considered as influencing its Part 1: “functioning and disability”, which contains participation. Therefore, the ICF as a framework is lacking the complexity needed to understand participation outside the home for persons living with dementia.

Expanding on the ICF view of participation, Levasseur et al. (2010) defines social participation as a “*person’s involvement in activities that provide interaction with others in society or the community*” (Levasseur et al., 2010). This definition considers participation as being socially anchored and less static, by conceptualizing a continuum of involvement from relatively passive to increasingly more active engagement. Taking an even further stand from considering participation as only a level of performance, researchers like Magasi and colleagues (2009) have advocated for participation as a fulfilment of one’s choices and wills regarding the activities performed, also referred to as an occupational gap by Eriksson (2007). An occupational gap represents a discrepancy between what the person wants to do and what he or she actually does (Bergström et al., 2017; Eriksson, 2007). Still the concept of participation has been consistently and repeatedly claimed as being more complex and showing more variability than exposed even by consideration of both objective and subjective perspectives (Aw et al., 2017; Brown et al., 2004; Ghul & Marsh, 2013), especially when referring to persons living with dementia.

Evaluating participation as a concept has long been identified as a challenge (Whiteneck & Dijkers, 2009), mired in conceptual and operational confusion. Tools for evaluating participation have been developed since after the publication of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (World Health Organisation, 1980), mostly related to impairments, skills or activity performance. A criticism of this evaluation strategy is that persons may not want to engage in the fixed set of items provided by the assessment tool (Brown et al., 2004). Other instruments have emerged that try to recognise personal preferences in participation, and seek to measure the person's appraisal of their own level of participation. As such, subjective satisfaction with participation was found associated with global life satisfaction as a better indicator of quality of life (QoL) than objective performance, interpreted as participation (Brown et al., 2004). In the Assessment of Motor and Process Skills (AMPS) (Fisher & Jones, 2010), an observational assessment, individuals may choose the type of tasks that they want to perform, but it measures the performance quality in activities of daily living in a natural context, referred to participation in the ICF, and not the satisfaction of their performance. Participation and occupational performance are thus often mixed up with one another, or used indiscriminately (Hemmingsson & Jonsson, 2005; Vessby & Kjellberg, 2010).

Assessment tools developed for persons living with dementia in mind tend to focus primarily on activities of daily living within the home, often linked to cognitive level, and typically using caregiver or professional judgments as evaluation responses, i.e., the Disability Assessment for Dementia (DAD) (Gélinas et al., 1999), the Activity Card Sort (Baum & Edwards, 2008), or more recently the Functional Capacity Card Sort (FCCS) (Verrier Piersol et al., 2016). Other instruments focus on the use of technology inside and outside the home, such as the Management of Everyday Technology Assessment (META) (Nygård, 2006a) and the Everyday Technology Use Questionnaire (ETUQ) (Nygård et al., 2016). Recent research has developed and evaluated assessments for screening risks outside the home (Bantry White & Montgomery, 2016) or designing dementia-friendly environments (Fleming et al., 2016), but these tools do not provide specific information about places where older adults living with dementia go to perform such out-of-home activities. Moreover, to our knowledge, no assessment tool aims to capture detailed information on places and activities *in combination*.

Hence, participation is defined here as an engagement in everyday occupations, embedded and situated in places (Ward et al., 2017), and experienced by individuals. Thus, issues of interest include having opportunities to (a) reach the space outside the home, (b) have places that are experienced as familiar and in which one may engage in occupations, and (c) create experiences of belonging, identity and agency, adequacy, and well-being, are issues of interest. These issues regarding participation will be expanded further in this thesis.

Importance and benefits of participation outside the home

Although an age-related reduction in activities outside the home is well documented (Cox, 2006; van Nes et al., 2012), further evidence demonstrates a substantial "shrinking world" for persons living with dementia (Duggan et al., 2008). In an early study, Duggan et al. (2008) separately interviewed 22 persons living with mild-to-moderate dementia and their caregivers, focusing on going outdoors, getting lost, and unfamiliar places. Using a grounded theory approach, they reported the importance of the outdoors, the impact of dementia on outdoor life and the importance of familiarity with the outdoor environment. Their conclusion at the time was that persons with dementia were experiencing an outdoor world that was "shrinking". The familiarity of the environment is reported as being a significant attribute; its loss, due to changes happening in the neighbourhood that lead to confusion, may cause them to stop going out altogether.

Further research has shown that the usual social and physical boundaries of their out-of-home participation seems to shrink over time for older adults living with dementia, restricting their participation (Olsson et al., 2013; Oswald et al., 2010). Life-space constriction has been shown to be a risk factor for frailty, transfer to nursing homes, and cognitive decline. Life-space reduction correlates with older age, lower education, functional limitations, cognitive impairment, depression symptoms, health problems, social isolation, inability to drive, and fewer amenities (Choi et al., 2014; Huisingh et al., 2017; Marottoli et al., 2000). Persons living with dementia and their significant others report shopping, using transport, and maintaining mobility outside the home as challenging, causing them to withdraw from occupations. Research shows that little by little they disengage from social occupations outside the home, like belonging to associations or clubs, or going to social gatherings, expositions, or concerts (Argyle et al., 2017; Kuosa et al., 2014). Persons living with dementia often report a feeling of being "disconnected" to the outside world. In contrast, continuity of participation outside the home is associated with social and health benefits, like perceptions of belonging, adequacy, and connectedness to other people (Clare, 2010; Ward et al., 2017).

Research suggests that older adults, including those living with dementia, value participation outside the home for various reasons. Benefits related to participation outside the home include physical activity, contact with nature, meaningful relationships and social interactions, and an awareness of the environment (Keady et al., 2012; Pollock, 2012). Physical activity has been shown to prevent depression and to positively influence cognitive functioning, quality of sleep, and perception of self and identity (Sugiyama & Ward Thompson, 2007). It also has an impact on performance in activities of daily living (Burge et al., 2012). Contact with nature offers a restorative effect linked to greenery that increases positive affects (Bantry White & Montgomery, 2016), and reduces anger, and helps heighten awareness of self, identity, and agency (de Bruin et al., 2017). Walking outside in nature offers enjoyment, aesthetic pleasure, and well-being (Rappe et al., 2006; Ward Thompson & Travlou, 2007). Opportunities for social contact provided by participation outside the home (Clarke & Bailey, 2016), while being identified as an important protective factor for cognitive decline (Desai et al., 2020; Livingston et al., 2020), also increases the experience of connectedness and belonging (Kearney, 2006; Ward et al., 2017). Being able to engage in occupations and participate outside the home has increased awareness of their close environment for older adults living with dementia, and heightened their perception of self, even in a more advanced form of dementia (Clare, 2010; Kuosa et al., 2014).

The literature on participation outside the home for older adults living with dementia has underscored the importance of a specific place, often referred to as the neighbourhood. Blackman (2006) identified the neighbourhood as a "*walkable zone of experience*" (p. 2) and "*a local boundaried space that holds within it various attributes that are both physical and social*" (pp. 20-21), emphasizing this specific place for people with dementia. Mitchell and colleagues (2003) identify attributes, namely familiarity, legibility, distinctiveness, accessibility, comfort, and safety that would enable people with dementia to navigate their immediate outdoor environment, making their neighbourhood "dementia-friendly". These environmental attributes play a role in how people with dementia interact and access the outside place and have been shown to support and enhance the functional and cognitive capacities of people with dementia to navigate outdoor environments (Brorsson, 2013). Although participation outside the home offers benefits to the well-being and health of older adults living with dementia, it comes with challenges and risks.

Challenges and risks of participation outside the home

Going out and about becomes a challenge for many persons living with dementia and their families. In fact, this situation may be seen as fraught with risks (Bailey et al., 2013). Space outside the home has been repeatedly considered to be hazardous and risky for older adults living with and without dementia, due to the increasing complexity of navigating the outside world (Chaudhury et al., 2020), such as traffic, crowding, noise, variety of urban furniture on walkways, and unpredictable road work. This underlines the assumption that persons living with dementia are unsafe and unable to negotiate the outside the world, use public transportation, or engage in occupations in places outside the home. Yet, how they manage to navigate public space and interact with places to participate outside the home is unknown, due to insufficient research exploring how the perception of risks might influence participation outside the home (Manthorpe & Iliffe, 2018; Sandberg et al., 2017). Moreover, the way the environment, in which participation is situated, is described - as hostile, unfamiliar, and risky -, increases the stigmatisation and labelling of older adults living with dementia (Nguyen & Li, 2020).

Furthermore, Brorsson and colleagues (2016) observing pedestrians with dementia using zebra crossings, have underlined that problematic situations occur when the participants had to manage unfolding traffic situations; only one aspect of the problem could be kept in focus in that situation, thus creating disharmony. For participants to maintain control of everything was also exhausting, as they were easily disturbed by the outside noise and other sensory inputs. Crossing the street is a specific part of navigating the space outside the home, but a risky and critically important one for a safe journey (Brorsson et al., 2016).

How risks are constructed and perceived has been identified as playing a role in dementia care and participation outside the home (Bailey et al., 2013; Clarke, 2011). On one hand, risks can be depicted as negative and dangerous, stressing the potential loss. As such, persons living with dementia may experience family, friends, and service providers framing risks as "unwanted", "undesirable", or "to be avoided". This construction of risks is based on the importance given to safety in dementia care. As a result, older adults with dementia have reported reducing their involvement in occupations outside the home and confining themselves to home as a way of increasing safety (Berry et al., 2015; Lloyd & Stirling, 2015). On the other hand, there are positive aspects of risk taking, like expressing one's individuality, independence, and control over one's life; these positive aspects could reframe occupations outside the home that appear hazardous into ones perceived as positive and identity enhancing (Alaszewski, 2000; Fischhoff & Kadvany, 2011). This approach enables persons living with dementia to experience a sense of independence, freedom, and control.

A study on risk construction and perception conducted in Switzerland involving triads of persons living with dementia, their significant others, and home-health professionals, has shown that risks need to be understood as dynamic and co-constructed (Droz-Mendelzweig et al., 2014). Coping strategies are often used by persons living with dementia to manage situations fraught with risks, such as staying home and withdrawing from out-of-home activities, asking for help to be driven to appointments, and relying on significant others to go out. For some persons, coping strategies include simply being aware of risks, tolerating them when going out, and even experiencing them as challenges to be overcome (Sandberg et al., 2017). Informal caretakers will often become so anxious with the idea of the person living with dementia going out alone that they will try to limit the access this person has to the outside environment. Risks perceived as acceptable by the person with dementia may not be viewed as such by family members or formal caregivers who might be more preoccupied with the management of physical risks (such as falling, getting lost, dying of exposure, getting hit by a car), than with threats to personal and social identities (Brittain et al., 2010; Robinson et al., 2007). How risks are depicted, constructed, and experienced in the situation of persons living with dementia may shape their participation outside the home.

Persons living with dementia and their families report difficulties related to finding one's way (Sheehan et al., 2006). Getting lost is a commonly perceived risk by persons living with dementia and their families. Oswald and colleagues (2010) used GPS tracking devices in the SenTra study, following persons living with dementia in their whereabouts outside their homes. Their data showed hesitations at crossings (time spent) and instances of getting lost. Getting to the intended place without taking too much time, and without getting lost and unable to get back on the right path, are challenges when older adults living with dementia go outside alone. In the literature, the risk of getting lost is often associated with wandering behaviour and is often used as a reason to limit participation outside the home (Emrich-Mills et al., 2019; Pai & Lee, 2016). Getting lost while driving has been reported in a study by Hunt, Brown & Gilman (2010) as a risk for getting harmed. They also reported that most persons living with dementia were driving to or from a familiar place, such as the grocery store, the post office or the home of one of their adult children. Falling is another commonly perceived risk, by both persons living with and without dementia, and fear of falling is an aggravating factor for restricting participation outside the home. Research suggests that approximately half of all falls occur in the street or in places outside the home (Nyman et al., 2013), since pedestrian falls are often caused by barriers in the environment (Brorsson et al., 2016; Wennberg et al., 2009). Feeling stressed or embarrassed are also identified as a risks in dementia studies (Bantry White & Montgomery, 2016). Research has shown that older adults living with dementia face different types of risks (getting lost, falling, being stressed or embarrassed) when going out and about, but we do not know how older adults perceive these risks in specific places. There is also a knowledge gap about how these risks are associated with participation outside the home for older adults living with and without dementia.

In summary

Participation outside the home is an important part of everyday life, but presents challenges for community-dwelling older adults living with-early-to-moderate-stage dementia. Few studies have investigated the patterns of engagement in occupations and participation outside the home for older adults living with dementia (Dawson-Townsend, 2019), especially regarding places visited. This knowledge gap is relevant, because: (a) from a clinical stand point, participation outside the home is not the first issue to be addressed, and professionals (general physician, nurses, physiotherapists and occupational therapists) report a lack of confidence and tools, as well as feelings of inadequacy (Bartlett & Brannelly, 2018; Hunter & Divine, 2020; Linehan, 2021); (b) from a societal and civil right stand point, participation outside the home is a field in which social representation, stigmatization and recognition are easily made visible and enhanced; and (c) from a theoretical standpoint, participation outside the home represents a converging knot between the individual's experience, the environment in which the individual is embedded, and the individual's engagement in occupations. Person-place relationships may also change in relation to the development of dementia, as the relationships that were once central to one's life can be disrupted by the loss of familiarity, the loss of ability to navigate and access places, or by fear of embarrassment. This will be described in detail in the next section of the background.

UNDERSTANDING PLACES AND SITUATIONS OUTSIDE THE HOME

To understand the issues persons living with dementia face when participating in places and activities outside the home, there is a need to consider the term: outside the home. Here, I will construct and argue for a relational understanding of the environment outside the home. First, I will acknowledge the need of having an "inside" space in order to go out and about in a space outside the home. Then, step by step, I will move from a focus on space towards a concept of place that is relational and situated, building on a transactional and occupational perspective. Spaces have a cognitive weight that can be "read" and comprehended, making space legible. Environmental docility offers people possibilities to modulate spaces and transforming them into places that become familiar and can provide a sense of belonging

(Moser, 2009), based on the relationship between the person and the environment (Bechtel & Churchman, 2002).

This concept of place is determinist, functional, and analytic, and based on cause and effect relationships. Only recently, has the vision on places become more complex, dynamic, and fluid, offering a perspective that is relational (Andrews et al., 2013; Clark et al., 2020; Cummins et al., 2007). Although many of the concepts presented here are inspired from environmental gerontology, geography, and psychology, they are formatted through an occupational and transactional perspective, in link with the theoretical framework of this thesis.

Inside and outside home

Trying to understand the concept of places and situations outside the home without first considering the concept of home would be futile. Looking at places outside the home creates a tension between the inside (home) and the outside (out-of-home), like a threshold or a membrane separating the inside (safe, comfortable and positive relationships) from the outside (full of risks, dangerous and confusing). Home is often referred to as a ”safe place”, a place of comfort and positive relationships without considering it as an area for conflicts, discomfort, and dangers (Hillcoat-Nallétamby & Ogg, 2014; Penney, 2013; Petersson et al., 2012). Research on ageing-in-place has strongly supported the idea of having a “sense of home” or “homeness” as a point of departure for place attachment (Cutchin, 2003; Lewicka, 2010), that can be extended outside home. Feeling at home is thus not solely connected to the “home” dwelling, but rather to people, occupations, and an atmosphere of comfort that is often attributed to the physical and social design of the home, by considering its characteristics (Lim et al., 2019). Home-likeness would thus qualify places that confer this identical feeling of being at home, also referred to as being-in-place (Chaudhury et al., 2018; Rowles & Chaudhury, 2005). Feeling at home is often taken for granted, and usually goes unnoticed situations of being-in-place (feeling comfortable and familiar with one’s everyday world), and creates a sense-of-home experienced as a sense of belonging and comfort (Johansson et al., 2020). Feeling at home or the sense of being-in-place have been expected to apply to familiar places outside the home. As stated by Johansson et al. (2020), a sense-of-home cannot be attributed to a place outside the home without first considering the people, the social practices, and atmosphere created by engaging in occupations outside the home and is linked to familiarity. A sense-of-home is partially based on the experience of the socio-cultural legibility of place, i.e., of knowing how to “act and behave” at a specific place, which is particularly important in the context of living with dementia (Johansson et al., 2020; Ramadier, 2011).

Space outside the home

The environment that exists outside the home is referred to as a space by many authors in research, with a focus on defining what sort of space that is. For example, urban planning uses “public space” as a space that is open to the public and offers degrees of accessibility and possibilities to meet; life space is used in gerontology as it relates to mobility and navigating outside the home; and in health and geography, activity space is used to identify a space holding activities performed by humans. A recent study proposes that 14 days of tracking by GPS are needed to identify an activity space (Zenk et al., 2018), but this fails to increase the understanding of the complexity of the interactions that take place between persons and their environments. Still, before we consider places and how space becomes a place, space has a characteristic that allows humans to read it. Socio-cognitive legibility of space is especially interesting for people living with dementia as it links the physical and visual boundaries to the ability to read the meaning of the space.

Legibility of space

Physical, social and cognitive legibility of space (Lynch, 1960) influences the ease of use of the environment, as for example the ease of getting to a shop and buying groceries. Outside the home, each space is delimited by borders (walls, rivers, highways, etc.), interconnected by ways (walkways, roads, stairs, bridges, etc.), and shared by others (family, strangers, shoppers, etc.), all of which increases the complexity of cognitive space for older adults living with dementia (Moser, 2009; Ramadier, 2003). Still, to navigate and use the outdoor space, and to participate in everyday life, older adults living with dementia need to comprehend the environment they are in; this implies cognitive abilities, such as reading signs, walking on curbs, or using traffic lights safely, but also must display appropriate behaviour for the situation. Social legibility includes information on the behaviour expected in that space (Moles et al., 1998; Ramadier & Moser, 1998). The ability of the person living with dementia to navigate public space and understand social legibility also has an impact on their relatives, family or caretakers, as they may be embarrassed by the person's disinhibited behaviour in shops or in the streets when meeting other people, e.g., touching unknown children or babies, urinating in the street, or moving goods from one place to another in stores. Erratic or deviant behaviour is often reported by informal caretakers or significant others as a reason for not going out anymore (Brittain et al., 2010), since spaces have specific and organised cognitive and behavioural expectations.

Socio-cognitive legibility allows people to split and organize space into cognitive units recognized as places (Ramadier, 2011). Research has shown that the mobility of people in an urban setting is mostly made up of spatial routines, familiarity of space being an important component. Familiarity is understood here as a visualisation of places (Moser & Weiss, 2003), and can be increased by a general principle called replacement, which is to physically move from home to a destination and back. It creates a cognitive link between the two places, by going from one place to the other, thus minimizing the cognitive difference between the two places (Ramadier, 2010). Still, legibility of space only focuses on the environment as a separate entity from the person and their occupations. The concept of place here provides a limited understanding, which is not enough to consider the complexity of participation outside the home for older adults living with dementia.

From Space to Place

Space is often used as an undetermined, unlimited, and sometimes unspecified environment within a three-dimensional view that can somehow be qualified, like public versus private space, or the space outside the home of older adults living with and without dementia. As discussed before, this space can be seen as a container for life, activities, or navigation. The life-space enables people to experience and interact with the world and is mostly used to describe the space outside the home in relation to the people using it (Lloyd & Stirling, 2015). This life-space offers a geographical image to the space outside the home in which people navigate going from one place to another; it could be seen as a series of zones, ranging from within one's home to the neighbourhood, the town, the region and so forth, using an eco-systemic model (Bronfenbrenner, 1979). Based on an eco-systemic perspective of the environment, places have been recognised as increasingly important (Cresswell, 2015; Rowles & Bernard, 2013) in understanding the life-space mobility outside the home (Baker et al., 2003), how older adults age in place (Fung, 2020; Van Dijk et al., 2015), and how older adults living with dementia participate outside the home (Chaudhury et al., 2020; Clark et al., 2020; McGovern, 2017). The relationship between ageing and places has long been of interest in the field of dementia (Keady et al., 2012; Rowles & Chaudhury, 2005).

To better understand the potential of places in dementia research, there is a need to elaborate on how space becomes a place. From an occupational perspective, space becomes a place as people perform occupations in that space (Townsend et al., 2009). Based on the relationship people maintain with their environment, undefined space outside the home transforms into multiple places that can be identified and named. By repeatedly performing activities in places, older adults – as do all people – experience a relationship with their environment, transforming the space into a place that has meaning and into which the individual inserts life stories (Kielsgaard et al., 2021; Townsend et al., 2009). As such, as occupations are performed, the place becomes a part of the individual's life story and life world, linked to their identity (Huot & Rudman, 2010). Within an occupational and transactional perspective, the individual is seen as embedded in places, i.e., in constant relation with the environment through the occupation (Cutchin & Dickie, 2013; Hamilton, 2010). Nyman & Isaksson (2020) refer to an "enacted togetherness" that situate occupations into socio-culturally meaningful places. They argue that performing occupations together creates shared meanings that connects persons and places through unfolding stories.

Aging-in-place models support this relationship that enables older adults to be embedded in places (Fung, 2020), because the places are recognised as familiar, having meaning, and offering a sense of belonging. From an occupational perspective, occupations understood as doing, being, becoming and belonging have been linked to health and well-being (Wilcock & Hocking, 2015), and support the relationship with the place (Kielsgaard et al., 2021). By repeatedly being engaged in visiting places outside the home, the older adults living with dementia build a sense of familiarity and belonging toward their life-space (Clark et al., 2020) or places. As the disease progresses, the opportunities for engaging in occupations outside the home are become more restricted to close and familiar places, such as the neighbourhood.

Being able to access important places where occupations are performed is essential for maintaining participation outside the home for older adults living with dementia (Ward et al., 2017).

Place outside the home

Now that space has transformed into place in this thesis, there are aspects pertaining to places that I would like to present. Research has identified familiarity as important in the relationship with places (Fung, 2020; Sheehan et al., 2006), but has not been clearly defined, nor has the relationship with places been explained. Furthermore, the literature review highlights specific places in dementia research, such as the neighbourhood or zebra-crossing.

Familiarity, landmarks and embodiment

Familiarity is recognised as important not only in facilitating participation outside the home (Bontje et al., 2019) for all persons, including those living with a cognitive disability, but also in linking persons to places they visit outside their homes. Familiarity has been reported as being especially important for older adults living with dementia (Brorsson et al., 2016; Malinowsky et al., 2019).

Experiencing familiarity of place is developed over time by repeatedly reaching places outside the home and performing occupations that also feel familiar. Maintaining familiarity in places and occupations, by regularly and repeatedly visiting the same places, is important for participation outside the home (Phillips et al., 2011). Experiencing loosing familiarity may lead to insecurities and disorientation, fear of going out and a disengagement in occupations outside the home (Phillips et al., 2013). Experiencing risks such as getting lost or being embarrassed increases the unease of going to previously familiar places that now feel unfamiliar (Phillips et al., 2011). Individual landmarks may emerge from the experience of going to places and returning (Seetharaman, 2018), by frequent and repeated visits to familiar places, using procedural memory (Bier et al., 2015; Zanetti et al., 2001). Familiarity and hence landmarks are triggered without conscious thought to facilitating navigation between places outside the home (Mossabir, 2018). Landmarks have saliency, which is based on how well they contrast with the context they are set in. Structures, urban furniture, and art tend to be recognized as landmarks due to their singularity and familiarity. Clear form, visual or structural contrast, enables these items to be recognized as landmarks. Saliency thus includes visibility, location, noticeability, identifiability, recognizability, and memorability (Seetharaman, 2018). The impact of those attributes on participation outside the home is increased through familiarity (Mossabir, 2018).

However, familiarity is not just attached to places within an environmental viewpoint, but is also included in occupations as they are performed in places visited. Familiarity, therefore, transforms places into “familiar and lived places” (Mossabir, 2018), within a transactional and occupational perspective. Thus, the concept of place becomes relational. As people are embedded in places within a transactional perspective, it might be possible to consider them as being included in the places where they live and experience relationships – in transaction –

with the familiar places outside their homes (Andrews et al., 2013; Cresswell, 2015). Using a relational, transactional understanding of place, people experience being in a familiar place as a continuity of their identity and a creation of meaning and purpose, which includes having an affective (place attachment) and cognitive (identity) link to that place (Meijering, 2019). So familiar occupations performed in familiar places are situated, while persons are embedded in situations in a transactional relation (Margot-Cattin, 2018). Places may come to embody familiarity through the familiar occupations that people perform there while embedded in situations. As there is a permeability between inside and outside, so familiar places outside the home may also embody the familiar feeling-at-home, as presented herein, and supported by a relational transactional understanding of places. Familiarity is the link between the sense-of-home and the places outside the home.

In summary, the concept of familiarity is understood here as situated, embedded, and enacted in the experience of embodied places to which older adults with dementia travel (Kontos & Martin, 2013; Seetharaman, 2018). Familiarity is an important but understudied concept when addressing participation outside the home for older adults living with dementia. The familiar becoming unfamiliar may increase the disengagement that older adults living with dementia experience. Familiarity may also be eroded by both recurrent urban renewal and the progression of cognitive decline. There is a knowledge gap as to how older adults living with dementia experience familiarity in places, occupations and situations, and how they handle losing familiarity. We also do not know how familiarity, or progressively losing familiarity, may contribute to participation outside the home.

RATIONALE

Based on the state of the art presented above, there are several areas in which further knowledge is needed in order to gain a better understanding of participation outside the home for older adults living with and without dementia. Together these issues build up the justification for the studies in this thesis. Although there are many evaluation and screening tools pertaining to the field of dementia research, including some which focuses either on the performance of activities or on the environment, there is no known tool to evaluate participation in places and activities outside the home, in combination, which led to the development of the ACT-OUT questionnaire in Study I.

There is a considerable body of knowledge about the challenges that persons living with dementia face when going outside their home. Research has shown a general reduction in the life space of people living with dementia, but knowledge about how this reduction might take place across various types of places, and in comparison with persons without dementia, is missing. Furthermore, there is a need to develop knowledge on which types of places are maintained or abandoned by persons living with dementia, in order to better calibrate support offered in the community. How risks are appraised by older adults living with and without dementia while visiting places outside the home would also increase our knowledge on factors that contribute to the perception of participation outside the home. Furthermore, how perceived participation might be influenced by the quantity and variety of places visited, is missing and would inform on designing dementia-friendly places. Knowledge about how and by which factors perceived participation is influenced is also missing and would inform on how to best support inclusion of older adults living with dementia in the society, which led to conducting Study II and III.

Familiarity is often listed as necessary for older adults living with dementia to participate in places and activities in different environments, also outside the home. Familiarity can be both attached to the place and / or the occupation performed there, making places lived. However, it is rarely described or defined in relation to the experience of persons living with dementia; neither is there an explanation as to how familiarity could be used by persons living with dementia in their participation outside home. Although some studies have investigated how older adults living with dementia cope with unfamiliar places, the transition between familiar and unfamiliar has not been explored. This knowledge gap led to conducting Study IV.

Furthermore, this new knowledge on the issues presented above might challenge the representation, prevalent in civil society and in the medical model, of older adults living with dementia remaining in the boundaries of their home without much interaction with the outside world. As the picture of how older adults living with dementia spend their everyday lives becomes clearer, it will help stakeholders plan ahead for the increase of this population group in the years to come. To provide such information and facilitate improvements, a tool such as the ACT-OUT is needed. Information on the type and number of places visited, the most maintained or abandoned places, or the factors, including risks, that help maintain a feeling of participation outside the home, as well as how familiarity might be experienced, are a major step in better understanding the living conditions and experiences of older adults living with dementia in our society, and how their participation can be facilitated.

RESEARCH AIMS

OVERALL AIM

The overall aim of this thesis was to explore and provide new knowledge on participation in places outside the home for older adults with mild-to-moderate dementia as compared with older adults without dementia. The overall aim also includes increasing knowledge about transactions between persons living with dementia and the places outside their homes. Finally it also includes developing an understanding of places outside home and how they are associated with participation outside home.

STUDY AIMS

Study I :

- To develop the ACT-OUT questionnaire for older adults with cognitive impairment, using a systematic cross-cultural process.
- To align ACT-OUT and OGQ for community-dwelling older adults living with dementia so that they can understand and answer the questionnaires.

Study II:

- To explore and describe the similarities and differences between older adults living with and without dementia in participation outside the home, with regard to:
  - Reported places visited outside the home,
  - Reported maintainance and abandonment of places visited outside the home, and
  - Associations between the number of places currently visited and the perceived occupational gaps.

Study III:

- To explore the relationships between the number of places visited and the perception of their participation outside home for a sample of persons living with and without dementia
- To explore what aspects, e.g. amount and types of places visited, socio-demographic variables and perceived risks, might be associated with the perception of participation outside home

Study IV:

- To clarify how familiarity is experienced by persons living with dementia, in performing occupations and visiting places outside the home.
- To illuminate how this experience of familiarity might contribute to maintaining their participation in activities outside the home.

METHODOLOGICAL CONSIDERATIONS AND METHODS

This section is organised in three parts, starting with presenting an overview of the design of the four studies. Then, it will be separated into two sub-sections: one focusing on the development of ACT-OUT, from describing the construction, revision and alignment phase to present the outcome version and future developments; second focusing on presenting what was done in Studies II and III together, and IV, including ethical considerations of involving older adults living with dementia in research and using multiple languages simultaneously.

The population of main interest in all studies is the older adults (65+) with mild-to-moderate stage dementia living at home in their communities, but not in a nursing home. Older adults without dementia were included for comparison in Studies II and III, and contributed to the development of ACT-OUT in Study I.

STUDY DESIGNS

Quantitative and qualitative approaches were used in this thesis to explore and gain knowledge of the likely complex nature of participation in activities outside the home for older adults living with dementia (Table 1), as compared to older adults without dementia. The choice of using multiple methods in the thesis (Maudsley, 2011; Sommer Harrits, 2011) was based on the need to generate multiple points of view to explore this complex issue. The use of concurrent quantitative and qualitative methods in the thesis is understood as a pragmatic approach to research (Al-Hamdan & Anthony, 2010; Andrew & Halcomb, 2009; Bryman, 2007; Sommer Harrits, 2011), as there is a need to collect data from both paradigm due to the rationale and research questions of this thesis. All data collection in the studies in this thesis was conducted in the French-speaking region of Switzerland.

Table 1. Overview of the studies.

	Study I	**Study II**	**Study III**	**Study IV**
Focus	Develop ACT-OUT Align ACT-OUT for older adults living with dementia Translate OGQ	Explore stability and change in places, and associations with OGQ	Explore factors that influence perceived participation outside home	Clarify how familiarity is experienced and how it influences maintenance of participation
Design	Longitudinal instrument development	Quantitative, cross sectional		Qualitative, ethnographic

Data collection	Cognitive interviews	Questionnaires in semi-structured face-to-face interview at one occasion		Home-based and mobile interviews, field notes
Participants	26 older adults, 5 older adults with dementia	35 older adults with dementia and 35 without dementia		9 older adults with dementia
Recruitment	Senior associations and Alzheimer association.	Memory clinics, Alzheimer association; senior associations, ads in grocery shops.		From the group of 35 persons with dementia.
Instruments	ACT-OUT, OGQ	OGQ, ACT-OUT, MoCA, and a socio-demographic questionnaire		
Data analysis	Constant comparison, content analysis and triangulation of views from experts.	Descriptive and inferential statistics.	Regression analysis.	Constant comparison and theory iteration.

Study I focused on testing and revising the ACT-OUT with older adults living without dementia, aligning ACT-OUT for older adults living with dementia; and checked the feasibility of the data collection procedure. To support the development of ACT-OUT, a three-phase design (**Figure 1**.) was implemented. To translate OGQ into French, a back-and-forth translation process was implemented (Beaton et al., 2000). Phase A is described below in the development of ACT-OUT. Phases B and C involved participants who were interviewed with ACT-OUT and OGQ.[1]

Studies II and III used a cross-sectional design to explore participation outside the home for 35 older adults with dementia as compared with 35 older adults without dementia (Fowler, 2009; Groves, 2009). Questionnaires were used to collect data in face-to-face interviews.

Study IV examined experiences of familiarity in a sample of 9 older adults with dementia in a qualitative, ethnographic design using multiple interviews (home-based and mobile) (Hammersley & Atkinson, 2010; Nayar & Stanley, 2015).

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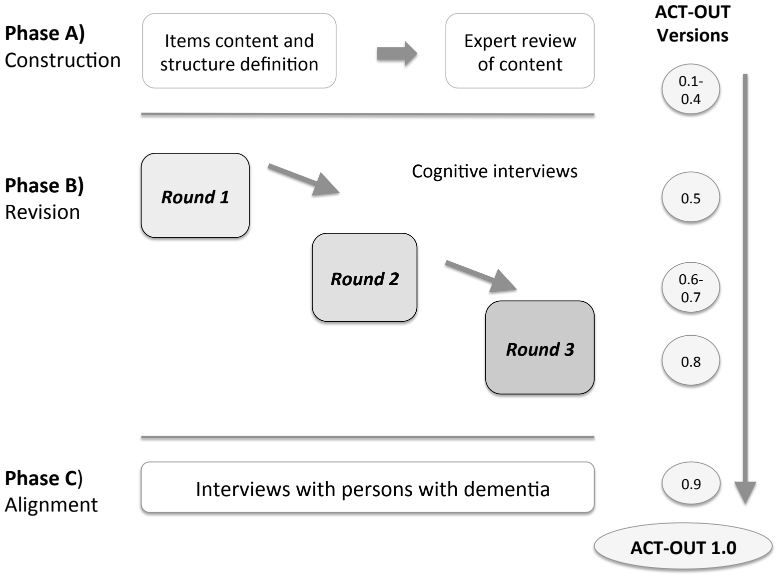
[1] The translation process of OGQ was not reported in the article pertaining to Study I, but Study II, which is published in the Canadian Journal of Occupational Therapy.

Figure 1. Description of the phases in Study 1.



DEVELOPMENT OF ACT-OUT (STUDY I)

The ACT-OUT tool was developed over the course of several years, starting in 2012 at the initiation of the PhD-plan and using a transactional and occupational perspective. This means that it uses places as a relational and transactional concept, with the individual being embedded there while engaging in an occupations. The ACT-OUT was constructed to support and facilitate interviewing older adults living with dementia about aspects that could be related to this. It was developed in three consecutive stages following Willis (1999) and Wild and colleagues (2005): construction, refinement and alignment. Refinement and alignment phases are presented in Study I.

Construction phase

Given the occupational perspective, the first entry-point used was a list of activities that older adults might commonly do outside their homes (versions 0.1 and 0.2), inspired by the focus of occupational therapy on activity performance (Baum et al., 2015; Wales et al., 2012) and engagement in occupations (Hasselkus, 2011; Stav et al., 2012). Tools based on activity performance and aiming for older adults living with dementia already existed in occupational therapy, like the Disability Assessment for Dementia (DAD) (Gélinas et al., 1999) which lists activities of daily living inside the home and assesses initiation, planning and execution. However existing tools did not address activities outside the home, nor places that older adults go to, which showed that a new tool was needed.

Still, when considering an approach based on creating an activity list to inform on participation outside home also showed some issues in the construction of ACT-OUT: a) people usually perform more than one activity in the same place and even at the same time; b) the way people perform activities outside home varies, and c) activity performance are influenced by socio-cultural contexts and scripts. Taken together, these issues suggested that a comprehensive list of activities would not be possible, which is of importance here as the ACT-OUT's development was carried out in French, English and Swedish simultaneously in order to be usable in different contexts.

Based upon these insights, the entry-point was changed to a list of places in version 0.3 (Part I of ACT-OUT). This step first took inspiration from the SenTra Study (Oswald et al., 2010) which used questionnaires on both activities and places, albeit separately. Wanting to collect information on activities and places in the same questionnaire, and directly linked to each other, led to the development of Part II of ACT-OUT, regrouping questions around the activity performed from the entry-point of specific places. Based upon a transactional and occupational perspective, places embody the activities and activities are embedded in places. So, to shed further light on the transactions between the activities and places, additional questions were phrased in Part II about frequencies of visiting the place, time of day, traveling, accompanying person, familiarity and risks, as relevant contextual aspects (Phinney, 2006; Van Steenwinkel et al., 2014), in addition to identifying the activities performed in specific places. Phrasing questions about perceptions familiarity and risks were considered with care, as they were new concepts introduced in a tool about participation outside the home and there was little knowledge about how older adults would respond, especially older adults living with dementia. The questionnaire was separated into two parts, I and II, for clarity, but it was constructed to be an iterative process in the interview, reflecting that places and activities cannot be separated.

Still, using places as an entry point to collect data on participation outside the home, raised the issue of how to organise such a comprehensive list of places in order to facilitate an interview. It was therefore decided to create domains of places, based on the type of activities mostly performed there and on the name and purpose of the place (socio-cultural legibility). Consequently, we grouped places under four domains: (a) consumer, administrative, and self-care places; (b) places for medical care; (c) social, cultural, and spiritual places; and (d) places for recreational and physical activities.

This created version 0.3, which was submitted to a panel of experts, in order to address face content validity (Gillham, 2007; Hardesty & Bearden, 2004). Face validity represents the degree that respondents or experts judge that the items of a tool are appropriate to the targeted construct of the tool (Hardesty & Bearden, 2004). The experts panel was constituted of two senior researchers in geography and gerontology, two representatives of the Swiss Alzheimer's Association, one physician with extended clinical and research experience in dementia, one professor of social work, and three occupational therapists with clinical experience with people living with dementia, of which one had extensive research experience. From the comments of the experts panel we created a Part III to elaborate on the idea of risks by adding closed questions about four risks identified in the literature about participation outside home. We also included general questions about life satisfaction, attitudes about challenges, and perceived participation. The experts panel's comments also led us to include the idea of change in the tool, by asking questions about the past and the future, in addition to the question in the present. We then adapted Part II to two versions, one for places where there was no change and one for places where a change had taken place, for example no longer visiting a place that used to be visited.

To underline ACT-OUT's cross-cultural features, it was constructed to allow some modifications, like deleting places that were not relevant and adding places at the end of each domain. For example, the Swedish version does not have an administrative place which exists in the Swiss version in French. To allow for the identification of unlisted important places, the final domain included an "additional" place, to be named by the informants as needed.

The ACT-OUT with three parts was version 0.4. This version was then tested through cognitive interviews in Study I, in the refinement and alignment phases as described in the next sub-headings.

Further development in testing and revising, then aligning ACT-OUT

Population and recruitment

In Study I, phase B participants were older adults without known cognitive impairments, and phase C participants were older adults with dementia (**Figure 1. and Table 2.**). Phase B participants were interviewed about their understanding of the ACT-OUT questionnaire and the translated version of OGQ, in three successive rounds of nine, nine, and eight persons, respectively. They lived in various urban and suburban areas (*n*=13) in villages or small towns (*n*=11), and in the mountains (*n*=2). People who used a wheelchair for outside mobility were not included, as such mobility restriction was expected to be more decisive, placing the main topic (i.e. living with dementia) in the background.

Table 2. Participants characteristics in phases of development of ACT-OUT

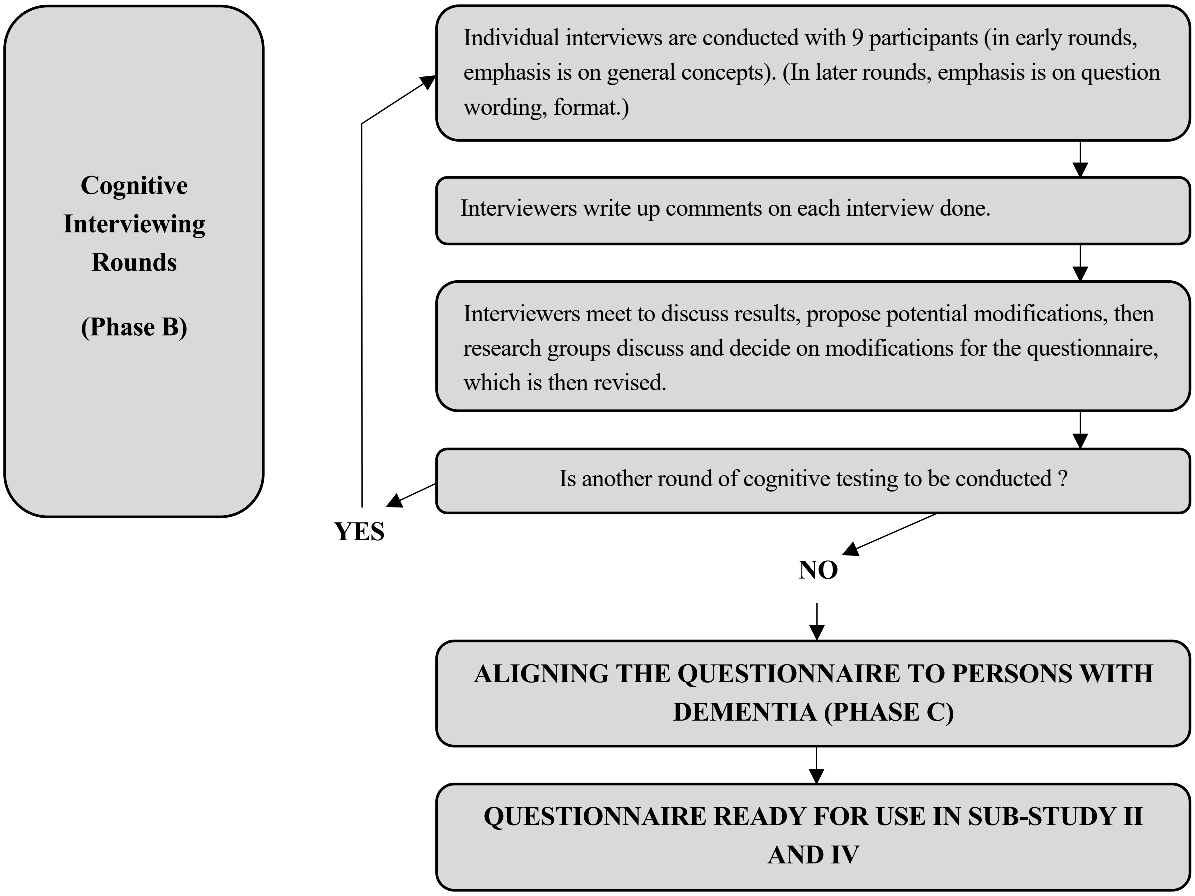
Phases and rounds	n	Mean age	Living alone (n)	Driving (n)	Formal Home Care (n)	ACT-OUT Version
B : Revision						
Round 1	9	79.22	8	6	1	0.4
Round 2	9	82.11	4	5	3	0.5 / 0.6
Round 3	8	76.13	4	4	2	0.7
C : Alignment	5	76.6	2	1	4	0.8 / 0.9

Data collection and analysis procedures

Cognitive interviews (Lee, 2014) were used in Study I to revise the ACT-OUT and further develop it. We used an adapted version of the Willis (1999) decision chart (**Figure 2.**) and organised three rounds of interviews conducted by three interviewers—including the author from January to December 2014, with three participants each. This increased trustworthiness through pooling and confronting interviewers' experiences (Ridolfo & Schoua-Glusberg, 2011). Each interview was structured in a three-step protocol (think-aloud, verbal probing, debriefing) including observations of respondents’ reactions (Hak et al., 2008).

Figure 2. Decision chart sequencing cognitive interviewing activities in Study I, adapted from (Willis, 1999), p. 20.

FIRST DRAFT OF QUESTIONNAIRE IS AVAILABLE FOR TESTING	
PREPARATION FOR INTERVIEWING	**RECRUITMENT**
Expert appraisal: review questionnaire, and make suggestions for modifications prior to testing (phase A)	Determine the types of participants to be interviewed
Develop basic probes to use in the first round of interviewing	Develop and implement recruitment strategy
	Recruit and schedule participants
SECOND DRAFT OF QUESTIONNAIRE READY FOR COGNITIVE INTERVIEW ROUNDS	



In Study I, a mixed technique of both think-aloud and verbal probing was used in the cognitive interviewing rounds, followed by more general debriefing questions that focused on both specific questions and the entire questionnaire. Specifically, the debriefing questions allowed us to: identify words, terms, or concepts that pose problems; assess question sensitivity; evaluate the effectiveness of questionnaire changes during the various rounds; and obtain suggestions for revising the questions or the questionnaire as a whole (Hughes, 2004). Debriefing questions yield insight into the nature of any problems encountered and provide suggestions for dealing with the problem (DeMaio & Landreth, 2004; DeMaio & Rothgeb, 1996).

The cognitive interview method is valuable for specific groups for whom questionnaire completion is an issue, and in pre-testing complex questions (Drennan, 2003; Presser, 2004), which was the case here with older adults living with dementia and some questions in ACT-OUT about familiarity and risks. The cognitive interview method is specifically appropriate for learning about: (a) the topic under research (exploring the nature of the underlying concepts to be measured and the specific topic material, assuming the participant to be an expert on the topic); and (b) the non-cognitive defects in the questionnaire (structural or logical problems, unclear layout, flawed questions, using the wrong term) (Willis, 1999). When answering questions in a survey, cognitive processes have an impact on how people answer various questions (Jansen & Hak, 2005). Some of these processes might be conscious while others are not. The way the question is phrased might also influence how people respond (Willis, 2005). For example, autobiographical questions place a burden on retrieval processes, which may not be appropriate for people with dementia.

Researchers cannot know in an absolute sense what goes on in the respondent's mind as he or she fills in the surveys; therefore, the cognitive interview technique allows checking for validity by revealing these cognitive processes (Willis, 2005). Rounds of cognitive interviews with three interviewers conducting three independent interviews were necessary to address both the general understanding of the concepts used and the specific wording of the questions. This triangulation of researchers' perspectives increased trustworthiness (Ridolfo & Schoua-Glusberg, 2011). There is a progression from general aspects of the questions, including assumptions and understanding of concepts, to more specific aspects like use of terminology and specific wording, or response categories and scales.

For aligning ACT-OUT to older adults living with dementia, two interviewers—including the author—conducted face-to-face interviews to adapt ACT-OUT questions to the intended target respondents living with dementia (Presser, 2004). This was done to ensure that: (a) participants understood and interpreted the questions as intended; (b) they demonstrated safety and confidence when responding; and (c) the setting of the data collection procedure (including sequencing) was appropriate for this population in terms of comfort and burden (Hellström et al., 2007).

Cross-cultural development in an international collaboration

The development of ACT– OUT was based on a collaboration among research teams in Sweden, Switzerland, and the United States, using an overarching process and structure across all phases of instrument development (construction, revision, and alignment). We used a dual-panel method developed by Hagell and McKenna (2003) to systematically communicate ideas, suggestions, and modifications among the teams, including ongoing discussions, translations, and meetings; some communications were audio recorded, and all decisions were documented through minutes. A variety of viewpoints, literature reviews, and clinical expertise provided a diversity of perspectives during the construction, revision, and alignment phases of the questionnaire (Gillham, 2007). Within this cross-cultural process, we used recommendations based on similar multi-language research projects (Haak et al., 2013; van Nes et al., 2010).

Soliciting expert critique in the early stage of development of ACT-OUT resulted in a reduction of the number of rounds necessary to reach saturation in the cognitive interviews (Presser, 2004). To identify a wider range of potential problems in the questionnaire, the experts should be a heterogeneous group with diverse backgrounds. However, they must have expertise with either the target population or the survey methodology, or have specific knowledge of the subject under scrutiny. To be as close as possible to situations experienced by people with dementia in Switzerland, a representative of the Swiss Alzheimer association was included (Reuben et al., 2009).

Although the cognitive interview method is embedded in a quantitative approach, recorded verbal data were produced, which must be analysed using a qualitative method to produce reliable results (Blair & Brick, 2010). Each round of data collection was followed by constant comparison analysis of the responses (Ridolfo & Schoua-Glusberg, 2011; Strauss & Corbin, 1998), which resulted in adaptation of the questionnaire, involving the cross-cultural teams. Using the constant comparative method allowed for a richer understanding of the constructs that the survey questions were likely to capture, thus requiring less rounds of cognitive interviews.

The results of the analysis were then implemented into the questionnaire, by changing the phrasing of some questions, restructuring the questionnaire, changing the order of the questions, deleting items, or regrouping items, etc. The order of answering questionnaires and the sequencing of Parts I and II were determined for persons living with dementia.

Presenting ACT-OUT

The ACT-OUT questionnaire consists of three parts (I-III). In the Swiss version in French, Part I includes a list of 25 pre-determined types of places grouped into four domains: (a) consumer, administrative, and self-care places (n=7); (b) places for medical care (n=5); (c) social, cultural, and spiritual places (n=6); and (d) places for recreational and physical activities (n=7). Participants were asked three questions for each of the 25 places in Part I: (a) if they currently visit the place; (b) if they had earlier visited the place; and (c) if they would likely visit the place in the future. No specific cut-off point in time was given to participants. Answers are given as yes or no in a fixed dichotomous scale. Part II poses detailed questions with a set of fixed responses about factors potentially influencing participation in places: frequencies, time of day, mode of transportation, travelling time, accompanying persons, and familiarity. Other questions were open, asking about the activities performed and reasons, and risks perceived outside home. Part III consists of general questions about perceived participation, life satisfaction, and attitudes towards risk-taking including factors for concern, such as getting lost, falling, being stressed or embarrassed. Answers are given in the form of a

4-steps Lickert-type scale of fixed responses ranging from “very satisfied” to “very dissatisfied”, or “very concerned” to “very unconcerned”.

To offer a better overview of the content of ACT-OUT, the three parts are presented in columns in **Table 3**.: I) a list of places mapping participation outside the home; II) two specific places with and without change described with contextual questions; and III) questions about the person’s perceived participation, satisfaction and risk-taking.

Table 3. Overview of the content and questions in the Participation in Activities and Places Outside Home (ACT-OUT) questionnaire.[2]

Part one (I)		**Part two (II)**		**Part three (III)**
Mapping participation in 25 places (+ one other place)		Describe a place: (i) where there was no change; (ii) where there was a change		General questions
Domain	**Place Type** Present, past and future participation in …	**Questions about activity and place**	**Questions about going there and back**	**Questions about perceived participation, satisfaction and risk taking**
A	Small grocery shop Mall, supermarket, big shop Small shop Pharmacy Hairdresser, salon or barbershop Bank or Post office Administration	What kind of activity do you do there? Why do you go to that particular place? When during the day (year) do you go there? How often do you go there? (Likert-scale response) How well do you know the place? (Likert-scale response) Picture yourself in that place. What do you have to be careful about or pay extra attention to?	How do you get there? And back? Does somebody go with you? If yes, why does somebody go with you? How long does it take you to get there? And back? According to you, is it close by or far away? (Likert-scale response) How well do you know the way to get to that place? (Likert-scale response) Imagine getting there. What do you have to be careful about or pay extra attention to?	Perceived participation Perceived life satisfaction Attitude to risk-taking Perceived concern about getting lost Perceived concern about falling Perceived concern about being stressed when going out Perceived concern about getting into an embarrassing situation
B	Doctor’s surgery Hospital or health centre Dentist’s surgery Therapy Day care			
C	Friend or family member’s place Restaurant, café or bar Senior centre or social club’s premises Building for worship Cemetery or memorial place Entertainment or cultural places			
D	A garden in your backyard Park, green areas, or community garden/ allotment Forest, mountain, lake, or sea Cottage, summer house, or chalet Neighbourhood Sports facility Transportation centre			

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[2] Table adapted from Sophie Gaber’s thesis (2021), with permission.

In ACT-OUT, a place is *not applicable* if the participant reports neither going there in the present or past, nor plans to go there in the future; applicable overall participation in activities outside the home was reported through the total number of places that people currently visit. A place is *applicable* when the participant reports going there either in the present, past, or future. Then an applicable place can be *currently visited*, meaning the participant goes there in the present; and it can be *affected by change*, meaning for example the participant does not go there in the present, but has gone in the past or likely will go in the future.

Future developments

As the development of ACT-OUT took place in a parallel design in three languages with three research teams, it was not translated from one language to another, but developed in three languages at the same time. Although it was tested in French with cognitive interviews, the results and ensuing changes were implemented in all languages at the same time. Translated instruments are expected to measure similar concepts or constructs on a similar metric, but this is very difficult, as specific linguistic groups also have specific cultural and social factors that influence how they consider abstract concepts (Angel, 2013; Im et al., 2016). The cultural differences between Sweden, the USA, the UK and Switzerland was made apparent as places were not exactly the same between all the countries involved in the process. As presented before, ACT-OUT was constructed to allow for some flexibility in the list of places in domains.

In 2018, a harmonization of language between the four existing versions (Fr, Sw, En(US), and En(UK)) was conducted by a professional translator who pointed out the slight differences of words and meaning, using the English version for the UK was used as a reference point, as it has undergone the most scrutiny (Gaber, 2021) and because English is often used as a common language in international research. The harmonization showed that only the question on participation existed in the Swiss version in French and that the risk question was still phrased slightly differently in all versions.

Furthermore, an international research group is working on analysing the pooled data from the various studies conducted around the world. Validity is an important property of developing questionnaires, as it shows the extent to which it captures what it was intended to address; and in the absence of a gold standard measure, which is the case with ACT-OUT, indirect methods for appraising validity can be used, such as a validity content analysis (Yusoff, 2019). A study using a Content Validity Index is currently under way to provide more information on the validity of ACT-OUT. Based on this pooled data and on-going studies, ACT-OUT will be further revised and psychometrics addressed in the coming months and years, using the same processes for parallel development in multiple languages, aiming to make ACT-OUT available for research and use in clinical settings.

STUDIES II, III AND IV

Participants and recruitment

Sample size for Study II and III was calculated based on the difference of the mean total number of places visited by the older adults living with dementia (15.63) and those living without dementia (17.14), associated with a pooled standard deviation of 2.20. This indicated a sample size of approximately 34 for each group (α=.05; power=.80). So, the number of participants was estimated at 35 in each group for Study II and III.

Using a non-probability purposive sampling method (Nayar & Stanley, 2015), participants with dementia (n=35) were recruited in five French-speaking areas of Switzerland between December 2015 and May 2017 through memory clinics, day hospitals, and the Swiss Alzheimer association. Diagnosis of dementia was established based on DSM by medical professionals from memory clinics in the area covered by the study. Participants in the comparison group (n=35) were recruited through senior associations or ads in grocery stores. Targeting grocery stores for recruitment purposes was chosen because an earlier study had shown its importance (Brorsson et al., 2013) and it was a well visited place in Study I. The comparison group was designed to match the demographics of the group of older adults living with dementia regarding age, gender, living areas and settings, and education level, but participants were not individually paired. Recruitment strategies for the comparison group targeted specific regions, age groups, or living areas to match the demographic variables as closely as possible, at the group level.

Nine participants for Study IV were recruited from the sample of 35 older adults living with dementia in Studies II and III, based on their willingness to participate in further interviews, using a convenience sampling method (Sedgwick, 2013). Four out of five men lived with their spouses; all women lived alone. They were living in rural or suburban surroundings (See **Table 4**).

Table 4. Participants' characteristics in Study IV.

Participant (not real names)	Age	Sex (F/M)	Type of dwelling	Year in the dwelling	Urban / Rural	MoCA score[3]	Sig. other present 1st interview
Edith	65	F	2 apartments house	40	Urban	17	No
Georges	74	M	Apartment block	50	Urban	16	Yes
Charles	71	M	Individual house	30	Rural	21	Yes

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[3] The MoCA (Nasreddine et al., 2005) score is given here as an indication of cognitive level, higher score indicates higher cognitive function (maximum 30).

Henri	65	M	Individual house	35	Rural	21	No
Samuel	69	M	Individual house	15	Rural	24	No
Fanny	85	F	Individual house	50	Urban	27	No
Anita	72	F	Apartment block	48	Urban	20	No
Paul	82	M	2 apartments house	62	Rural	19	No
Rose	90	F	Apartment block	25	Rural	9	No

Ethical considerations for involving persons living with dementia in research

Because of memory deficits and verbal communication limitations, people with dementia are often perceived as unable to answer questions or participate in interviews, making it difficult to include them in research. Still, for over two decades researchers have included people with dementia in their studies, gaining insight into the person's perspective (Hillman et al., 2020; Kielsgaard et al., 2021; McKeown et al., 2010). There has long been a call for including persons with dementia in research as primary respondents and participants, limiting the use of proxies (Goodman et al., 2011; McKeown et al., 2010; Sugarman et al., 2007). Reports on ethics of Alzheimer Europe support this call (Alzheimer Europe, 2011), with an added focus on perception and portrayal of dementia through research (Alzheimer Europe, 2013), as an important aspect to consider when designing research. Involving people with dementia in research is also a way to give them a voice (Alzheimer Europe, 2013; Higgins, 2013; Hillman et al., 2020). In a familiar setting and with the support of someone they trust, people with early-to-moderate-stage dementia are able to respond to clear and unequivocal questions (Nygård, 2006b).

Another reason for people with dementia are often being excluded from participation in research studies is their assumed inability to give informed consent (Cridland et al., 2016). Even though persons with dementia may be cognitively impaired, they are still able to give consent and participate if the process is modified and assent monitored, as described below.

Obtaining consent and assent

The process consent method (Dewing, 2002) was used to obtain informed consent throughout the study process. This method is person-centred, and enables researchers to include consent communicated through behavioural and non-verbal means by the person with dementia (Dewing, 2007). Monitoring consent through behaviour has also been used before by the applicants in clinical settings for people with dementia (Cridland et al., 2016; Margot-Cattin & Nygård, 2006). Dewing (2007) offers an organized method comprising five steps: background and preparation; establishing the basis for capacity; initial consent; on-going consent monitoring; and feedback and support.

To ensure no stress or burden was put on participants, ongoing consent monitoring was implemented throughout the entire data collection process by observation of behaviours (Cridland et al., 2016). The interviewer had to monitor participants for signs of distress while asking questions and evaluate continued assent to participate. In case of signs of distress (meaning assent was compromised), the interviewer would stop asking questions, might take a walk with the participant, offer a glass of water or any other concrete action that was deemed appropriate, until the participant reported being fine to continue.

Creating a relationship

Building a relationship of trust and human rapport is necessary to facilitate the participation of older adults living with dementia as participants in a research study. As recommended by Dewing (2007), appropriate time was dedicated, the interviewer remained flexible to change, and the interview was constantly adapted to the person living with dementia. Things that were modified were for example the pace of the interview, the taking of breaks, or giving information about oneself to create rapport. The topic of the research was explained with clear sentences and in everyday, concrete language. To that end, the interviewers had an in-depth knowledge of the topic and were able to explain it in various ways to ensure understanding by the person with dementia (Cridland et al., 2016; Li et al., 2021). All researchers and interviewers had clinical backgrounds in the field of dementia, and were used to interacting with people with dementia. It was important to create a relationship of trust, with both the person with dementia and their significant other.

Adapting the interview situation and location to the setting

As context supports performance and how people act and engage in face-to-face interviews, the setting of the interview is crucial. The environment in which people live supports their self-image and identity (Hillman et al., 2020; Sturge et al., 2021). Upon entering the participant’s environment, a researcher becomes part of the context and influences the way participants will relate to them.

The interviews were conducted in the participants’ home in all studies, as well as outside the home in Study III, allowing the environment to be a supportive and a reminder of the on-going activity, i.e., the content of the interview (Sturge et al., 2021). The support provided by a significant other of someone with dementia was included here as a way of “*…broadening the view to include the person’s immediate context in terms of the social environment, rather than validating the accounts of the respondents with dementia”* (Nygård, 2006, p. 105). Significant others, when included, were there for support and not as proxy reporting. Including significant others during the interview was sometimes also challenging, as they had many issues they needed and wanted to talk about. It was important to set aside time for the significant other before the interview, to address these issues, provide information and make clear each person’s role in the interview.

Data collection and analysis procedures

In this sub-section the procedures for both data collection and analysis are described in a chronological order. Study II and III are presented together as they had the same data collection procedure, using the same questionnaires.

Data collection instruments for Studies II and III

In addition to ACT-OUT presented above, two data collection instruments were used, the Occupational Gaps Questionaire (OGQ) (Eriksson et al., 2013) and the Montréal Cognitive Assessment (MoCA) (Nasreddine et al., 2005).

The OGQ was used to collect data on perceived occupational gaps in Study II. Initially developed for people with Acquired Brain Injury (ABI) to measure participation in everyday occupations (Eriksson et al., 2013), the OGQ is a checklist with 30 items representing Instrumental Activities of Daily Living (IADLs), work or work-related activities, and leisure and social activities performed both inside and outside the home. For each activity, the person is asked to answer yes or no to the questions: (a) do you perform this activity?; and (b) do you want to perform this activity?. The internal validity scale has been tested in cognitively impaired populations with stroke or ABI, using a Rasch analysis, and was found acceptable (Eriksson et al., 2013). The instrument's sensitivity allows it to separate between groups of people based on their occupational gaps, but is not sensitive enough to show the effects of intervention (Eriksson et al., 2013). Norms calculated with a population reporting no disabilities, show that the older people are the less gaps they report; the median was one gap for the older adults group (65 - 85 years old).

For these studies, the OGQ was translated from Swedish to French, using a combined method from Beatton et al. (2000) and Wild et al. (2005), and cognitive interviews (Willis, 2005). First, forward translations were performed by two persons (a professional translator with no knowledge of the field [T1] and one mundane translator with knowledge of the field [T2]). Then the team in Switzerland combined T1 and T2, to produce one translated version [T12] that was then back translated into Swedish by two persons (again, a professional translator with no knowledge of the field [T3] and one mundane translator with knowledge of the field [T4]). The team in Sweden combined T3 and T4, to have one version [T34] which was compared to the original tool and to the existing English translation. Reports from this process and all versions of translation were then used in a joint meeting and discussion s were held by both teams to decide on the final version to be used in cognitive interviews. The product of this process was the OGQ, version Suisse romande (2017) (OGQ-CH-Fr) (Eriksson et al., 2017).

The MoCA was used as a screening tool, covering all key domains of cognition (Lischka et al., 2012) for assessing and describing the level of cognitive functioning. According to a number of studies, the MoCA has no ceiling effect and is sensitive to early cognitive deficits (Thomann et al., 2018). We applied a cut-off score (cognitive impairments) of 22 out of 30 for increased specificity while maintaining sensitivity of the instrument, and for compensating higher age groups and an education effect (Dong et al., 2012; Hsu et al., 2015; Lischka et al., 2012).

Data collection for Studies II and III

Two experienced occupational therapists—including the author—conducted all data collection from January 2016 to June 2017 in single sessions, using the data collection tools; participants preferred not to have a second interview scheduled. Sessions did not last more than two hours and were conducted in the participants' home. Both interviewers had prior knowledge of using ACT-OUT, OGQ, and MoCA (Study 1), and had coordinated the way they conducted the interviews (Pezalla et al., 2012). Data collection with the comparison group was started only after about 15 participants with dementia had been included, so as to match both groups as closely as possible regarding age, settings, and type of accommodations.

To describe the characteristics of the groups, independent samples *t*-tests was used for the continuous variables (age and cognitive level [MoCA], which were normally distributed), and Fisher's exact test for the ordinal variables (gender, education, income, living arrangement, access to using a car, and health mobility limitations), and calculated with Statistical Package for Social Sciences (SPSS) computer software, version 25.

For Study II, data from ACT-OUT (Part I and the question on participation in Part III), OGQ, and MoCA were used. For Study III, socio-demographic data, total number of places visited by domains in ACT-OUT, and questions on risks (ACT-OUT, Part III) were used in relation to perceived participation (ACT-OUT, Part III).

Data analysis for Studies II and III

All analyses were undertaken with a significance threshold set at $p<.05$ and were undertaken in the SPSS computer software, version 25. Non-parametric tests where used when the variables were not normally distributed.

First in Study II, sum scores of participation in applicable, currently visited, and affected-by-change places (Part I of ACT-OUT), and the total number of occupational gaps (OGQ), were compared between the two groups using independent sample *t*-tests. Fisher's exact test was used for perceived participation and life satisfaction (Part III of ACT-OUT). Second, the difference between the groups for currently visited places was calculated with Fisher's exact test for each place in ACT-OUT; a description of the number of currently visited places per domain was also calculated. Third, "change" in currently visited places were expressed as ratios per visited place. The ratios were also compared between the two groups. A line has been drawn at the ratio of 10,88% of abandonment of places visited for both groups, as that is the ratio found for the number of places affected by change for the comparison group, which could be considered as the "norm ratio" of abandonment for the sample of older adults. Fourth, Fisher's exact test was used for each item in OGQ.

In Study III, 15 variables from the socio-demographic questionnaires (n=6), risks concerns (Part III; n=4) and number of places visited (Part I; n=5) were described using descriptive statistics. The dependent outcome variable was the perceived participation outside the home question asked in Part III of ACT-OUT (How do you perceive your participation outside home to be?) to which participants responded using a Likert scale (4 = I participate as much as I want; 3 = I do participate; 2 = I participate only a little; 1 = I do not participate). Bivariate logistic and multinomial regressions were run for the variables, first for the full group, then for each group separately. All independent variables that were significant at the bivariate level were introduced in a multivariate regression for search of a model. The type I error was set to .05 for all analyses. Results are given as relative risk ratios (RRR) with 95% confidence intervals for the multinomial regressions, and as odds ratio (OR) with 95% confidence intervals for the logistic regressions.

Associations between the total number of currently visited places (Part I of ACT-OUT) and the total number of occupational gaps (OGQ) (Study II) were explored using Spearman's rank correlation coefficient (two-tailed) (Howell et al., 2017), and associations between total number of places and the perception of out-of-home participation (Study III) were explored using the same method. The cut-offs applied to measure the strength of correlation used in these studies follow Cohen's (1988) guidelines from social sciences (.1–.3 = small association, .3–.5 = medium association, and .5–1.0 = large association) (Cohen, 2005).

Data collection for Study IV

Data collection comprised two types of qualitative interviews: home-based and mobile interviews (Kullberg & Odzakovic, 2018); the interviews were conducted by the author from May 2017 to September 2018 and audio recorded. Here, we refer to the data collection outside the home as mobile interviews, as walking was only partially appropriate due to some participants driving. Mobile interviews were included to allow participants to enact their experiences of familiarity, as familiarity is a situated experience (Mossabir, 2018). The outdoor participant observation during the mobile interview in familiar places contributed essential information to the data (Brorsson et al., 2013; Kullberg & Odzakovic, 2018).

The initial home-based interview sought to build trust, and lasted between 60 and 90 minutes. Discussion in this initial interview focused on participants' interests, routines, activities and participation outside home, and about familiar places. At the end of the home-based interview, we discussed with the participants where we should go for the mobile interview; participants chose the familiar places they wanted to visit. Some mobile interviews were quite short (30 minutes) while others lasted up to 150 minutes. We went to many different places, from the pharmacy to get a prescription filled, to churches in the mountains (to take pictures, for a participant writing an article for the village journal), or on a hike in the forest (to collect mushrooms). Mobile interviews were done in all seasons, during the day only, but in any weather, rain and snow included. After each interview, home-based or mobile, the author wrote memos about the settings, their state of mind, and reflections about the interview itself. These were included in the data, to inform the analysis (Hammersley & Atkinson, 2010).

Interview recordings were transcribed verbatim by a certified transcriptionist, then verified by the author.

The data collection took place in the French speaking cantons (states) of Switzerland, with participants who spoke French as a first language or had used French as a second language for many years. With the exception of Dr. Kühne, the author's supervisors did not understand French, as was the case for many of my co-authors in the different studies. Additionally, the organization of health services is context-dependent, forcing consideration of how best to adapt research designs. The issue of language was less present in Studies II and III, as the data were quantitative in nature, and the strategies and methods for analysis were not country or language specific.

Data analysis for Study IV

For qualitative studies such as Study IV, methodological issues with language and culture include whether or not to translate the data (van Nes et al., 2010), and how to maintain the clarity and nuances of the data when writing results for publication in English (Haak et al., 2013). The authors decided to keep all data in French, using a software in the analysis process with codes in English, forfeiting the translation of data, as too much of the data might be lost (van Nes et al., 2010). Software like N'VIVO offers advantages in terms of structuring data; it can be remotely shared and accessed by team members, and the tentative themes can emerge in English as researchers work together. Concepts needed to be discussed in English, while referring to data in French (Haak et al., 2013), as perfect equivalence of concepts in different linguistic and cultural contexts was not possible (Angel, 2013).

The analysis was performed in parallel to data collection in this ethnographic research process (Hammersley & Atkinson, 2010; Nayar & Stanley, 2015), and the transcribed interviews and field notes were gradually added to N'VIVO software (V 11.4.3).

The transcripts and field notes were read several times to immerse us in the participants' experiences and to get a grasp of important aspects and feelings they generated (Boeije, 2002; Bryman & Burgess, 1994). A constant comparison method was used to highlight words and sentences as focal points of the experience of familiarity (Charmaz, 2014). Codes were used to describe contents, then compared with each other, matched, and opposed, and themes started to take shape. An iterative process was then used that compared the emerging scheme of themes with the theoretical framework of the study, to enrich the analysis (Hammersley & Atkinson, 2010; Tavory & Timmermans, 2014). Inspired by an abductive approach (Tavory & Timmermans, 2014), ideas of themes were looked at using a transactional perspective and theories of place, until themes became more reliable and solid enough to be presented as results.

FINDINGS

This section presents the findings of Studies I through IV that were conducted for this thesis. A synthesis of the main findings of the thesis provides converging and diverging trends, questions assumptions, and deepens understanding of participation in places and activities outside the home for older adults living with and without dementia. The synthesis will then help to inform and structure the discussion.

SUMMARY OF MAIN FINDINGS BY STUDIES

Study I

The aims of **Study I** were to: (a) prepare the questionnaires to be used in Studies II and IV; (b) to develop and align ACT-OUT for older adults living with dementia.

The findings in Study I show that the development of the ACT-OUT questionnaire was based on back-and-forth modifications of the questions, in both content and form. Face validity of the items in ACT-OUT have been addressed both by experts and by participants living with and without dementia, leading to modifications of the list of places in Part I, the phrasing of the questions about risk and some of the scales in Part II, as well as the phrasing of the overall challenge / risk question in Part III. Furthermore, cultural issues appeared in the way the list of places was organized in Part I, and, for example, the names given to specific places that were not the same in different countries. Additionally, the way the health care system is organised in the various countries also influenced the structure of the places in domain B/places-for-medical-care. For example, in Switzerland, the physician's office is the place people go for primary care, but in Sweden primary care physicians are organised in clinical centres. These issues were discussed by research teams as they arose and involved many persons in Sweden and Switzerland, increasing the face validity of the items in ACT-OUT in relation to culture. It also raised its adequacy of use for the regions and countries where studies were planned.

The results also indicated that older adults attribute a high importance to places they visit outside the home, because of the activities that are performed there. Places where activities are performed, are more than just delimited space; they hold specific meanings for participants. As such, participation outside the home is linked with perceived risks and familiarity, and the questions related to perceived risks were delicate to phrase in Part II of ACT-OUT.

Study II

The aims of **Study II** were to : (a) explore and describe perceived stability and change of participation in places visited outside the home; (b) to explore associations between the number of places currently visited and the perceived occupational gaps.

The findings in Study II demonstrated that participants living with dementia participated in places outside the home, to a lesser degree than participants living without dementia (*p*<.001). They also reported having a closely similar mean for the number of applicable places (according to places of ACT-OUT), showing no significant difference, as shown in **Table 5**; and reported more applicable places affected by change (26,75%) than the group of participants living without dementia (10,88%). As participants living without dementia maintain 88,12% (100% of applicable places minus 10,88% of abandonment) of their applicable places, it offers a reference point as to what level of abandonment would be expected in these samples of older adults if they were not living with dementia.

Table 5. *Summary of total applicable, currently visited and affected by change in Study II.*

ACT-OUT (Part1)	Participants with dementia n=35	Participants without dementia n=35	Coef: *t*-test,	*p*-value
Nb of applicable places (ACT-OUT, max = 25) : Mean (SD)	21.66 (2.14)	21.23 (1.91)	*t* = -.883	.380
Nb of currently visited places (ACT-OUT, max = 25) : Mean (SD)	15.83 (3.34)	18.91 (3.28)	*t* = 3.893	<.001
Nb of places affected by change (ACT-OUT, max = 25) : Mean (SD)	5.80 (2.78)	2.31 (2.56)	*t* = -6.587	<.001
Percentage of applicable places affected by change	26.75%	10.88%		

Table 6. presents the type of places affected by change and their ratios for both groups of participants. As seen in the table above, participants living with dementia abandoned more places and to a higher extent than participants living without dementia. For the group of participants living with dementia, eight places were above 40% of abandonment, of which five belonged to domains C/social-cultural-spiritual-places and D/places-for-recreational-and-physical-activities of the ACT-OUT. Moreover, fifteen places were above 20% of abandonment in Study II. For the group of participants living without dementia, one place was above 40% of abandonment, and five places were above 20% of abandonment in Study II.

Table 6. *Overview of most maintained and most abandoned places for both groups of participants in Study II.*

Most abandoned places over time			
Participants with dementia n=35		**Participants without dementia n=35**	
Percentage	**Types of places**	**Percentage**	**Types of places**
58.33%	Senior centre, social club Sports facility	48.27%	Sports facility
56.25%	Cottage, summer house	38.46%	Hospital, health centre
52.94%	Bank, post office	27.59%	Building for worship
43.33%	Entertainment, cultural places	25%	Therapy
42.86%	Administration office	21.74%	Cottage, summer house
Most maintained places over time			
Participants with dementia n=35		**Participants without dementia n=35**	
Percentage	**Types of places**	**Percentage**	**Types of places**
100%	Garden around house Hospital, health centre Day hospital	100%	Forest, mountain, lake Doctor’s office Day hospital Friend, family’s place
97.14%	Doctor’s office	97,14%	Bank, post office
94.29%	Friend and family’s place	97,06%	Hairdresser Pharmacy
93.94%	Neighbourhood	96.88%	Restaurant, café, bar Garden around house
63.75%	Restaurant, café, bar	96.43%	Cemetery, memorial Neighbourhood

Participants living with dementia maintained a lower extent of places visited than participants living without dementia. For the group of participants living with dementia, six places were above 88.12% of maintenance, half belonged to domain B/places-for-medical-care, and two were located close to the home. For the group of participants living without dementia, eleven places were above 95% of maintenance; seven belonged to domains C/social-cultural-spiritual-places and D/places-for-recreational-and-physical-activities of the ACT-OUT.

Participants living with dementia had a mean of 4.94 gaps while the participants living without dementia reported a mean of 1.89. Although the difference for the total number of gaps between the groups was significant (*p*<.001), only seven items in the OGQ contributed to this result, of which only two items were related to an activity performed outside the home, as shown by **Table 7**.

Table 7. OGQ items showing a significant difference between groups in occupational gaps.

	Participants with dementia n=35	**Participants without dementia n=35**	**Coef: *t*-test, Fisher exact test**	***p*-value**
Total of gaps (max = 30): Mean (SD)	4.94 (3.80)	1.89 (2.16)	t = -4.132	<.001
OGQ item 4 / Cleaning : gap / no gap	8 / 27	11 / 24	6.360	.045
OGQ item 5 / Doing light maintenance of home, garden, car : gap / no gap	7 / 28	3 / 32	6.292	.030
OGQ item 6 / Doing heavy-duty maintenance of home, garden, car : gap / no gap	9 / 26	1 / 34	7.467	.013
OGQ item 7 / Managing personal finances: gap / no gap	13 / 22	2 / 33	14.151	.001
OGQ item 17 / Writing : gap / no gap	14 / 21	3 / 32	10.350	.003
OGQ item 19 / Playing computer games / surfing the Internet : gap / no gap	9 / 26	2 / 33	5.632	.034
OGQ item 23 / Involvement in activities in societies, clubs or unions : gap / no gap	10 / 25	2 / 33	6.409	.023

Results on relationship between the total number of places visited and the number of occupational gaps showed that there was a negative association of medium strength (r_s =-.46) for the group of participants living with no known cognitive impairments. For the participants living with dementia, this relationship was not empirically supported.

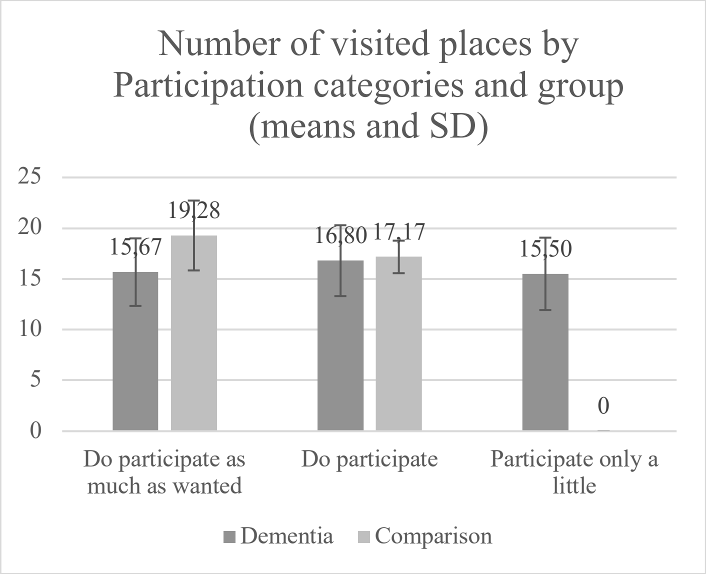
In conclusion, the results from Study II provided a better understanding of how older adults living with and without dementia participate outside their homes, by exploring the places they visit in the past, present and future, but also how visiting places is related to perceiving occupational gaps in their participation.

Study III

The aims of **Study III** were to: (a) explore the association between the number of places visited and the perception of their participation outside the home for persons living with and without dementia; (b) describe perceived challenges and risks encountered when participating in places outside the home; and (c) to explore which factors, e.g., amount and types of places visited, socio-demographic variables and perceived risks, might be associated with the perception of participation outside the home.

The results in Study III indicated that the relationship between the total number of places visited at present and perceived participation showed a positive association of medium strength (r_s = .344) for the group of participants living without dementia. For the participants living with dementia, this relationship was not empirically supported as shown in **Figure 3**. This result was similar in trend as the association between the total number of places and occupational gaps reported in Study II.

Figure 3. Mean number of places visited per level of perceived participation and per group.



The exploration of multiple variables as possible factors associated with perceived participation outside the home showed that few variables were significant, as seen in **Table 8**, with the *p*-value in bold. As the group variable was significant (*p*<.001), the exploration of the factors was also conducted for the participants with and without dementia separately.

Table 8. Summary of the results of the bivariate logistic regressions in Study III.

	All participants together		**Participants with dementia**		**Participants without dementia**	
Independent variable	Nagelkerke R2	*p*-value	Nagelkerke R2	*p*-value	Nagelkerke R2	*p*-value
Group (ref: dementia (1))	.314	**<.001**				
Risks						
Getting lost (ref: very unconcerned (4))	.212	**.008**	.287	**.037**	.166	.055
Falling down (ref: very unconcerned (4))	.206	**.010**	.340	**.014**	.199	.109
Stress (ref: very unconcerned (4))	.115	.129	.033	.904	.218	.086
Embarrassment (ref: very unconcerned (4))	.086	.263	.111	.462	.057	.544
Socio-demographic						
Age	.010	.753	.000	.994	.080	.191
Gender (ref: female (2))	.002	.934	.086	.250	.036	.383
Living situation (ref: with someone (2))	.050	.220	.028	.641	.084	.178
Access to car (ref: someone else drives (2))	.048	.577	.031	.914	.003	.971
Setting (ref: big city (2))	.064	.425	.136	.345	.038	.666
Places visited						
Total nb of places visited	.070	.118	0.29	.635	.090	.164
Total places visited in A	.070	.121	.008	.881	.022	.493
Total places visited in B	.095	.055	.037	.561	.061	.252
Total places visited in C	.046	.253	.115	.155	.027	.446
Total places visited in D	.176	**.004**	.167	.062	.331	**.005**

For all participants as a group, both the risks of getting lost and falling down and the total number of places visited in domain D/places-for-recreational-and-physical-activities were identified as being associated in the bivariate regression as shown in **Table 8.**. In the multivariate regression conducted in Study III, the risks seemed to cancel their reciprocate effect and the total number of places visited in domain D was found to be associated with the perception of participation outside the home. For the participants living with dementia, the same two risks were identified as being associated in the bivariate regression as shown in **Table 8.**, and also seemed to cancel their reciprocate effect in the multivariate regression, offering no model to understand what factors influence their perception of participation outside the home. For the participants without dementia, only the total number of places visited in domain D/places-for-recreational-and-physical-activities was found to be associated with perceived participation (*p*=.005); no further multivariate regression was thus conducted.

In conclusion, the results from Study III offered an exploration of multiple factors potentially associated with the perception of participation outside the home for persons living with and without dementia. Places visited in domain D/places-for-recreational-and-physical-activities and risks of getting lost or falling seemed to be the factors associated with perceived participation outside the home.

Study IV

The aims of **Study IV** were to: (a) clarify how familiarity is experienced by persons living with dementia, in performing occupations and visiting places outside the home; (b) illuminate how this experience of familiarity might contribute to maintaining their participation in activities outside the home.

The findings in Study IV indicate that participants living with dementia experience familiarity in a continuous way, as a whole and through occurrences. They enact it through maintaining a personal territory that can also include places outside the usually-considered neighbourhood, and they ground it in landmarks and objects in their personal territory.

The first theme, *familiarity is experienced in a continuous way, as a whole and through occurrences*, described how the experience of familiarity was embedded in everything persons living with dementia did outside their home, offering a feeling of continuity of their identity and helping to anchor them in what they were doing. Participants qualified this experience as a whole, although they used different ways to describe it: as knowledge, routine, security, social belonging and well-being, or as a cohesive whole. This idea of familiarity as a whole did not mean it was homogenous, but rather that it was a complete sensation, as the taste of a hamburger is a complete sensation, containing meat, cucumber, bread, salad and sauce. Furthermore, participants narrated personal stories related to places visited, supporting the idea of continuity and wholeness that accompanies the experience of familiarity, and offering the idea that familiarity is situated in the places and increases the continuity of one own's identity. In addition, the first theme of the results showed that the situations were reproduced over time as participants repeatedly went to the same places, creating an experience of occurrences. Although each individual occurrence could be seen as different in terms of contextual elements like the weather, how the person felt, or who was with them, the individual occurrences might also vary, as the experience of familiarity could fluctuate. Over time, these occurrences blurred to create an experience of familiarity described as a whole.

The second theme, *familiarity enacted through a personal territory*, presented how participants recognized and maintained familiarity in participation outside the home, by creating a territory that regrouped the familiar places they visited. The succession of places and activities in the personal territory are repeatable, one-time occurrences, enacted by participants in everyday life, and holding individual meaning. Participants could name the limits of their territories and could take risks inside those territories, such as Edith who let herself get lost in the city. They speak of themselves as belonging in their territory, as being in place there. This allowed the participants to move inside their territory in a fluent, flowing and safe way. Still, participants related that, in some occurrences, navigating such a territory often provided challenges, creating fluctuations in the feeling of familiarity. For example, Henri had to "reacquire" familiarity of the mountain paths after the winter when the snow had melted. So, participants were recognized as vulnerable in maintaining participation outside the home as fluctuations in familiarity occurred. Furthermore, some participants had a much bigger familiar personal territory than their neighbourhood, making the case that participation outside the home should not be limited to the neighbourhood. As such, familiarity does not always equate proximity.

The third theme, *landmarks and objects in the experience of familiarity*, showed how participants used landmarks as reference points, and objects to anchor themselves to their home. These objects were taken from their home and kept with them in all the occurrences; and not only for practical reasons, but also because they were familiar. This was a way for participants to bring with them some familiarity that they had at home.

In conclusion, the results from Study IV offered a way of better understanding how familiarity is experienced, but also how it could support participation outside the home for persons living with dementia.

SYNTHESIS OF THE FINDINGS

A synthesis of the results of the four studies is presented below. This synthesis is based on linking results from the different studies and determining how they influence common aspects of the overall aim of the thesis: to explore and provide new knowledge of participation in places outside the home for older adults with mild-to-moderate dementia, compared with older adults without dementia. The aim also includes developing ACT-OUT and an understanding of places as well as how visiting places are associated with participation outside the home.

The ACT-OUT questionnaire's development

To collect data on participation outside the home among older adults living with and without dementia, combining places and activities, we needed to develop the ACT-OUT questionnaire. The findings in Study I showed how developing this questionnaire needed to involve many persons with various viewpoints in two countries and coping with cross-cultural and language issues. The findings from Studies II and III indicated that using such a questionnaire allowed the researchers to record data on places visited/not visited by older adults living with and without dementia and learn about some specific places in terms of maintenance and abandonment. The participants in Study II and III did not wish to have a second interview, which would have split the data collection into two meetings. They also provided answers with no missing data in Part I and III of ACT-OUT. Participants provided data in Part II on at least one specific place per domain, with no missing data. It shows that ACT-OUT was easy to use, did not take too much time, was not too burdensome for older adults living with and without dementia, and provided a lot of information.

The development of ACT-OUT in Study I and its use in Study II and III offered results about various aspects of validity. In addition to experts, older adults who were interviewed in Study I have given their point of view on whether the list of places seemed adequate and face valid to represent the places they go to, and their participation outside the home. In Study I, II and III, the ease of answering the item questions showed by both participants living with and without dementia argues for face validity of the items included in ACT-OUT, as well as their order and organisation in domains in Part I. The questions about risks in Part III also were shown to reflect concerns that older adults faced when going outside their homes. ACT-OUT also appeared to be relevant to the participants for reporting their participation outside the home, and it showed to represent where participants were going while participating outside home. Relevance and representativeness are elements of importance for assessing content validity (Yusoff, 2019).

There is further validity evidence of ACT-OUT's outcomes in relation to other variables (e.g. diagnosis), as the group of older adults living with dementia demonstrate significantly lower score of total currently visited places, while having a non-significantly different score of adequate places in comparison to the group of older adults living without dementia in Study II. This is in line with other studies conducted with older adults living with dementia about life outside the home (Bantry White & Montgomery, 2015; Brorsson et al., 2011; De Witt et al., 2009; Duggan et al., 2008; Olsson et al., 2013).

Understanding participation in places outside the home

The results provide new knowledge about participation outside the home for older adults living with and without dementia in the samples recruited, as shown here:

Comparison between the two groups for visiting places: frequencies, abandonment, types

The results from Studies II and III indicate that participants living with dementia did participate outside the home, although to a lesser extent than their counterparts living without dementia. They also reported going more to places in domain B/places-for-medical-care in ACT-OUT and abandoned more places in domain C/social-cultural-spiritual-places and D/places-for-recreational-and-physical-activities than the group of participants living with no known cognitive impairments. The places most abandoned by persons living with dementia were places where social and cultural activities took place. What was most maintained by persons living with dementia were places for self-care, their neighbourhood, and their social network. Compared with the group of participants without dementia, they maintained fewer places, and abandoned more. 10.88% of abandonment (or 89.12% of maintenance) is the ratio of change in applicable places reported by the participants living without dementia. This was used as a reference point to compare the most maintained and abandoned places between the two groups in Study II. Only six places were above the reference point for maintenance. In comparison, the participants without dementia maintained three times more places outside the home, with 18 places above 89.12%. Findings from Study III seemed to indicate that the places in domain D/places-for-recreational-and-physical-activities, and to a lesser extent domain C/social-cultural-spiritual-places, are associated with perceiving to participate outside the home as much as wanted, and that being able to visit a variety of places might also be associated with it.

Furthermore, the results of Study II indicated that there was a negative association of medium strength between the total number of places visited and the total number of occupational gaps, but only for the group of participants living without dementia. The results of Study III indicated that there was a positive association of medium strength between the total number of places and the perception of participation outside the home, but again only for the group of participants living without dementia. This means that as participants living without dementia increased the number and diversity of places they visited outside home, they would perceive less occupational gaps and an increase in their perceived participation outside home. These associations were expected based on the assumption that going to many diverse places outside the home would be linked to a decrease in occupational gaps and increase of perceived participation. However, the results in Study II and III did not show significant associations with occupational gaps nor with perceived participation outside the home for participants living with dementia. This could be explained because the concept of participation outside the home is complex and multi-faceted. Living with a dementia further impacts participation outside the home by adding more layers to its complexity, for example by being partially dependent on someone else’s schedule and availability if needed to be accompanied. The sample size of the group of participants living with dementia might not have been big enough to show significant associations regarding the occupational gaps and the perceived participation variables.

Familiarity and risks in participation outside the home

The results of Study IV indicated that familiarity was an important aspect of participation outside the home, as it helped participants to freely navigate their personal territory, including feeling secure enough to take risks, like getting lost: they were sure that they would find their way. They relied on landmarks established by the repeated occurrence of visiting the same places. They also used familiar objects to stay linked to the familiarity of home while venturing outside. The results of Study III indicated that participants living with dementia perceived more risks than their counterparts in the comparison group, especially regarding the risks of falling or getting lost.

Understanding places outside the home

The results from Study I indicated that the list of places in Part I of ACT-OUT was easy to use, and offered a way of mapping the type of places that persons living with and without dementia were used to visiting. As the list of places is structured in domains based on the type of activities performed, there is a link between places and activities, although participants could perform various activities in different places.

The results from Studies II and III showed that the type of places visited by persons living with dementia was an important aspect of participation outside the home. First, places in domain B/places-for-medical-care were more visited, and places in domain C/social-cultural-spiritual-places and D/places-for-recreational-and-physical-activities were less visited by the participants living with dementia, compared to the group of older adults living without dementia. Furthermore, no significant association between the total number of places visited and the perception of participation outside the home was found in the results of Study III for the participants living with dementia, indicating that equating perceived participation outside the home to visiting a variety of places was not supported by our data. It might also indicate that some places might be more important than others to participants living with dementia, as showed by the results of Study II related to abandonment and maintenance of places.

The results from Study IV showed that places with familiarity are organised into personal territories for the participants, and help maintain a continuity of self. Identity was also embedded in places for the participants, who often told personal stories about their past or families that were associated with the places, giving them meaning. Furthermore, results showed that places and activities were often referred to at the same time by participants while telling stories; this indicated that participants gave meaning to places as they visited them and performed activities. Results from all the studies consistently indicated that places were more than delimited spaces, that they had personal meanings that influenced how participants would relate to them.

GENERAL DISCUSSION

The findings in this thesis have contributed new knowledge about participation outside home for persons living with and without dementia; and how it relates to places currently visited, in the past and the future; and how this construct can be evaluated. The findings have provided new knowledge about how places are understood and implicated in participation outside home; and about how familiarity is experienced in places. Here I will discuss the synthesised findings, by first considering instrument development issues, then discussing participation outside home, and at last the concept of place.

QUESTIONNAIRE DEVELOPMENT AND EVALUATION

This thesis is somewhat original in the way that one of its focus is on questionnaire development. There is a mixture of methodological and procedural considerations at the same time as a product outcome. Synthesis of the findings have shown that two main issues need to be discussed here, including the use of the theoretical perspective as presented in the background and a tentative assessment of ACT-OUT psychometrics.

Theoretical perspective in ACT-OUT

The aim of creating a questionnaire to ask about places and activities simultaneously was reached. Part I of the ACT-OUT is a list of places; Part II provides information on that link between places and activities with questions asked about the types of activities and reasons for visiting places, as well as about a variety of potentially influencing factors; and Part III offers insight into satisfaction, perceived participation, and risks. At a first glance, one could state that the transactional and occupational perspective is present in ACT-OUT as each Part could be related to a) the environment, b) the occupation and c) the person, collecting data on the core concepts in occupational therapy at the same time. However, that argument is actually another way of maintaining separate constructs and reinforcing the way models of practice are used in occupational therapy, which was not the aim of the Person-Environment-Occupation (PEO) model (Law et al., 1996; Margot-Cattin & Margot-Cattin, 2017). Rather, the ACT-OUT attempts to apply a transactional and occupational perspective in each part, all the time. For example, Part I being a list of places, has the activities performed embedded in the places and uses the idea of doing (e.g. occupation) as an organising factor for the domains. Furthermore, by asking questions related to the past, present and future, Part I is embedded in the experience of continuity in one's life and identity (Cutchin et al., 2008; Dewey & Bentley, 1949) while visiting places in which occupations are performed by the person (Cutchin & Dickie, 2013).

Although data from Part II of ACT-OUT were not analysed in the studies of this thesis, using data from Part I and III provided results that are embedded in a transactional and occupational perspective. This means that places in a transactional and occupational perspective offer results about experiences of situations (Cutchin & Dickie, 2013; Madsen & Josephsson, 2017; Margot-Cattin, 2018; A. Nyman & Isaksson, 2020), which would argue for ACT-OUT being a relational, transactional and occupational-centred tool (Fisher, 2013). We aimed to ground the development of ACT-OUT in theoretical resources that would make it occupational centred, as defined by Fisher (2013). The issue of ACT-OUT being seen as occupation-focused or occupation-based could be raised as Part I is a list of places. However, if places are considered as including the occupations performed there, then the ACT-OUT items would be focused on occupation, as defined by Fisher (2013). Still, grounding the development of ACT-OUT in an occupational perspective does not provide information as to how older adults living with and without dementia would consider the items of Part I as places including the occupations.

Evidence of validity in the ACT-OUT

The results of the studies show that face and content validity were addressed to some extent in this thesis. Face validity is the degree by which experts or respondents judge that the items of a tool, assessment or questionnaire are appropriate to the targeted construct (Clark & Watson, 2019), i.e. participation outside the home for older adults living with and without dementia. Content validity represents how well the items are a sample of the theoretical content domain of the construct; it is important to appraise validity because of the inferences that are calculated with the ACT-OUT (Creswell & Creswell, 2018; Perron & Gillespie, 2015). Before content validity can be appraised, it is necessary look at face validity of items.

The experts' judgment in Study I and participants' judgment in Study I, II and III offer some insight about face validity of the items and questions in ACT-OUT. Experts' views are often considered as a first step in instrument development and can identify problems about the construct that is deemed to be measured by the tool under construction (Colson & Cooke, 2018; Hyrkäs et al., 2003). Colson and Cooke (2018) indicate that experts' judgement is required when existing models cannot provide enough information, which was the case in the development of ACT-OUT. The experts' judgment was then further validated by the participants in Study I who provided judgment on the face value of ACT-OUT items in the cognitive interviews. As face validity is based on the relevance and the representativeness of the items in ACT-OUT for participation outside the home (Connell, 2018; Hardesty & Bearden, 2004; Yusoff, 2019), it seemed important to collect participants' judgment about the appropriateness of the items included in ACT-OUT and their potential to reflect older adults' participation outside the home.

The significant differences in Study II between the groups regarding the number of places visited outside home also provide evidence of validity in relation to other variables, as these results were expected from the literature on participation outside home showing that older adults living with dementia have a constriction of their life space, and experience a shrinking world (Choi et al., 2016; Duggan et al., 2008). They also are expected to have more abandoned places than their counterparts living without dementia (Brorsson et al., 2011; Keady et al., 2012; Sugiyama & Ward Thompson, 2007). A triangulation of judgment was comprised of the experts' and participants' appraisal of items with the literature on participation outside the home for older adults living with and without dementia (Creswell & Creswell, 2018; Kidder & Fine, 1987).

Furthermore, the results in Study II indicated that there was a negative association of medium strength between the total number of places visited and the total number of occupational gaps, but only for the group of participants living without dementia. The results about the total number of gaps reported showed significantly more gaps experienced by the group of older adults living with dementia. These results also contribute with evidence of validity of the ACT-OUT in relation to other variables as the scores of the OGQ indicated the same significant differences between both groups, which was expected (Eriksson et al., 2013; Guidetti et al., 2019).

In addition, ACT-OUT has been used with older adults living with and without dementia in different contexts (Sweden, the UK and Canada) and in Sweden also with a different population (survivors of stroke). Similar results to those of Study II about the number of places visited and maintenance/abandonment of places were found among older adults living with dementia in comparison to those without dementia in Sweden (Gaber et al., 2019), in the UK (Gaber, Nygård, Brorsson, et al., 2020; Gaber, Nygård, Kottorp, et al., 2020; Wallcook et al., 2021) and in Canada (Chaudhury et al., 2020). Furthermore, studies conducted in Sweden with stroke survivors with the ACT-OUT have shown that patterns of participation could be elaborated and that places in Part I were also relevant for this population group with adding some specific places for non-retired people, such as those related to work or taking care of children for example (Malinowsky et al., 2019; Olofsson et al., 2019). These studies all contribute with various types of validity evidence to argue that ACT-OUT addresses aspects of participation outside the home.

Reflections on the construct in focus

The knowledge about participation outside the home that was presented in the background section has shown participation as a multi-faceted and complex concept (Dawson-Townsend, 2019; Levasseur et al., 2010; Ward et al., 2017), with influences from the context (making it situated), the person (making it experienced), and the occupation being performed (making it dynamic and evolving with time in a continuity of personal identity). The ACT-OUT questionnaire was developed to capture some level of multi-facet and complexity related to participation outside the home (Noreau & Boschen, 2010), by constructing it based upon a transactional and occupational perspective. The construct in focus in ACT-OUT should reflect that multi-dimensional complexity of participation outside the home (Clark et al., 2020; Odzakovic et al., 2019). Furthermore, the domains in Part I of ACT-OUT are structured based on the type of occupations performed in places. It is not expected that the domains would create a unidimensional construct either, as that would surmise that occupations were not as complex and diverse as continuous and numerous research has shown them to be (Eklund et al., 2016; Ekstam et al., 2021; Ghul & Marsh, 2013; Hasselkus, 2011; Kielsgaard et al., 2021; Larsson-Lund & Nyman, 2017; Nyman & Isaksson, 2020; Whiteford & Hocking, 2012; Wilcock & Hocking, 2015).

Participation and social participation among adults and older adults have long been defined and redefined (Brown et al., 2004; Egan et al., 2006; Hammel et al., 2008; Levasseur et al., 2010; Magasi et al., 2009; Mangiaracina et al., 2019). Levasseur and colleagues (2010) propose a taxonomy, distinguishing six modalities of increasing levels of social participation from doing activities to be in contact with others, to actively contributing to society. The interaction with others has been central to definitions of participation before, as well as a form of "doing" (Hemmingsson & Jonsson, 2005). More than defining participation, health care research has been trying to measure it; and to relate that measurement with the environment or its factors (Whiteneck & Dijkers, 2009). Counting more or less places for participation outside the home seems at first glance to be quite naïve and reductive. However, considering the list of places in ACT-OUT as an embodiment of the occupations performed outside the home in a transactional and occupational perspective (Kontos & Martin, 2013; Penney, 2013; Varela et al., 2016), it offers that combination of examining the occupation and the place together. To better fit the perceived complexity of the concept of participation outside home, we used an iterative process in the development of ACT-OUT, aiming to produce a questionnaire that could capture a multi-faceted or -dimensional, complex and situated construct. As such, the ACT-OUT questionnaire would not be seen as a tool for capturing an unidimensional construct, but rather as a tool for supporting better grasping and discerning of participation outside the home by researchers, and potentially clinicians.

Investigating the quantity and diversity of places visited offers a new construct for participation outside the home for older adults living with and without dementia. It would have been interesting to also ask questions about the importance and value of places as attributed by older adults, especially regarding the patterns of abandonment and maintenance of places in results of Study II (Farias & Laliberte Rudman, 2016), because it might be linked to how older adults perceive the places they go to and whether they consider places in a transactional and occupational perspective, as surmised. However, this multi-dimensional construct for participation outside the home reflects what we know today about the development of ACT-OUT. Further research would be needed to implement the relationships between older adults' perception and value of places and participation outside the home.

UNDERSTANDING PARTICIPATION IN PLACES OUTSIDE HOME

The space outside home has been referred to by different names and constructs, like public space in relation its accessibility (Blackman et al., 2003; Brorsson et al., 2011; Gaber, 2021), life space in relation to mobility of older adults with and without dementia (Baker et al., 2003; Choi et al., 2016; Lloyd & Stirling, 2015), life world in mostly qualitative earlier research (Duggan et al., 2008; Öhman, 2007), lived space to acknowledge the relationship between the person and their environment (Førsund et al., 2018). However the space where participation outside home happens is named, we consider that places are a part of the space outside home and visiting them offers information on participation outside home.

Visiting diverse types of places outside home

The results from Study II and III indicated that participants living with dementia did not participate in places outside home as much as participants without dementia. Although older adults in general are expected to experience a decrease of their out-of-home participation, as their life-space mobility constricts over time (Choi et al., 2016), having a dementia showed this constriction to be significantly more pronounced. Life-space reduction correlates with cognitive impairments like having a dementia; and the inability to drive, which was the case for two thirds of the participants living with dementia in Study II and III. Our participants visited significantly less places outside home than their counterparts living without dementia, indicating that their life-space was being constricted and out-of-home participation restricted. This is in line with earlier research on "life world" (Duggan et al., 2008) or "lived space" (Førsund et al., 2018) for older adults living with dementia, showing a process whereby little by little the outside space was becoming smaller. This underscores the importance of considering the experiences of older adults living with dementia and the spatial dimensions of their life-space, as these directly impact out-of-home participation opportunities.

Furthermore, as older adults living with dementia experience a constriction of their life-space and participation outside home, they also face a diminishment of the variety of places they visit. The total number of places as it is reported through the ACT-OUT questionnaire represents not only a quantity of places but also denotes a variety of places that older adults visit. As such, having a diversity of places available in one's life space might be important. Although places are frequently highlighted as important related to well-being or quality of life (Clark et al., 2020; O'Rourke et al., 2015), the diversity that being able to visit many different places may bring about seldom investigated.

Visiting many different places in fact increases the diversity of occupations that can be performed outside home. Clark et al. (2020) argue that neighbourhoods might be considered as "communities of places", which could be understood as a variety of places in a proximate relationship of belonging. They also point out that promoting the development of local places might support older adults living with dementia to have more choices in their lives (Clark et al., 2020). Findings from Study III also support that being able to visit a variety of places might be associated with perceiving to participate outside home as much as wanted. Still, they do not include the idea of different places offering a diversity of occupations to be performed.

While the synthesis of the results in all four studies point toward a constriction of the space outside home and a restriction of participation for the older adults living with dementia, they also provide a more nuanced and dynamic understanding of participation outside home, than previous research presenting a straightforward, constant, stable and passively shrinking world (Duggan et al., 2008; Kuosa et al., 2014). There is a need to look more precisely at types of places visited outside home by older adults living with dementia.

Types of places being visited

The constriction as we have seen it in the results of Study II, is not straightforward, nor is it applied to all places in the same amount. Rather the restriction in places visited is shown to be a shift from abandoning some places and investing others more. Participants living with dementia reported in Study II that they were going more to places in domain B/places-for-medical-care in ACT-OUT and tended to abandon more places in domain A/consumer-administrative-and-self-care-places, C/social-cultural-spiritual-places and D/places-for-recreational-and-physical-activities than the group of participants living without dementia. So, for older adults living with dementia, there seemed to be a shift from consumer, social, cultural and recreational places towards places used for medical care, like visiting the physician's office and the day hospital. This is coherent with the fact that dementia is foremost considered a pathology, needing medical diagnosis as a gateway to services (Livingston et al., 2020). This is also mostly the case in Switzerland (Office fédéral de la santé publique (OFSP), 2019), where the health system is well developed and expensive. Furthermore, the medical model as it is still very prominent in Switzerland, might increase the need of the older adult population to rely on health care professionals when facing a diagnosis of dementia (Walmsley & McCormack, 2016). However, findings in Study IV have highlighted that other places are also important for older adults living with dementia to participate outside the home.

In addition, older adults living with dementia are expected to have to stop driving due to cognitive decline, thus increasing the constriction of their life-space (Liddle et al., 2016; O'Neill, 2010; Sanford et al., 2020). In order to reach some of those places in the A, C and D domains of ACT-OUT, older adults living with dementia would have to either ask family, friends or neighbours for help (to be driven) or use other transportation means, which are complex transportation systems or specialised drivers (taxis, disability transport, or senior associations). Knowing that Switzerland's health care system is strongly influenced by the medical model, there might be a social bias that older adults would refrain to ask to be driven to a place for recreational or leisure activity. At the same time, it would be acceptable to ask to be driven to a doctor's appointment or to spend the day at a nursing home with a special unit for people living with dementia. Older adults might also be feeling shame about having a dementia and having to ask for help (Lopez et al., 2020; Rotenberg et al., 2020), which is consistent with the Swiss culture.

Recent research has shown that little by little older adults living with dementia tend to disengage from social activities outside home, like being a member of associations or clubs, and going to social gatherings, expositions, or concerts (Argyle et al., 2017; Kuosa et al., 2014). Those activities typically put a cognitive and social weight on the older adult living with dementia, who need to "make believe" (Matsushita et al., 2018). Still, social activities like the ones provided by going to places in domain C/social-cultural-spiritual-places increase the experience of connectedness and belonging (Ward et al., 2017), and the awareness of self (Kuosa et al., 2014).

Results in Study IV pointed toward places in domain D/places-for-recreational-and-physical-activities were associated with perception of participation outside home, for participants living without dementia. Places in that domain are linked to nature, physical activity or leisure activities, like walking along the lake that many older adults in Switzerland enjoy doing. Benefits of going to these types of places have been identified by earlier research (Gilliard & Marshall, 2012; Keady et al., 2012; Travers et al., 2016) and tied to physical activities (Burge et al., 2012; Sugiyama & Ward Thompson, 2007), contact with nature (de Bruin et al., 2017; White et al., 2018) and aesthetic well-being (Rappe et al., 2006). Physical activity has been shown to positively influence perception of self and identity among other aspects which is very important for older adults living with dementia (Sugiyama & Ward Thompson, 2007). Contact with nature, like gardening, hiking in mountains or walking along the lake – some of the most performed leisure activities in the French speaking area of Switzerland by older adults – has also been shown to positively influence awareness of self, identity and agency (de Bruin et al., 2017), and is linked with aesthetic pleasure and well-being (Rappe et al., 2006).

Knowing those effects, our results that domain D places might be associated with perception of participation for older adults living without dementia only, are coherent as the participants living with dementia reported a retraction from the domain D places. This has been shown in an earlier study by Gaber and colleagues (2020). Unfortunately, having to live with a dementia might bring the older adults to abandon those places that are linked with restorative effects, especially on perception of self, identity and agency (Førsund et al., 2018; Meijering et al., 2019). As such, restoring access and use of those places in domains C and D for older adults living with dementia, might support their participation outside home longer.

Associations with the number of places visited outside home

In considering places visited as an essential component of participation outside home, there is an assumption that going to many and diverse places would indicate an association with the number of occupational gaps and the perception of participation reported.

Associations of the number of places visited with the number of occupational gaps in Study II were shown to be significantly negative, but only for the participants living without dementia. This means that the more older adults visit places outside the home, the less occupational gaps they experience. The OGQ has been shown to be linked with improved life satisfaction (Eriksson, 2007; Eriksson et al., 2009), and older adults reporting less occupational gaps also reported being more satisfied with their life. So visiting many diverse places outside home might also support life satisfaction.

The results of Study III indicated that there was a positive association of medium strength between the total number of places and the perception of participation outside home, but only for the group of participants living without dementia. It might indicate that for older adults living without dementia, the types and variety of places that they visit influences how they perceive their participation outside home. For the group living with dementia, there is no relationship. Many reasons can be expressed to discuss these results. Having a dementia bring about more dependency on significant others, which might change how, when and where they go outside and in which occupations they would engage in (Couture & Éthier, 2020).

Out-of-home participation would be inter-influenced between older adults living with dementia and their significant others in a way that might be identified as co-occupations (Ono & Kanayama, 2014). Co-occupations require that two or more persons engage together in occupations sharing physicality, emotionality and intentionality (van Nes et al., 2012). It might be possible to view the participation outside home of older adults living with dementia as co-occupations, which then might modify the meanings of going to places (by adding a significant other in the co-creation of meaning of the co-occupations). Performing everyday occupations outside home with others would be a constantly changing meaning-making process that supports connections to one's self and identity, and a sense of belonging (Kielsgaard et al., 2021). Using co-occupations to support older adults living with dementia maintain a sense of continuity and belonging in their lives, connecting to their physical, social and cultural environment through the places visited, might increase the quality of their perception of participation outside home (Kielsgaard et al., 2021). How these co-occupations modify the way older adults living with dementia perceive their own participation outside home is still unclear and would need to be further researched.

Also, as older adults living with dementia resign from social engagement and occupations, and reduce going to related places, they might lose the meanings that formerly had been attributed to them (Fang et al., 2016). As the disease progresses they would little by little lose the sense of familiarity in those places as seen in the results of Study IV. These results showed that familiarity may be challenged and rendered vulnerable, and thus make participation outside home difficult for older adults living with dementia. As older adults living with dementia progressively strain to maintain familiarity by using landmarks - which are also vulnerable - they may perceive the quality of their participation outside home as less than satisfactory. All these reasons combined might explain why the results in Study III show no associations between the total number of places visited and their perception of participation outside home. Looking at specific places that older adults living with dementia seem to retain, inspired from the results in Study II, might help continue better understanding participation outside home, without the common tendency of focusing on the losses or abandoned places, which puts the deficits to the front and amplify an assumed inability to participate outside home.

Specific places for participation outside home

Results from Study II show that the most retained places by older adults living with dementia were places with contact with nature, for medical care, for staying in touch with their social network, and the neighbourhood. Results included in this thesis and others (Brorsson, 2013; Gaber, 2021; Landry, 2020; Mossabir, 2018) suggest that some places may offer specific relationships to older adults. Through the focus on situated experiences and based on the most maintained places reported by older adults living with dementia, feeling at home could thus be extended to specific places outside home.

The garden around the house, the day care/hospital and the grocery store

The most retained place in Study II was the garden around the house, which is an easy way to keep in touch with nature (Gibson et al., 2007). It allows the older adult to walk along paths or on the grass, it might provide a bench to sit down and contemplate (Whear et al., 2014). It might have flowers, bushes or trees that would need trimming; and there might be a flower or vegetable garden, offering occupations of gardening in close proximate vicinity of the home (Hewitt et al., 2013; White et al., 2018). Of course having access to a garden around the house would be more available in rural and semi-urban settings, which was the case of the majority of the participants in Study II. Switzerland having mostly villages, small towns and small cities with consistent access to family gardens since World War II (Frauenfelder et al., 2015) might be related to the garden around the house being the most retained place for our participants; additionally, Switzerland is culturally known for having flowered plots around the house (Salomon Cavin, 2013). In the Swedish and Canadian samples, the garden around the house was not the most maintained place, probably due to their participants living in the urban areas of Stockholm and Vancouver (Chaudhury et al., 2020; Gaber et al., 2019).

Day care services for older adults living with dementia are becoming an important aspect of the medically-oriented services offered in the community. The aim of these services is to reduce institutionalization, support older adults living with dementia remain at home as long as possible and offer respite to the caregivers (Måvall & Malmberg, 2007; Myren et al., 2017). How these places are designed influences their effectiveness, enabling a passive or active role for the older adults living with dementia (Myren et al., 2017; Rokstad et al., 2017; van Haeften-van Dijk et al., 2015). Most day care services are implemented in nursing home settings, often without any thought about the dementia-friendly designs (van Haeften-van Dijk et al., 2015). Other research has shown that how the place is designed contributes to enabling activities and roles in everyday life at the day care service (Rokstad et al., 2017), with features linked to contact with nature being worthwhile (Hassink et al., 2019).

Although the grocery store did not appear above the threshold of the most maintained places outside home for older adults living with dementia in Study II, it has been consistently identified as an important place by earlier research (Brorsson et al., 2013, 2018; Gaber, Nygård, Brorsson, et al., 2020; Mossabir, 2018). Those earlier studies have been conducted in Sweden, the UK and the United States. The grocery store in the Swiss sample might have been less maintained than expected from the results of earlier research. Participants in the Swiss sample mostly lived in rural or semi-urban areas. Switzerland also has a long tradition of holding weekly or twice weekly markets with fresh vegetables and fruits directly from the producers, even in bigger cities like Lausanne. Older adults might be used to go to markets and the item in ACT-OUT named as grocery store might not have been understood as also referring to the market. The results could also be explained in relation to the fact that grocery stores owners or chains have long been implementing a marketing technique of rotating goods in the shelves, and put items on sale on specific display stands, in order to increase sales (Chandon et al., 2009; Cox, 1964). As stated by Brorsson and colleagues (2018), it will make it more difficult for older adults living with dementia to keep their routines and familiarity in the shops. Switzerland has mostly considered accessibility only from the physical viewpoint (Pfahl & Powell, 2014) and is lacking in policies to make private shops "dementia-friendly" (Alzheimer Disease International et al., 2020).

The neighbourhood

Not surprisingly, the neighbourhood was one of the most retained places for older adults living with dementia, and without dementia for participants in Study II. It is in line with recent similar results of the same type of studies conducted in Sweden, the UK and Canada (Chaudhury et al., 2020; Gaber et al., 2019; Gaber, 2021). The neighbourhood is primarily and mostly defined in the literature as a collection of geographically proximate locations determined by being at a walking distance (Blackman et al., 2003; Keady et al., 2012). Yet, this does not seem to reflect how our participants encounter and engage within their neighbourhoods. Such definition might produce a rather exclusive and uncritical view of the neighbourhood without considering the interactions that shape its form and usage by older adults living with dementia (Clark et al., 2020). The way that our participants living with dementia engage with their environment outside home and how it is connected to the neighbourhood is discussed in more details further.

Still, considering how the literature on the neighbourhood highlights its importance for participation outside home (Blackman, 2006; Keady et al., 2012; Mitchell & Burton, 2006), the results of this thesis are consistent. They also point out that older adults living with and without dementia both consider the neighbourhood as important and valuable in the participation outside home (Van Dijk et al., 2015). The relevance of the neighbourhood in participation outside home for all older adults might be linked to the sense of belonging produced through social connectedness and cohesion (Morgan et al., 2019; Odzakovic et al., 2019). Neighbourhoods, based on an implicit system of social support, offer opportunities for chance encounters with neighbours, active engagement in occupations like going to the market on Saturday morning, or drinking a coffee on a terrasse (Clark et al., 2020). These opportunities are used by older adults to engage in conversation or ask for help from other people sharing the same occupations in the same places. Results from Study IV have shown that older adults living with dementia engage in these encounters, regardless of their diagnosis, underscoring that neighbourhoods represent more than a collection of walkable-to-places and should be seen as encompassing relational and transactional places (Andrews et al., 2013; A. Clark et al., 2020).

Still, the construct of the neighbourhood is not yet consensual in the literature. In fact, there seems to be two main avenues in understanding this construct, as also reported by Gan and colleagues (2021). One is based on a vision of the neighbourhood as a geographically delimited space - i.e. walking distance – and attributing physical and social characteristics like walkability, holding landmarks, design features, and social capital (Blackman, 2006;

Brorsson et al., 2016; Odzakovic et al., 2019). This definition of the neighbourhood produces an image of a static homogenous plain container within which activities and relations take place. It is also aligned with the idea of fluctuation in its delimited space as constricting and expanding, according to the ability of the person to go out and about (Duggan et al., 2008; Kuliga et al., 2021; Odzakovic et al., 2018). The second is based on a vision of the neighbourhood as an experience of being outside and attributing support characteristics, like familiarity, connectedness and belonging, affective proximity, and agency (Bosco et al., 2019; Fang et al., 2016; Martyr et al., 2018). This definition of the neighbourhood produces an image of a diverse unique relationship that the individual entertains with their environment, without clear stated boundaries or limits to their scope and space. It is also aligned with the idea of continuity of self and identity, of social support and active engagement (Clark et al., 2020; Kielsgaard et al., 2021).

The results of all four studies in this thesis point towards the building of an aggregated construct of these two visions of the neighbourhood, that we have called "territory" in Study IV. In Study I, II and III, the item referred to as the neighbourhood was self-defined by participants with and without dementia. It is based on a reciprocal dynamic relation between how the person interacts with the neighbourhood and how in turn the neighbourhood shapes the everyday engagement of the person participating in it. Furthermore, in Study IV, the experience of familiarity while participating outside home, showed the territory to be a "*series of networked locations connected through paths and lines of travel*" (by walking, riding or getting a lift) (Clark et al., 2020).The experience of familiarity was simultaneously enhancing one's sense of active engagement and connectedness, creating an individually unique patterned canvas of social encounters and occupations, supporting habits, routines and belonging, but also risk taking (like getting lost) and challenges (Kielsgaard et al., 2021; Morgan et al., 2019; Odzakovic et al., 2019; Rotenberg et al., 2020; Sandberg et al., 2017). So as also proposed by Førsund and colleagues (2020), "territory" includes both visions of the neighbourhood, acknowledging the physical and social construct, supporting the preservation of continuity and identity, and understanding places as an existential experience for older adults living with dementia.

The experience of participation in places outside home: familiarity and risks

In this thesis, the experience of participation outside home is linked to the places visited. The concept of life-space (May et al., 1985), through which individuals experience and interact with the world, recognises the relationship between the environment and the individual, conferring a geographical image to the space outside home in which older adults living with dementia move from one place to another. This life-space could be seen as a series of zones, ranging from within one's home to the neighbourhood, the town, the region and so forth, using an eco-systemic model like Bronfenbrenner's (Bronfenbrenner, 1979). This is in line with the first definition of neighbourhood discussed above. As said before, the experience of participation outside home is not only limited to the geographical understanding of places, but also included in a more relational perspective, such as the transactional and occupational perspective applied in this thesis.

By repeatedly performing activities in places, older adults experience a relation with their environment, transforming the space into a place that has meaning and into which the individual inserts life stories (Kielsgaard et al., 2021; Townsend et al., 2009). The place becomes a part of the individual, linked to one's identity, while the individual is performing occupations (Huot & Rudman, 2010). Results in Study IV indicated that older adults living with dementia maintained continuity of self through the experience of familiarity. Identity was also embedded in places, as participants told personal stories about their past or families, giving meaning to the places. Furthermore, results showed that places and activities were often referred to at the same time by participants while telling stories. The idea that the place and activities could be experienced together has been a feature of occupational therapy literature before (Foley et al., 2019; Hasselkus, 2011). In her book, Hasselkus (2011) stated that the interaction between persons and places in which everyday life is carried out influences the experience of "doing-in-places", which is aligned with the transactional perspective (Cutchin & Dickie, 2013). This indicated that participants gave meaning to places as they visited them and performed occupations, considering them as familiar. Not only did results from all studies consistently indicate that places were more than a delimited space, which was expected from the theoretical perspective used in this thesis, but also that places had a personal meaning for the participants; and that this meaning influenced how they would visit them, maintain or abandon them, creating a relationship between the person and the places visited.

Aging-in-place models support this relationship that enables older adults to be embedded in places that are familiar to them (Fung, 2020), by transforming the delimited spaces into meaningful places. This happens by repeatedly and routinely performing occupations supporting the emergence of an occupational space (Kantartzis & Molineux, 2017; Nyman & Isaksson, 2020), which transforms into a place that include the "doing", giving it particular features like being familiar, having meaning, and a sense of belonging. Nyman & Isaksson (2020) refer to an "enacted togetherness" that situate occupations into socio-culturally meaningful places. They argue that performing occupations together creates shared-meanings that connects persons and places through unfolding stories. From an occupational perspective, occupations understood as doing, being, becoming and belonging have been linked to health and well-being (Wilcock & Hocking, 2015), and support the relationship with the place (Kielsgaard et al., 2021). Thus, older adults living with dementia experience the place and the occupation together, without separation. These experiences of situated occupations or occupations-in-place should not be understood as relevant local geographically named places, but rather as a network of recognised relational, habitual, and familiar sites that transcend geography to promote interconnectedness of places, occupations and individuals into "territories", as seen in the results of Study IV and supported by the study by Clark et al (2020).

In addition, Clark et al. (2020) also identified experiences, that were called occurrences in Study IV, based on a sense of familiarity, not just recognising, but rather repeatedly engaging in visiting places. They argued that the capacity for familiarity, recognition and belonging experienced in some places would mean that even further away places might be considered, stretching the experience of the neighbourhood. This idea is coherent with the results of Study IV, which based on familiar repeated occurrences proposes individual territories instead of the common use of neighbourhood. In the context of living with dementia, individual territories might create an image of enacted interconnectedness of multiple places of different and fluctuating sizes. In fact, territories could be seen as stretched-out neighbourhood places (Clark et al., 2020), and might cover greater distances than previously expected, with the aid of video conferences technology that has been used for the last year due to the pandemic. There is a need to further explore how these virtual spaces might be included in individual territories.

Familiar objects in the participation outside home

Results in Study IV have shown how older adults living with dementia used objects in a particular way, supporting them in participating outside the home. Taking objects with oneself when leaving the house seems at first glance to be nothing of interest. However, these objects, although some were quite practical (keys, wallet or umbrella), they were not consistently used for practical reasons such as closing the door of the house, paying in the store or protecting from the rain. Rather, these objects as described in Study IV, were so familiar to the participants that some of them even said they would not go out of the house without them. These objects were interpreted in Study IV as providing a red thread to link the participant to their home, giving them a feeling of being safe and secure. Feeling safe and secure outside home has been identified before as a factor to facilitate participation outside home (Alidoust et al., 2019; Loukaitou-Sideris et al., 2019). Interestingly, research results from neuroscience about the use of prosthetics have shown that external objects could be embodied through repeated use (de Vignemont, 2011; Schettler et al., 2019), and embodiment of self into an external object has also been discussed in other disciplines (Beyaert-Geslin, 2015; Henry, 2000).

This idea of embodiment of objects has also been explored with people living with dementia (Kontos & Martin, 2013). Kontos and Martin (2013) showed that dimensions of embodiment were a way of rethinking selfhood, based on results showing embodiment in habits and gestures in the experience of dementia, without the usual mind/body dualism. This can be understood as people living with dementia experiencing being-in-place (or in-the-world) in relation to an embodied selfhood (Cutchin et al., 2008; Kontos & Martin, 2013; Thibodaux, 2005), creating extensions of themselves into external objects. Based on this idea of embodied selfhood and embodiment of objects that human beings do in many situations, the objects seen in Study IV have been interpreted as linking the participant to their home, increase this feeling of being safe and secure, and thus facilitating participation outside the home.

Risks in the participation outside home

The results of Study III indicated that participants living with dementia perceived more risks than their counterparts in the comparison group, especially regarding the risks of falling and getting lost. Other risks, such as being stressed or embarrassed, have earlier been identified as playing a role in participation outside home, although not showing significant association in Study III (Bantry White & Montgomery, 2015). Being concerned about risks have been found to limit participation outside the home for people living with dementia (Emrich-Mills et al., 2019). It is therefore not surprising that participants living with dementia were more concerned by risks as they reported visiting less places. This suggests that people with dementia might have subtle risk insights if talking about concrete matters of everyday life (Öhman et al., 2008) which might indicate a readiness to also discuss risk perceptions with them, and how risks can be prevented and dealt with in supportive interventions

Risks of falling and getting lost have been investigated before (Nyman et al., 2013; Sandberg et al., 2017) and have been shown as refraining older adults living with dementia from participating outside the home. As risks of falling and getting lost have been identified as important, public places and private places open to the public, need to be made more secure and offer means to create landmarks, for example by increasing readability of features, buildings and signage as well as saliency in urban furniture and other features of places outside home (Seetharaman, 2018). Repeatedly visiting familiar places and performing familiar occupations, as exemplified by the participants in Study IV, might help mitigate the negative effects that being concerned by risks is having on participation outside home. Again, this underscores the importance of supporting maintained participation in life outside home among people living with dementia.

METHODOLOGICAL AND ETHICAL CONSIDERATIONS

Each choice made in the methodology section, be it study design, recruitment strategies or data collection and analysis will have an impact on the results presented in this thesis. Although plans have been made with utmost care and consideration regarding potential outcomes, being confronted with real life participants in unpredictable situations have also contributed to the research results presented here. I will first discuss the choices (methodological and ethical) made regarding the participants, then the data collection methods.

Including older adults living with dementia in research and the issue of metacognition

Older adults living with dementia are increasingly engaged in research processes, not as study subjects, but also as partners in planning, executing and disseminating research (Milne, 2018); which they have advocated for. Despite calls for greater engagement in research, older adults living with dementia continuously face barriers, like their perspectives were not prioritised, or opportunities for engagement were not adequate (Bethell et al., 2018). The research in this thesis sought to include older adults with and without dementia as participants, giving them an arena to be heard and understood. There is a concern that older adults living with dementia might not be reliable and that their answers might not be authentic, based on a broad generalisation that having a dementia makes one unable to manage the cognitive demands of participating in research (Darby & Dickerson, 2017). Metacognition research especially highlight the functional impairments in dementia, including executive functioning like decision-making, initiation, volition, working memory, maintenance of goal-directed behaviour; awareness of deficits like emotional and motivational limitations. Metacognition is needed to adapt one's behaviour on the assessment of practical situations (Darby & Dickerson, 2017). This has led to either rely on proxy reporting to compensate for unreliable and unauthentic reports about their personal dated history, abilities and needs (Novek & Wilkinson, 2019), or adapting the data collection process to accommodate support of significant others and offering flexibility, transparency, and assent (Nygård, 2006b), following the process consent method (Dewing, 2007). The purpose of this research was not to ascertain the validity or the accuracy of the participants' authentic and reliable physical participation in visiting places outside home, but rather to explore their perception of their participation. The experience of having a dementia is a social process (Førsund et al., 2018; Hillman et al., 2020) and its perception will be socially biased through relations of power wielded by formal and unformal caregivers (especially in a country like Switzerland where the biomedical model is significant).

Furthermore, the way older adults living with dementia would be engaged in this research was first discussed and adapted in Study I, based on discussions with participants who supported the research team adapt the ACT-OUT questionnaire and how to best collect data. Participants living with dementia were included in this thesis via the Swiss Alzheimer Association, who informed the design of the tools and the data collection processes. The order of the data collection for Study II and III were also discussed and decided based on the experience of members of the Alzheimer Association. Although there were many socio-demographic determinants collected in both studies, this was done close to the end of the process so as not to burden the participant living with dementia, and could be filled in by a proxy or through referral at the time of recruitment. The group of participants living with and without dementia in this thesis has the particularity of mainly living in rural or semi-urban settings, making this research unusual in term of socio-demographic characteristics (Innes et al., 2020), as most participants living with dementia involved in research live in urban contexts. Still, one needs to be careful with urban vs rural comparisons as there is no consensus on how to classify rural vs urban communities (Isserman, 2005).

Population, recruitment and sampling

The MoCA was included in the data collection in order to document the cognitive functioning of the participants, and to check that the groups were significantly different in that regard in Study II and III. It was preferred to the Mini Mental Status Examination (MMSE), for its better sensitivity (Abd Razak et al., 2019; Friedman, 2012). However, using the MoCA for this purpose in research is somewhat problematic as it was developed as a screening tool for mild cognitive impairment (Julayanont & Nasreddine, 2017) among a highly educated population. The MoCA has now been translated into many languages and normative data exist for most populations. Still, research from different countries has shown that the cognitive performance screened by MoCA might be influenced by demographic factors like age, gender and education (Julayanont & Nasreddine, 2017; Kang et al., 2018). As this thesis included older adults living with and without dementia, and based on earlier studies, the indicative cut-off score was set at 23, and one point was added for less than 12 years of education, to mitigate the age and education effect (Nasreddine et al., 2005). Furthermore, as the participants were interviewed in French, but living in Switzerland, the version used here was in French, developed in Québec, Canada (Nasreddine & Patel, 2016), raising the question of effects from the socio-cultural context. Since the MoCA was only indicative and not used to separate the groups, the choices made to mitigate age and education were appraised to be sufficient. Still, although we used a tool for screening cognitive impairments to statistically describe the groups in this thesis as different, we are aware this is an artificial way to separate older adults into two groups. Older adults are offering a singularity, diversity and richness of needs, resources and situations that living with or without dementia and cognitive performance are only one aspect defining them (Enßle & Helbrecht, 2020).

Recruitment and the issue of sample size

The recruitment of participants was conducted following a non-probability purposive sampling method (Nayar & Stanley, 2015), and happened through the referral by others (physicians, neuropsychologists, nurses in memory clinics for older adults diagnosed with dementia; family, senior associations, ads in grocery stores for older adults not diagnosed with a dementia). The purposive sampling method was useful in Study II and III to include participants living with dementia who could inform the research questions under investigation, selecting them based on their willingness to participate and pre-defined characteristics (Valerio et al., 2016). Also it was used to adjust the socio-demographic factors, like age, sex and living conditions, so the comparison group would be as similar as possible on those factors that were deemed to influence the issues under study, i.e. participation outside home. The choice of this sampling method also had the consequence of being dependent on others for referral to the study. This implied to keep in contact with the key gatekeepers and prolonged the recruitment process.

A convenience sampling method (Sedgwick, 2013) was used in Study IV, and consisted of participants who had been included in Study II and III, and who were willing to participate in mobile interview. This method poses the risk that the selected participants were those who were more active, and were more interested in participation outside home (Etikan, 2016). Still, as the issue under scrutiny in Study IV was related to the experience of familiarity in participation outside home, the method of sampling helped having a group of participants who were actively engaging in participation outside home, for whom this was important and who were able to share and enact their experiences. Thus, the results in Study II, III and IV cannot be generalised to all older adults living with dementia.

The sample size calculation for the sample in Study II and III was performed based on the data collected in Study I, which included 26 older adults living without dementia and only five living with dementia. This tentative sample size calculation was based on the difference of the mean total number of places visited by the older adults living with dementia (15.63) and those living without dementia (17.14), associated with a pooled standard deviation of 2.20. This indicated a sample size of approximately 34 for each group (α=.05; power=.80). So, the number of participants was estimated at 35 in each group for Study II and III. This can be viewed as speculative as the ACT-OUT questionnaire at that point in time had never been used for larger data collection samples.

The sample size calculated with the Swiss sample used in Study II and III, with a mean of 18,91 for the group living without dementia and 15,83 for the group living with dementia, and a standard deviation of 3,31; this indicated a sample size of approximately 19 participants. The variations in sample size calculation between both calculations is probably due to the bigger difference between the means of total places currently visited in the sample of older adults living with dementia in Study II and III, than the sample in Study I, which was very small.

The sample size in Study III is still considered small with 35 participants in each group, as the methods used for analysis, i.e. logistical regressions, would need enough participants for each of the factors added to the model (Munro, 2005). Some outcomes of the logistical regressions (e.g. education levels) could not be used in Study III, because there wasn't enough participants in some categories of the variable, which led us to not include education in the model, although education level is recognized as an important variable for influencing participation outside the home (Gilmour, 2004; Nordbakke, 2019; Stubbs et al., 2014; Wang et al., 2002).

Data collection and analysis methods

The data collection scheme was designed to highlight the perspective of the older adults with and without dementia, based on the recognition that they would be able to share their world views on participation outside the home (Moore & Hollett, 2003), and on the discourses about dementia being a disability (Shakespeare et al., 2019). So, face-to-face interviews were prioritised in Studies II and III, and mobile interviews in Study IV. Interviews are understood as being a method for giving voice (for participants) and for accessing experience (for the researchers) (Brinkmann et al., 2018). In addition, researchers often assume that the participants will offer a detached analysis of their actions and connect these actions to some underlying source of motivation or emotion, while being interviewed; and that the interviewer can access it. Evidently, this is a naïve way of considering the interview method. The purpose of the interview method is to interpret meaning of central themes in the lifeworld of the participant. It is descriptive and qualitative by nature. The interviewer records and interprets the meaning of what is said and how it is said (Kvale & Brinkmann, 2009). Being immersed in an interview provides recordings, words, field notes, or material (data); and images, memories, and feelings or immaterial (what the interviewer gains as a researcher that can inform the data).

Furthermore, the interviewee's answers can sometimes be ambiguous and reflecting contradictions in the world the participant lives in (Brinkmann et al., 2018); and this can happen whether the person lives with dementia or not. Kvale and Brinkman (2009) state that "*the aim of the qualitative research interview is not to end up with unequivocal and quantifiable meanings in the themes in focus*" (p.31). The responsibility of the interviewer is not to suppress this ambiguity (Ferrari et al., 2016), but to ensure that they are not due to a failure of communication in the interview situation or due to the researcher's personality. The contradictions that emerge may reflect effective contradictions in the life world of the interviewee (Brinkmann et al., 2018).

Doing interviews with older adults living with and without dementia, researchers will also have to cope with ambiguity and contradictions. The interview needs to focus on concrete, everyday activities and not rely on episodic memory for answers (Seixas-Lima et al., 2020). Adding mobile interviews and field notes in Study IV increased the possibilities for the older adults living with dementia to enact their everyday life outside the home (Kielsgaard et al., 2021). Enactment of everyday life in interviews allows the older adult living with dementia to be embedded in situations, thus gaining support from the places to stay in touch with meanings, self-presentation and identity (Nyman et al., 2012).

Having a dementia is not only a disease that progress, it is also a social process; it might produce social biases in the interview, like wanting to keep face, creating confabulations, over-evaluating their own abilities, or wanting to please the interviewer (Bosco et al., 2019). As a research interview is an encounter between two individuals, relations of power in a wider social and cultural context influence the data collection process. As such, the perceptions and experiences of persons living with dementia need to be situated within the wider socio-cultural context of the interview encounter. Storytelling about places was used by participants to tell about their participation outside the home. Storytelling also has social conventions and can support temporality, which was used in Studies II and III. Participants were encouraged to tell stories while being asked about the places they visited outside the home. The findings show that participants were able to tell about the places they visited, and to take the researcher there in Study IV. The ACT-OUT questionnaire uses concrete questions and clear examples to support the cognitive processes necessary for recall of the older adult living with dementia. The examples are grounded in practical situations of everyday life, with evocations of places close to the participant's home, offering flexibility as to which place the participant is referring to.

CONCLUSIONS AND IMPLICATIONS

The findings of this thesis provide insights and new knowledge regarding participation outside the home for older adults living with and without dementia. The contributions of this thesis are first the development of the Participation in Activities and Places Outside Home (ACT-OUT) questionnaire; second, it contributes complexity to the construction of participation outside the home and refinement to the concept of place. It has also contributed to a further understanding of familiarity as an overarching concept that links place with participation outside the home, as personal territories including places support participation outside the home for older adults living with dementia.

Based on the empirical findings, this thesis discussed the complexity of participation outside the home through the lens of a transactional and occupational perspective. It recognises the importance for older adults living with and without dementia to have access to the out-of-home locations, to maintain and transform them into familiar places through the occupations performed there. It also points to aspects that can contribute to better support interventions and design places to facilitate their participation.

CONTRIBUTIONS

Study I focused on the development of the ACT-OUT questionnaire, grounding it in a theoretical perspective and an iterative process reflecting the combination of places and occupations together, also adding aspects such as familiarity and being concerned by risks. It provides researchers in various countries with a questionnaire that collects data about places and occupations in combination.

In Study II, participants living with dementia were found to visit places to a lesser extent than the comparison group. The differences in stability and change in places visited for both groups of older adults living with and without dementia clarify the type of places that they currently visit, abandon or maintain, picturing a complex, nuanced and diverse participation outside the home. The differences in occupational gaps reported increase the picture of older adults living with dementia as having to cope with disengagement inside and outside the home. However, these differences between the two groups also present older adults living with dementia as participating outside the home by maintaining familiar places, sometimes closer to their homes, although with less participation in social and cultural, recreational and physical places.

Study III explored and examined the relationship between perceived participation and factors such as socio-demographic variables, the number of places visited in total and per domain, and the risks of getting lost, falling, being stressed and embarrassed. Findings showed that number of places visited were associated with the perception of participation outside the home, but only for the group of persons living without dementia, while risks of falling and getting lost were associated for those living with dementia. These associations contributed to the complexity of our conception of participation by showing links between how people perceive their participation and the type of places they visit as well as the risks they are concerned with. Furthermore, Study III raised the issue of these relationships being different for the groups; and inquires why these expected relations are not present for older adults living with dementia.

Study IV focused on the experience of familiarity by older adults living with dementia solely, by going out with them to the places they wanted to visit. This study contributed insights about the complexity of participation outside the home by introducing the idea of personal territories created through repeated occurrences in familiar places where participants performed their everyday familiar occupations. These territories were not limited to the places close to home, but it included further away places than the neighbourhood defined as a walking distance from home. Familiar landmarks and objects were used by participants to support their participation outside home and contributed to the understanding of its complexity.

IMPLICATIONS

Older adults living with dementia have to cope with a world outside home that is restricting their participation opportunities. Participation outside home is important for mental health, well-being and social connectedness. Reaching familiar places, and performing familiar occupations outside their homes offers benefits for all, including older adults living with dementia. Developing the ACT-OUT and using it in these studies, and others, has also shown the unmet needs of older adults living with dementia in order to participate outside home as much as they want.

In light of the public health situation created by the COVID-19 pandemic, the issue of participation outside the home for older adults living with and without dementia has increased in importance. The impacts of "lockdown" measures have highlighted the importance of maintaining sufficient social participation outside the home for older adults living with and without dementia (Manca et al., 2020). As social isolation and loneliness, which are increased by being restricted from visiting places outside the home, negatively impact mental health and might increase cognitive decline for older adults living with a dementia or might predispose to cognitive decline those without dementia (Manca et al., 2020). Long-term impacts of these restrictions to visit places outside the home are yet to be explored, yet it seems reasonable to assume that the issue of participation outside the home will take more importance in the years to come. As such, this thesis may might have the following implications:

- The ACT-OUT questionnaire offers a way to collect information about participation outside home for older adults in an easy-to-use and timely manner.

- Occupational therapists and other healthcare professionals may benefit from increased awareness of the relational nature of participation outside the home, to better develop interventions enabling participation for older adults living with dementia.
- Occupational therapists and other health care professionals might become more sensitive to transferring some of their interventions with people with dementia from an institution-based to a more community-based context, including performing everyday aoccupations outside the home.
- When developing interventions for older adults living with dementia to support participation outside the home, occupational therapists and other health professionals are encouraged to search for information about abandonment vs. maintenance of places, personal therritories and the use of landmarks.
- Supporting familiarity outside home, by designing features in urban planing that can be trasnformed in landmarks, is important to enable participation outside home for older adults living with dementia.
- Understanding the role that risk concerns play in participation outside the home might support the development of interventions towards enabling visiting places oztside the home, especially those that might increase the feeling of participating as much as wanted, such as parks, forests, walking trails in mountains or lakeside.
- Policies addressing inclusive communities such as “dementia-friendly” or “disability-friendly” may benefit from considering ways to render the at-risk-of-abandonment places easier to reach (accessibility), easier to use (usability), easier to be included in a personal territory (familiarity); and thus easier to participate.
- Designing the out-of-home spaces need to consider how older adults transform space into place by performing occupations; only removing the physicial barriers in the environemnt as ways of increasing accessibility, usability and social participation is not enough.
- Finally, increased awareness of the importance of participation outside home for older adults living with dementia in Switzerland and other countries, is the first step towards designing services that address this issue.

FUTURE RESEARCH

The research area focusing on participation outside the home for older adults living with and without dementia is important, and needs to be further expanded and developed. This thesis has generated new questions that would be interesting to pursue in future research.

In this thesis, the ACT-OUT was developed and used for data collection in a Swiss context, but it has in parallel been used also in different contexts and with different populations. Reflections on its validity are ongoing, including the construct that it might be addressing. A study using a Content Validity Index (Yusoff, 2019) is being conducted in Sweden, but further testing would be needed to gain a better understanding of ACT-OUT’s properties and inform forthcoming revisions of it.

This thesis has shown that the places in the domain D/places-for-recreational-and-physical-activities, and to some extent also in the domain C/social-cultural-spiritual-places, might be important for perceiving satisfactory participation. This was more pronounced for older adults living without dementia, but we do not know whether and what other factors might be at play regarding older adults living with dementia. In the same line, ACT-OUT did not ask about the value older adults attribute to the places they visit or abandon. Further research would be needed in order to discover if and how such aspect of places influences on their perception of participation outside the home.

Furthermore, this thesis has shown that places for social and cultural occupations, as well as for recreational and physical activities were abandoned by older adults living with dementia to a large extent, in contrast to places for medical care. Research would be needed to further explore the type of places that older adults abandon more, and the reasons and consequences of this disengagement in those specific places. In the same trend, exploring the types of places that are most maintained and the reasons why, would increase our knowledge of places in relation with participation outside the home, and help us develop appropriate support.

Still, unanswered questions remain about the experience of becoming disconnect and losing familiarity. This thesis has started to explore familiarity and its role in participation outside the home, and has provided some insights as to how familiarity might be experienced by older adults living with dementia, but insights into how places and occupations become unfamiliar is still missing. Future research using longitudinal designs would offer more in-depth knowledge as to how places and occupations together become unfamiliar.

Finally, it would be interesting to use ACT-OUT in the pandemic situation we are going through to gain insights of the impacts for older adults living with and without dementia on the places they visit outside home.

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