

Karolinska Institutet http://openarchive.ki.se

This is a Peer Reviewed Accepted version of the following article, accepted for publication in Canadian Journal of Occupational Therapy.

2019-06-12

Everyday technologies and public space participation among people with and without dementia

Gaber, Sophie Nadia; Nygård, Louise; Brorsson, Anna; Kottorp, Anders; Malinowsky, Camilla

Can J Occup Ther. 2019 Dec;86(5):400-411. SAGE Publications http://doi.org/10.1177/0008417419837764 http://hdl.handle.net/10616/46803

If not otherwise stated by the Publisher's Terms and conditions, the manuscript is deposited under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. Copyright © 2019 Canadian Association of Occupational Therapists. The manuscript is protected by copyright and reuse is restricted to non-commercial and no derivative uses. For permission to reuse an article, see SAGE Publications Process for Requesting Permission.

Everyday Technologies and Public Space Participation among People with and without

Dementia

Sophie N. Gaber

PhD candidate, MSc, OT Reg. Karolinska Institutet

Fack 23 200, SE 141 83, Huddinge, Sweden

Tel: +44 (0) 7912 607 659 Email: sophie.gaber@ki.se

Louise Nygård

Professor, OT Reg. Karolinska Institutet

Fack 23 200, SE 141 83, Huddinge, Sweden

Anna Brorsson

Dr, OT Reg. Karolinska Institutet

Fack 23 200, SE 141 83, Huddinge, Sweden

Anders Kottorp

Professor, OT Reg. Malmö University

Faculty of Health and Society, 20506, Malmö, Sweden

Camilla Malinowsky

Dr, OT Reg. Karolinska Institutet

Fack 23 200, SE 141 83, Huddinge, Sweden

Abstract

Background. Occupational therapists support Everyday Technology use however it is necessary to consider the challenges that people with dementia encounter with Everyday Technologies when participating in various places within public space. **Purpose**. The purpose of the study is to explore stability and change in participation in places visited within public space, in relation to the relevance of Everyday Technologies used within public space. **Method**. People with dementia (n=35) and people with no known cognitive impairment (n=34) were interviewed using the Participation in ACTivities and Places OUTside Home Questionnaire and the Everyday Technology Use Questionnaire. Data analysis used modern and classical test theory. **Findings**. Both samples participated in places within public space however participation and relevance of Everyday Technologies was significantly lower for the dementia group. **Implications**. To enable participation, occupational therapists need to be aware of challenges that technologies and places within public space present to people with dementia.

Keywords: Dementia; Technology; Community participation; Environment; Geriatrics.

Everyday Technologies and Public Space Participation among People with and without Dementia

Dementia is a world health priority (World Health Organization [WHO], 2012). Globally, 47 million people are living with dementia (Winblad et al., 2016). In the Americas alone, there are an estimated 7.8 million people living with dementia and this is projected to nearly double every 20 years (Alzheimer's Disease International/BUPA., 2013). According to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), people living with and without disabilities, including dementia, have the right to live independently and participate fully in all aspects of life (United Nations [UN], 2006). Opportunities exist for occupational therapists in enabling participation in places and activities to support well-being as a human right (Whalley Hammell, 2017). The majority of people with dementia live in the community which means not only residing in their homes but also participating in a range of activities and places within public space that are cognitively demanding in various ways, e.g. noise, crowding, technology requirements (Brorsson, 2013; Winblad et al., 2016).

Dementia-friendly communities are considered a priority for governments internationally and yet little is known about the ways in which people with dementia participate in their community, in particular within public space (EFID, 2016). Increased knowledge about the ways in which occupational therapists can facilitate participation in public space for people living with dementia may help to elucidate the role of occupational therapists in dementia-friendly communities. Public space has been defined as the space outside a person's home that all citizens have access to (Brorsson, 2013). Due to the pervasiveness of technology in today's society, the ability to use Everyday Technologies (ETs) is increasingly considered a prerequisite in order to access and participate in activities, places and services within public space (Emiliani, 2006). ETs encompass a broad range of technological objects and devices that people encounter in their everyday lives. ETs refer to common domestic technologies e.g. kettles, alarm clocks, and those technologies within public space e.g. ATMs, self-service checkouts. ETs also include portable devices e.g. smartphones and tablets, which transcend typical geographic bounds in their use both at home and within public space (Greenfield, 2017).

A number of studies indicate that increased availability of relevant ETs is associated with higher activity engagement among older adults (Walsh et al., 2018). However research shows that people with cognitive impairment experience increased challenges using ETs (Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2017). Greater challenges using ETs may hinder, for instance their use of public transport, e-Health services and online banking (Malinowsky, Almkvist, Kottorp & Nygård, 2010; Nygård, Pantzar, Uppgard & Kottorp, 2012). Research underlines the duality of ETs as both an enabling and disabling mechanism in various areas of everyday life for people living with cognitive impairments (Lindqvist et al., 2018). Involvement of ETs has been shown to be a particular hindrance in activities which occur within a public space context e.g. managing finances and getting around, and occupational therapists need to be aware of how this may in turn limit opportunities for people living with cognitive impairments to participate in places within public space (Lindqvist et al., 2018). Profiles of decreased engagement in activities, in particular activities within public space e.g. shopping, socializing and driving, have been linked to cognitive severity in people with mild cognitive impairment (MCI) and Alzheimer's disease (AD) (Nygård & Kottorp, 2014). The earlier research suggests that these groups may be most at risk of challenges using ETs and occupational therapist may be able to support those susceptible to restrictions in their participation in their everyday lives, which is otherwise a potential catalyst to social exclusion.

In recent years opportunities to participate in community-based activities have increased for people with disabilities (UN, 2006). A determinant of increased participation is an accessible community which has previously been considered from a physical viewpoint (Dashner, Hollingsworth, Gross, & Gray, 2017; Harada et al., 2016). Research demonstrates that remaining active and independent in places and activities within public space, in particular familiar environments such as a local neighbourhood and grocery store, continues to be prioritized by older people with and without dementia (Argyle, Dening, & Bartlett, 2017; Brorsson, 2013; Brittain, Corner, Robinson, & Bond, 2010; Burton & Mitchell, 2006). Such research demonstrates a desire for ongoing participation within public space, including social involvement. This may require a dementia-friendly community. Research shows that occupational therapists are well positioned to address participatory barriers and to foster social participation for older people (Turcotte, Carrier, Roy, & Levasseur, 2018). Increased knowledge about stability and change in participation for older people living with and without dementia may help to challenge the prevailing discourse of Duggan, Blackman, Martyr, & Van Schaik (2008), among others, that the world, both in a physical and virtual sense, of the person with dementia "shrinks" in a straightforward declining trajectory.

The study seeks to acknowledge the multiplicity of interactions required for participation in activities and places, beyond the corporeality of public space (Kumar & Makarova, 2008). Previous research has underlined changes in participation, in particular, the significance of the familiar, local neighbourhood environment in relation to challenges with memory and way-finding for the person living with dementia (Keady et al., 2012; Kullberg & Odzakovic, 2018) It is also important to explore the relevance of public space ETs and portable ETs in which people living with dementia interact with in the environments that they participate in. Moreover, there is a lack of knowledge about what places people with dementia continue to participate in and we do not know if their participation differs from people in the same age group without dementia. This knowledge gap compels the aim of the study, to explore stability and changes in participation in places visited within public space, in relation to the relevance of Everyday Technologies used in public space. Stability and change are identified among a Swedish sample of older people with or without mild to moderate stage dementia.

Method

Study Design

A cross-sectional study design was used for this exploratory research to discover stability and change in participation in places visited within public space. Correlations were used to explore potential associations between participation in places visited within public space and the relevance of public space ETs and portable ETs, used within public space. The Swedish sample consisted of two groups, a group of older people with mild to moderate stage dementia (n=35) and a matched control group of older people with no known cognitive impairment (n=34). Ethical approval was granted by the Regional Board of Research Ethics at the Karolinska Institutet, 2015/77-31-5, and informed consent was obtained from all participants.

Participants

In this cross-sectional study older people with dementia were recruited via three memory investigation units in the Stockholm region, in addition to open, voluntary community-based activities for people with dementia organized by local Stockholm municipalities e.g. cafes and day care services. The inclusion criteria were: i. diagnosis of dementia in the mild to moderate stage, given by a physician (DSM-IV and DSM-V, American Psychiatric Association, 2000, 2013); ii. ability to consent to the decision to take part in the research themselves; iii. aged 55 years or over; iv. living in ordinary housing in the community; v. to some extent, undertaking activities within public space independently or with support; vi. a user of at least some ETs; vii. without any vision or hearing limitations which cannot be compensated via technical aids; and viii. without any other condition that may impact the person's participation and use of ETs.

The dementia group was matched to a control group of older people with no known cognitive impairment based on age, gender, years of education and living arrangements e.g. living alone or cohabitation. Control participants were recruited through local leisure and social groups for older people, in addition to open recruitment activities for retirement people. A detailed description about the calculation of the sample size of 31-36 participants per group ($\alpha = .05$; power = .80) may be found in earlier research (Margot-Cattin et al., 2019).

Data Collection

The data was collected by four occupational therapists who have experience working with older adults with dementia. Interviews were undertaken in the participant's home or another location of their choice, and in the company of a significant other based on their expressed preference. Interviews occurred over a maximum of two sessions, lasting no longer than 90 minutes per session, and were comprised of three tools and questions about demographics.

The Participation in ACTivities and Places OUTside Home Questionnaire (ACT-OUT) aims to capture detailed information on places and activities *in combination*, specifically identifying participation restrictions and pointing out barriers and facilitators in different contexts (Margot-Cattin et al., 2019). The ACT-OUT has three parts. In part one, the participants report their perceived participation in the past, present and future for each of the 24 places. These 24 places are categorized according to the following four domains: domain A. places for purchasing, administration and self-care e.g. bank (n = 6); domain B. places for medical care e.g. doctor's office (n = 5); domain C. places associated with social, spiritual and cultural activities e.g. restaurant (n = 6); and domain D. places of recreation and physical activity e.g. neighbourhood (n = 7). The interviewer asks for example in the case of a pharmacy; "Do you go to a pharmacy?", "Did you go there in the past?", "Do you see yourself going there in the future?". The interviewer elicits a yes or no response and indicates where there has been a change across past, present or future participation in each place. In this study, data from only Part one was used. A detailed description about the development of the ACT-OUT and all parts is available in an earlier publication (Margot-Cattin et al., 2019). Testing of the psychometric properties of the ACT-OUT is ongoing.

The Everyday Technology Use Questionnaire (ETUQ) assesses the participant's perceived ability and relevance using 90+ Everyday Technologies (ETs). A person measure of perceived ability to use ETs was generated based on each participant's ability to use all 90+ ETs in the ETUQ (Nygård, Rosenberg & Kottorp, 2016). This study specifically investigated the use of 33 portable ETs in detail, these include ETs that can be used both at home and in public space e.g. mobile phones, hearing aids, in addition to 16 public space technologies e.g. public transport ticket machines.

Through an interview, the data collector uses the ETUQ to collect information about each ET and first, records whether the participant perceives the ET as relevant; according to the following definition: the ET is available to the respondent, and has been previously used, is currently used or is intended to be used by the participant (Nygård et al., 2012). The use of relevant ETs is rated across a scale: with no difficulty, with uncertainty, with extensive difficulty, only with another person, or not currently being used (Nygård et al., 2016; Walsh et al., 2018). The ETUQ has shown good psychometric properties when used in research exploring various diagnoses and across different countries (Malinowsky et al., 2017; Nygård et al., 2012; Patomella et al., 2017).

The Montreal Cognitive Assessment (MoCA) version 3 was undertaken with the participants, as a means to assess current levels of cognitive function (Nasreddine et al., 2005). A minimum cut-off score of 23/30 was adopted for the control group with no known cognitive impairment, as a means of distinguishing cognitive levels between the groups (Carson, Leach, & Murphy, 2017). In order to keep a viable sample size for comparison and because the MoCA is used as a guide rather than a definitive cognitive assessment in this study, two control participants slightly below the cut-off (scores 22 and 21) were retained.

Data Analysis

Preparatory data analysis.

A computer application of the Rasch model, WINSTEPS® version 3. 69. 1 (Linacre, 2017) was used to transform ordinal raw scores for all 90+ items from the ETUQ into linear, interval-like measures in logits of the person measure of ability to use ETs (Bond & Fox, 2007). The person measure of ability to use ETs is generated based upon the pattern of responses across all items and all participants in the sample. The higher the measure (in logits), the higher the ability using ETs (Bond & Fox, 2007). An in-depth justification of using the Rasch model to analyze the ETUQ is provided in other studies (Nygård et al., 2012). Furthermore, the ETUQ ratings for public space ETs (n=16) and portable ETs (n=33) were dichotomized into relevant (1) or not relevant (0), in order to give information about the number of relevant public space ETs and portable ETs for each person.

Then, participation was presented according to hierarchies based on the participation in total number of places visited within public space using raw score counts from the binary ACT-OUT data. The Kolmogorov-Smirnov (KS-test) and Shapiro-Wilk (SW-test) tests used in the Statistical Package for Social Sciences (SPSS) computer software, version 24 (IBM Corp, 2016) revealed that the data was not normally distributed with the exception of age, years of education and number of relevant public space ETs which were normally distributed. Due to non-normally distributed data, non-parametric tests were used for those variables (Altman & Bland, 2009) and for normally distributed data parametric tests were used.

Primary data analysis.

First, descriptive statistics including the *t*-test and chi-squared (χ^2) test, were used to ensure that the dementia and control groups were sufficiently matched regarding age, gender, years of education and living arrangements, and to mitigate against potential confounding factors (Peacock & Peacock, 2011). Table 1 provides an overview of the demographics and comparisons of the two groups. The groups are generally well matched however there is as expected, a significant difference in MoCA score and a number of demographic characteristics, including driving a car, use of a transportation service and support from others.

[Table 1 here]

For each place within the ACT-OUT, the difference between present participation between the control and dementia groups was calculated using the Fisher's Exact Test (see Figure 1) (Powers & Knapp, 2010). Moreover, to evaluate if the places within public space had changed (abandoned or retained), counts from past participation in places were subtracted from present participation for each place and compared between the control and dementia groups (see Figure 2). Finally, associations were explored between participation in the total number of places visited within public space (ACT-OUT) and i. the number of relevant public space ETs, ii. the number of relevant portable ETs, and iii. the person measure of ability to use ETs (ETUQ), among the control and dementia groups, using Spearman's rank correlation coefficient (two-tailed) (Peacock & Peacock, 2011).

The cut-offs used to measure the strength of associations in this study follow Cohen's (1988) guidelines from social sciences (.1 - .3 = small association, .3 - .5 = medium association and .5 - 1.0 = large association). Due to the non-normally distributed data, the effect size was calculated for the Mann-Whitney U-test findings. Effect size was expressed as a correlational effect of *r*, according to Cohen's (1988) effect size threshold (small=.1, medium=.3, large=.5, very large=.7). All descriptive analyses were undertaken with a significance threshold set at *p*<.05.

Findings

Participation in the Total Number of Places Visited within Public Space (ACT-OUT)

Participation in the total number of places visited within public space was significantly greater for the control group than the dementia group (see Table 2). The U-value was statistically significant, U = 425.000 (Z = -2.06), p = .039, and the effect size was small (r = -.248).

[Table 2 here]

The Number of Relevant Public Space and Portable ETs, and the Person Measure of Ability to Use ETs

The number of relevant public space ETs was significantly greater for the control group than the dementia group (see Table 2). The U-value was statistically significant, U = 392, 500 (Z = -2.444), p = .015, and the effect size was small (r = -.294). The number of relevant portable ETs was significantly greater for the control group than the dementia group

(see Table 2). The U-value was statistically significant, U = 394.500 (Z = -2.416), p = .016, and the effect size was small (r = -.291). The person measure of ability to use ETs was significantly greater for the control group than the dementia group (see Table 2). The U-value is statistically significant, U = 125,000 (Z = -5.641), p =<.001, and the effect size was large (r = -.679).

Participation in places visited within public space (ACT-OUT), among the control and dementia groups is presented according to frequency hierarchies (see Figure 1). The hierarchies show commonalities in participation between the groups for the majority of places. Five places were however associated with a statistically significant difference in participation (mall, supermarket; bank, post office; doctor's surgery; forest, mountain, lake, seaside; and day care). In all places the control group showed greater participation with the exception of the day care where the dementia group had higher participation. Sub-scales for the four domains of place type showed that domain B (places for medical care) were associated with the largest range of both higher and lower participation among the control and dementia groups.

[Figure 1 here]

Hierarchies of counts comparing changes in past and present participation in places visited within public space (ACT-OUT) indicated commonalities across the groups. Across both groups, the neighbourhood was associated with higher participation which remained stable from the past to the present. With the exception of the neighbourhood, places of recreation and physical activity (domain D), specifically the sports facility and forest, mountain, lake, seaside indicate change as these places were most frequently abandoned (lowest count), for both the control and dementia groups (see Figure 2). Conversely, the type of places retained (highest count) among the control group (hairdresser and mall,

supermarket) differed from the dementia group (day care and building for worship).

[Figure 2 here]

Relationships between Participation in Total Number of Places Visited and the Number of Relevant ETs

For both the control and dementia groups, there was a positive but not statistically significant correlation between participation in total number of places visited and i. the number of relevant public space ETs (control group $r_s = .306$, p = .078; dementia group $r_s = .222$, p = .201); ii. the number of relevant portable ETs (control group $r_s = .147$, p = .408; dementia group $r_s = .328$, p = .054). There was however a statistically significant positive correlation between the dementia group's participation in total number of places visited and the person measure of ability to use ETs ($r_s = .551$, p = .001) but not among the control group ($r_s = .219$, p = .213) (see Table 2).

In summary, both groups participated in a number of places within public space however participation and relevance of ETs was significantly lower for the dementia group. Despite changes in participation, stability across time is also evident as both groups maintained higher participation in the neighbourhood. No significant relationship was found between participation in total number of places visited and the person measure of ability to use ETs, with the exception of the dementia group.

Discussion

Both groups participated in a broad range of places within public space and perceived many ETs as relevant. This suggests that there is not a straightforward decline in participation among people living with dementia, it is a more nuanced and complex situation. The findings recognize that there are group-level differences indicating lower participation among the dementia group. However this does not suggest that there is a decline in participation for all individuals living with dementia or that dementia alone is a cause for such changes in participation. Consequently, it is vital to question the assumption that the world outside the home of the person with dementia, in both a physical and virtual sense, inevitably must shrink in a linear way (Duggan et al., 2008). For maintenance of activities, it is important for occupational therapists to be aware of those four places that the dementia group reported a significantly lower participation (mall, supermarket; bank, post office; doctor's surgery; forest, mountain, lake, seaside) and the one place associated with significantly higher participation (day care) (see Figure 1).

While the Government of Canada (2017) is in the process of developing and implementing a national dementia strategy following the passing of Bill C-233, *An Act respecting a national strategy for Alzheimer's disease and other dementias*, the study's findings do align with global dementia policies. For instance, the finding that there was significantly lower participation for people with dementia in places for purchasing, administration and self-care (mall, supermarket and bank or post office) corroborates with the United States of America's *National Plan to Address Alzheimer's Disease: 2017 Update* (U.S. Department of Health and Human Services, 2017) which proposes a need for dementia-friendly communities to support the ability of people living with dementia to remain in their community and to participate in activities in places such as the store and bank. Research indicates that technology may serve as a facilitator or barrier to the everyday lives of people living with cognitive impairments (Lindqvist et al., 2018). For this reason it is important to consider the double-edged role of ETs in the development of dementia-friendly communities, and more research is needed to explore the mechanisms that are in play when it comes to the

role of ETs for people with dementia's participation in public space. There are broader implications for occupational therapists in supporting people and helping to adapt specific places, as more usable activities and services may support the caregiver as the person with dementia lives more independently, in addition to facilitating accessibility for all people, including those living with various disabilities (UN, 2006) and older adults, as outlined by the WHO's *Age-Friendly Cities: A Guide* (2007).

Earlier research has revealed descending participation in leisure and out-ofhome activities as mild cognitive impairment develops into dementia, yet little is known about participation in places and activities within public space for people with and without dementia (Hedman, Nygård, & Kottorp, 2017). This study provides insight into changes in participation which was particularly apparent among those places abandoned in domain D (Places of recreation and physical activity) e.g. sports facility; forest, mountain, lake, seaside; cottage, summer house; transportation centre. For both groups, the transportation centre illustrates higher participation in the past but there was abandonment in the present. Commonalities between the groups indicate that diagnosis is not the only factor influencing abandonment but rather a number of other intrinsic and extrinsic interacting factors, to which occupational therapists may need to be aware of e.g. functional health issues and levels of physical mobility, coping strategies used for transportation, and in particular, driving and access to support from others which differed significantly between the groups (see Table 1) (Provencher, Desrosiers, Demers, & Carmichael, 2016).

While the findings demonstrate a count of the total participation in different types of places and those places associated with stability or change, the findings do not reveal the way in which groups of people living with and without dementia assign value to participation in a higher or lower total number of places, or indeed the value of participation in particular types of places. Earlier research does however underline the perceived significance which people with dementia assign to participating in their community and more specifically, the perceived importance of the neighbourhood (Brorsson, 2013; Ward, Clark, Campbell, & Keady, 2017). The findings show that the neighbourhood was associated with higher participation for people with and without dementia, across time. Similarly the building for worship was retained by both groups, across their reports of past and present participation which may be attributed to the perception of participation in this type of place as a life-long occupation associated with one's spirituality, personal and collective cultural identity (Kielhofner, 2008). Further investigations are required to critically consider the veneration of specific activities and places at the expense of others, in order to enable occupational therapists to facilitate participation according to elected or imposed patterns of abandonment and retention in specific places within public space (Njelesani, Gibson, Nixon, Cameron, & Polatajko, 2013).

Even if the correlations between participation in total number of places visited and the number of relevant i) public space ETs, and ii) portable ETs were not significant, the association tended to be stronger for the dementia group between participation in total number of places visited and the person measure of ability to use ETs (see Table 2). Earlier research demonstrates that access and use of ETs may be influenced by a variety of factors beyond diagnosis (Kottorp et al., 2016). Numerous other factors may contribute to a decline in participation, including changes in memory and way-finding abilities which may underline the significance of familiar, local neighbourhood environments and social participation (Keady et al., 2012; Kullberg & Odzakovic, 2018). Research has shown that people with dementia value and seek to maintain participation in familiar places within public space, which in turn may necessitate adaptive behaviours in order to use ETs, such as shopping in grocery stores (Brorsson, 2013). An understanding about the participatory barriers to use of ETs within public space is crucial to occupational therapy's conception of the interrelationship between a person's abilities, the demands of preferred occupations, and the context of the environment (Smith, 2017). Increased knowledge about stability and change in participation in places visited within public space and how this relates to the relevance of ETs used within public space, among people with and without dementia, may assist occupational therapists to tailor interventions accordingly. Such occupational therapy interventions may benefit from recognition of the role of ETs as a facilitating or disabling mechanism to everyday life (Lindqvist et al., 2018).

Limitations and Future Research

Recognition of the specificity of a Swedish, predominantly urban and suburban sample, may be of significance in terms of the generalizability of the findings. Sweden has among the highest technology adoption rates for over 65 year olds in the world and future research may benefit from consideration of different contexts as daily life activities, use and attitudes towards ETs are strongly influenced by values and habits within the context and culture (OECD, 2012; Taylor, 2017; Woetzel et al., 2018).

This exploratory study used a small sample size however the two groups of people with and without dementia satisfied the power calculations for the purposes of the study aim (Margot-Cattin et al., 2019). One participant with dementia was an outlier according to a MoCA score of four, however this participant was retained due to potential language barriers within the cognitive screening process as Swedish was not the native language. There was no significant change in findings when this participant was excluded from preliminary analyses. This suggests that increased attention should be afforded to issues of cultural sensitivity and literacy in future research (O'Driscoll & Shaikh, 2017).

The reliance on self-report, especially with people living with dementia may be considered a limitation. Functional assessments typically rely upon proxy reports from caregivers or professional raters and there is evidence that proxy reports may differ, or not reflect the views of the person with dementia (Edelman, Fulton, Kuhn, & Chang, 2005; O'Rourke, Fraser, & Duggleby, 2015). However, objective measurements of activity, for example using observation, may be criticized for a disregard of the subjective experiences of participation which this study addresses through foregrounding the lived experience of participation, as perceived by people with and without dementia (Whalley Hammell, 2009). There is a precedent for the sensitivity of the ETUQ (short version) to detect changes according to self-report of ET use among older adults with and without cognitive impairment (Malinowsky et al., 2017).

Conclusion

Occupational therapists have a role in enabling participation among older people living with and without dementia. Participation is however complex (Canadian Association of Occupational Therapists [CAOT], 2011; Turcotte et al., 2018). The complexity of participation is underlined through the findings that show on a group-level there was lower participation in total number of places visited within public space by the dementia group. However, this is not indicative of shrinking participation for all individuals based on their diagnosis of dementia alone. In fact, the findings demonstrate a degree of commonality according to the stability of higher participation in neighbourhoods and changes according to decreased participation in places for recreation and physical activity, for both groups across time. This study forms part of an emerging evidence-base that emphasizes a need to address the complexity and range of participation within an increasingly technological society and among different communities and contexts, specifically older adults living with or without dementia. Such knowledge may support occupational therapists in research and practice to consider the match between assessments and interventions within various cultural, personal, temporal and also virtual contexts (AOTA, 2014).

Key Messages

- To enable equitable participation as a human right, it is important for occupational therapists to explore, and attend to participation which acknowledges interactions with ETs in places within public space.
- The findings suggest that there may be a role for occupational therapists in facilitating participation for older people living with and without dementia who were both shown to participate in places within public space, in particular the stability of the neighbourhood versus changes in places for recreation and physical activity, including transportation.
- Occupational therapists may contribute to participation within age and dementiafriendly communities through increased awareness of the types of places older adults with no known cognitive impairment retain (hairdresser and mall, supermarket) and those places retained by people with dementia (day care and buildings for worship).

Acknowledgments

We express gratitude to the older adults that gave time to this study, to the occupational therapists that facilitated data collection, and to the funders – the Swedish Council for Health, Working Life and Welfare (FORTE) and the H2020 Marie Skłodowska Curie Actions – Innovative Training Networks, H2020-MSCA-ITN-2015, under grant agreement number 676265.

- Altman, D. G., & Bland. J. M. (2009). Parametric v non-parametric methods for data analysis. *British Medical Journal*, *338*, a3167. <u>http://doi.org/10.1136/bmj.a3167</u>
- Alzheimer's Disease International & BUPA. (2013). Dementia in the Americas: current and future cost and prevalence of Alzheimer's disease and other dementias. London: ADI/BUPA.
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: cluster and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1-S48. <u>http://doi.org/10.5014/ajot.2014.682006</u>
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders : DSM-5*. (5th ed.). Arlington, VA: American Psychiatric Association.
- Argyle, E., Dening, T., & Bartlett, P. (2017). Space, the final frontier: outdoor access for people living with dementia. *Aging & Mental Health*, *21*, 1005-1006. http://doi.org/10.1080/13607863.2016.1222351
- Bond, T. G., & Fox, C. M. (Eds.). (2007). *Applying the Rasch model: fundamental measurement in the human sciences* (2nd ed.). Mahwah, NJ: Erlbaum.
- Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. (Report). *Sociology of Health & Illness, 32*, 272-287. http://doi.org/10.1111/j.1467-9566.2009.01203.x
- Brorsson, A. (2013). Access to everyday activities in public space, views of people with dementia. (Doctoral thesis, Karolinska Institutet, Stockholm). Retrieved June 20, 2018, from https://openarchive.ki.se/xmlui/handle/10616/41677

- Burton, E., & Mitchell, L. (2006). *Inclusive urban design: streets for life*. Oxford, UK: Architectural Press.
- Canadian Association of Occupational Therapists. (2011, revised). CAOT position statement: *occupational therapy and older adults (2011)*. Retrieved October 4, 2018, from https://www.caot.ca/document/3708/O%20-

% 200T% 20 and% 20 Older% 20 Adults.pdf

- Carson, N., Leach, L., & Murphy, K. J. (2017), A re-examination of Montreal Cognitive Assessment (MoCA) cutoff scores. *International Journal of Geriatric Psychiatry*, 33, 379-388. https://doi.org/10.1002/gps.4756
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum.
- Dashner, J., Hollingsworth, H., Gross, J., & Gray, D. B. (2017). Environmental determinants of quality of participation in healthcare settings among people with impairments and limitations. In A. H. Eide, S. Josephsson, & K. Vik (Eds.), *Participation in Health and Welfare Services. Professional Concepts and Lived Experience* (pp. 41-52). New York, NY: Routledge.
- Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of early dementia on outdoor life: A 'shrinking world'?. *Dementia*, 7, 191-204. http://doi.org/10.1177/1471301208091158
- Edelman, P., Fulton, B. R., Kuhn, D., & Chang, C. (2005). A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff, and observers. *The Gerontologist*, 45, 27-36. https://doi.org.proxy.kib.ki.se/10.1093/geront/45.suppl_1.27

Emiliani, P. L., (2006). Assistive technology (AT) versus mainstream technology (MST): The research perspective. *Technology and Disability*, 18, 19-29. http://doi.org/10.1177/0308022618776879

European Foundations' Initiative on Dementia (EFID). (2016). *Mapping dementia-friendly communities across Europe*. Brussels: EFID.

Government of Canada. (2017). *National Strategy for Alzheimer's disease and other dementias act*. Retrieved June 15, 2018, from http://lawslois.justice.gc.ca/eng/AnnualStatutes/2017 19/page-1.html.

Greenfield, A. (2017). Radical technologies: the design of everyday life. London, UK: Verso.

- Harada, K., Lee, S., Park, H., Shimada, H., Makizako, H., Doi, T., ... Suzuki, T. (2016).
 Going outdoors and cognitive function among community-dwelling older adults:
 moderating role of physical function. *Geriatrics & Gerontology International*, 16, 65-73. <u>http://doi.org/10.1111/ggi.12437</u>
- Hedman, A., Nygård, L., & Kottorp, A. (2017). Everyday technology use related to activity involvement among people in cognitive decline. *The American Journal of Occupational Therapy*, *71*(5), 7105190040p1-7105190040p8. http://doi: 10.5014/ajot.2017.027003
- IBM Corp. (2016). IBM SPSS Statistics for Windows (Version 24.0) [Computer Software]. Armonk, NY: IBM Corp. Retrieved from <u>https://www.ibm.com/analytics/data-science/predictive-analytics/spss-statistical-software</u>
- Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., ... Elvish, R. (2012).
 Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*, 22, 150-163. <u>http://doi.org/</u>10.1017/S0959259811000268

- Kielhofner, G. (Ed.) (2008). *Model of human occupation: theory and application*. (4th ed.).Philadelphia, PA: Lippincott Williams & Wilkins.
- Kottorp, A., Nygård, L., Hedman, A., Öhman, A., Malinowsky, C., Rosenberg, L., ... Ryd, C. (2016). Access to and use of everyday technology among older people: An occupational justice issue but for whom?. *Journal of Occupational Science*, 23(3), 382-388. https://doi.org/10.1080/14427591.2016.1151457
- Kullberg, A., & Odazakovic, E. (2018). Walking interviews as a research method with people living with dementia in their local community. In J. Keady, L. Hydén, A. Johnson, & C. Swarbrick (Eds.), *Social research methods in dementia studies*. *Inclusion and innovation* (pp. 23-37). New York, NY: Routledge.
- Kumar, K., & Makarova, E. (2008). The portable home: The domestication of public space. Sociological Theory, 26, 324-343. https://doi.org/10.1111/j.1467-9558.2008.00332.x
- Linacre, J.M. (2017). *Winsteps*® (Version 3.93.0) [Computer Software]. Beaverton, Oregon: Winsteps.com. Retrieved from http://www.winsteps.com/
- Lindqvist, E., PerssonVasiliou, A., Hwang, A. S., Mihailidis, A., Astelle, A., & Sixsmith, A. (2018). The contrasting role of technology as both supportive and hindering in the everyday lives of people with mild cognitive deficits: a focus group study. *BMC Geriatrics, 18*, 1-14. http://doi.org./10.1186/s12877-018-0879-z
- Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., & Damant, J. (2017).
 Technology-based tools and services for people with dementia and carers:
 mapping technology onto the dementia care pathway. *Dementia*, 0, 1-7.
 http://doi.org/10.1177/1471301217691617
- Malinowsky, C., Kottorp, A., Wallin, A., Nordlund, A., Björklund, E., Melin, I., ... Nygård, L. (2017). Differences in the use of everyday technology among persons with

MCI, SCI and older adults without known cognitive impairment. *International Psychogeriatrics*, *29*, 1193-1200. <u>http://doi.org/10.1017/S1041610217000643</u>

- Malinowsky, C., Almkvist, O., Kottorp, A., & Nygård, L. (2010). Ability to manage everyday technology: a comparison of persons with dementia or mild cognitive impairment and older adults without cognitive impairment. *Disability and Rehabilitation: Assistive Technology*, *5*, 462-469. http://doi.org/10.3109/17483107.2010.496098
- 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. *The American Journal of Occupational Therapy*, *73*, 7301205030p1-7301205030p10. https://doi.org/10.5014/ajot.2019.027144
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., ... Chertkow, H., (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, *53*, 695–699. http://doi.org/10.1111/j.1532-5415.2005.53221.x
- Njelesani, J., Gibson, B. E., Nixon, S., Cameron, D., & Polatajko, H. J. (2013). Towards a critical occupational approach to research. *International Journal of Qualitative Methods*, *12*, 207-220. <u>https://doi.org/10.1177/160940691301200109</u>
- Nygård, L., Rosenberg, L., & Kottorp, A. (2016). Users' manual: everyday technology use questionnaire (ETUQ) everyday technology in activities at home and in society.
 Department of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Stockholm.
- Nygård, L., & Kottorp, A. (2014). Engagement in instrumental activities of daily living, social activities, and use of everyday technology in older adults with and without

cognitive impairment. *British Journal of Occupational Therapy*, *77*, 565–573. https://doi.org/10.4276/030802214X14151078348512

- Nygård, L., Pantzar, M., Uppgard, B., & Kottorp, A. (2012). Detection of activity limitations in older adults with MCI or Alzheimer's disease through evaluation of perceived difficulty in use of everyday technology: a replication study. *Aging and Mental Health, 16*, 361–371. https://doi.org/10.1080/13607863.2011.605055
- O'Driscoll, C., & Shaikh, M. (2017). Cross-cultural applicability of the Montreal Cognitive Assessment (MoCA): a systematic review. *Journal of Alzheimer's disease, 58*, 789-801. http://dx.doi.org/10.3233/JAD-161042
- OECD. (2012). *OECD Internet economy outlook 2012*. OECD Publishing. Retrieved June 15, 2018, from http://dx.doi.org/10.1787/9789264086463-en
- O'Rourke, H. M., Fraser, K. D., & Duggleby, W. (2015). Does the quality of life construct as illustrated in quantitative measurement tools reflect the perspective of people with dementia?. *Journal of Advanced Nursing*, *71*, 1812-24.
 <u>https://doi.org/10.1111/jan.12667</u>
- Patomella, A., Kottorp, A., Ferreira, M., Rosenberg, L., Uppgard, B., & Nygård, L. (2017). Everyday technology use among older adults in Sweden and Portugal. *Scandinavian Journal of Occupational Therapy*, 1-10. https://doi.org/10.1080/11038128.2017.1311940
- Peacock, J. L., & Peacock, P. J. (2011). Oxford handbook of medical statistics. Oxford: Oxford University Press.
- Powers, B. A., & T. R., Knapp. (Eds.). (2010). *Dictionary of nursing theory and research* (4th ed.). New York, NY: Springer Publishing Company.
- Provencher, V., Desrosiers, J., Demers, L., & Carmichael, P. (2016). Optimizing social participation in community-dwelling older adults through the use of behavioral

coping strategies. *Disability and Rehabilitation*, *38*, 972-978. http://doi.org/10.3109/09638288.2015.1070297

- Smith, R. O., (2017). Technology and occupation: past, present, and the next 100 years of theory and practice. *The American Journal of Occupational Therapy*, 71, 1-15. http://doi.org/10.5014/ajot.2017.716003
- Taylor, R., (2017). *Kielhofner's Model of Human Occupation* (5th ed.). Philadelphia, PA:Wolters Kluwer.
- Turcotte, P., Carrier, A., Roy, V., & Levasseur, M., (2018). Occupational therapists' contributions to fostering older adults' social participation: A scoping review. *British Journal of Occupational Therapy*, 81, 427-449. http://doi.org/ 10.1177/0308022617752067

United Nations. (2006). Convention on the rights of persons with disabilities. Vienna: Author.

- U.S. Department of Health and Human Services. (2017). *National plan to address Alzheimer's disease: 2017 update.* Washington, DC: U.S. Department of Health and Human Services.
- Walsh, R., Drasga, R., Lee, J., Leggett, C., Shapnick, H., & Kottorp, A. (2018). Activity engagement and everyday technology use among older adults in an urban area. *American Journal of Occupational Therapy*, 72, 1-7. http://doi.org/10.5014/ajot.2018.031443

Ward, R., Clark. A., Campbell, S., & Keady, J. (2017). The lived neighbourhood: understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, 1-14. http://doi.org/10.1017/S1041610217000631 Whalley Hammell, K. (2017). Opportunities for well-being: The right to occupational engagement. *Canadian Journal of Occupational Therapy*, 84, 209-222. http://doi.org/10.1177/0008417417734831

Whalley Hammell, K. (2009). Self-care, productivity, and leisure, or dimensions of occupational experience? Rethinking occupational "categories". *Canadian Journal of Occupational Therapy*, 76, 107-114. https://doi.org.proxy.kib.ki.se/10.1177/000841740907600208

- Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H. . . Zetterberg, H. (2016). Defeating Alzheimer's disease and other dementias: a priority for European science and society. *Lancet Neurology*, 15, 455–532. http://doi.org/10.1016/S1474-4422(16)00062-4
- Woetzel, J., Remes, J., Boland, B., Lv, K., Sinha, S., Strube, G. . . von der Tann, V. (2018).
 Smart cities: digital solutions for a more livable future. McKinsey Global Institute. [online report]. Retrieved June 21, 2018, from https://www.mckinsey.com/industries/capital-projects-and-infrastructure/ourinsights/smart-cities-digital-solutions-for-a-more-livable-future
- World Health Organization. (2012). *Dementia: a public health priority*. Geneva: World Health Organization.
- World Health Organization. (2007). *Age-friendly cities: a guide*. Geneva: World Health Organization.

Demographic characteristic		Control group (n = 34)	Dementia group (n = 35)	Comparison test with Significance value (p)
Age	Mean (SD)	76.68 (8.03)	74.40 (7.19)	t-test
	Range	62 - 96	59 - 90	.219
Sex	n (%)			Chi ²
	Female	21 (61.76)	22 (62.86)	Test
	Male	13 (38.24)	13 (13.14)	.925
MoCA ^a	Median (IQR)	27.00 (3)	19.00 (9)	Mann Whitney U
				test
	Range	21 - 29	4 - 30	<.001
Years of education	Mean (SD)	12.37 (3.34)	11.13 (3.29)	<i>t</i> -test
	Range	6 – 19	6 - 18	.125
Living arrangement	n (%)			Chi ²
8 8	Cohabit	13 (38.24)	16 (45.71)	Test
	Live alone	21 (61.77)	19 (54.29)	.529
Place of residence ^b	n (%)	()		Chi ²
	Urban	16 (47.06)	14 (41.18)	Test
	Rural	18 (52.94)	20 (58.82)	.625
Years of residence	Median (IQR)	17.00 (19)	20.00 (33)	Mann Whitney U
rears of residence	integration (1Q10)	17.00 (17)	20.00 (00)	test
	Range	1 - 60	0 - 57	.135
Driving license	n (%)	1 00	0 01	Chi ²
briving needse	Driving license	28 (82.35)	23 (65.71)	Test
	No driving license	6 (17.65)	12 (34.29)	.116
Driving a car	n (%)	0 (17.05)	12 (34.27)	Fisher's exact
Driving a car	Driver	19 (55.88)	4 (11.43)	Test
	Non-driver	15 (44.12)	31 (88.57)	<.001
Transportation		13 (44.12)	51 (00.57)	Fisher's exact
Service	n (%) User	4 (11.76)	26 (74.29)	Test
Service	Non-user	30 (88.24)	9 (25.71)	<.001
Employed		30 (88.24)	9 (23.71)	Fisher's exact
Employed	n (%)	2(0,0)	0 (0 00)	
	Employed	3 (8.82)	0(0.00)	Test
	Unemployed	31 (91.18)	34 (97.14)	.175
	Volunteer	0 (0.00)	1 (2.86)	T'1 1
Support from others ^c	n (%)	7 (21.21)	21 (0 (00)	Fisher's exact
	Support	7 (21.21)	31 (96.88)	Test
	No support	26 (78.79)	1 (3.13)	<.001
Home help	n (%)		1.1.(10.00)	Chi ²
	Home help	8 (23.53)	14 (40.00)	Test
	No home help	26 (76.47)	21 (60.00)	.142
Functional	n (%)			Fisher's exact
health issue ^d	Functional health issue	33 (97.06)	31 (96.88)	Test
	No Functional health	1 (2.94)	1 (3.13)	.999
	issue			

Table 1. Demographic Characteristics of the Control and Dementia Groups

Note.

IQR: interquartile range; M: mean; MoCA: Montreal Cognitive Assessment (potential score range 0–30; higher scores indicate higher cognitive status); SD: standard deviation. M and SD are presented for normally distributed data and median and IQR are presented for skewed data.

^a1 participant with dementia is an outlier according to MoCA score of 4 but see Data Analysis section for inclusion rationale.

^bMissing data (1 participant with dementia).

^cMissing data (1 participant without dementia and 3 participants with dementia).

^dMissing data (3 participants with dementia).

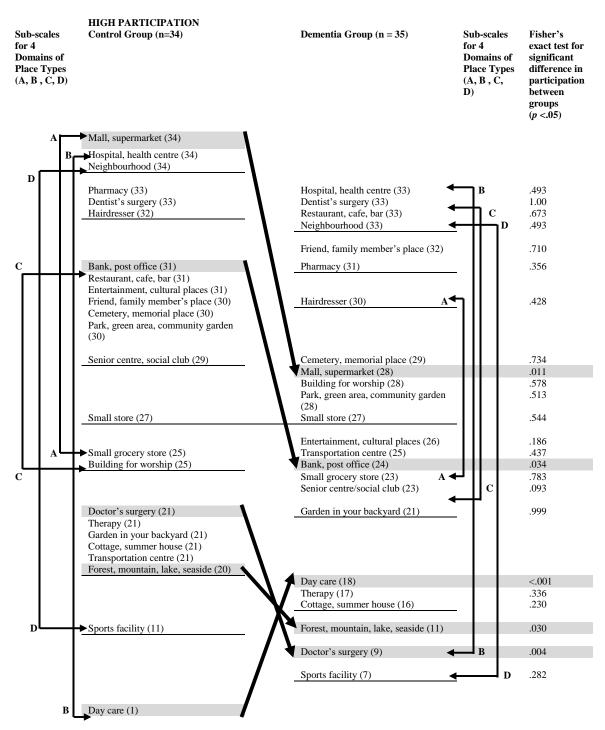
Table 2. Descriptive Statistical Findings of Participation in Total Number of Places Visited within Public Space (ACT-OUT), Number of Relevant Public Space and Portable ETs, and the Person Measure of Ability to Use ETs (ETUQ), among the Control and Dementia Groups

		Control Group $(n = 34)$	Dementia Group $(n = 35)$	Mann-Whitney U-test of Significant Difference between Groups (p)
Participation in Total Number of Places Visited (max. 24)	Median (IQR)	19.00 (3)	18.00 (4)	<i>p</i> <.05
	Min-Max	13 – 23	2 - 21	
	Mean Rank	40.00	30.14	
Number of Relevant Public Space ETs (max. 16)	Median (IQR)	9.00 (5)	8.00 (4)	<i>p</i> <.05
	Min-Max	4 – 16	3 - 14	
	Mean Rank	40.96	29.21	
Number of Relevant Portable ETs (max. 33)	Median (IQR)	10.00 (5)	7.00 (7)	<i>p</i> <.05
	Min-Max	2-19	1 - 15	
	Mean Rank	40.90	29.27	
Person Measure of Ability to Use ETs	Median (IQR)	60.71 (7.38)	53.24 (7.08)	<i>p</i> <.001
	Min-Max	53.88 - 83.61	42.44 -65.75	
	Mean Rank	48.82	21.57	
Spearman's Rank Correlatic	on Coefficient			
Participation in Total Number of Places Visited	Significance	.078	.201	
& Number of Relevant Public Space ETs	Correlation Coefficient	.306	.222	
Participation in Total Number of Places Visited & Number of Relevant Portable ETs	Significance	.408	.054	-
	Correlation Coefficient	.147	.328	
Participation in Total Number of Places Visited	Significance	.213	.001	-
& Person Measure of Ability to Use ETs	Correlation Coefficient	.219	.551	

Figure 1. Hierarchies of Counts of Participation in Places Visited within Public Space, among the Control and Dementia Groups (ACT-OUT)

Figure 1. Hierarchies of Counts of Participation in Places Visited within Public Space, among

the Control and Dementia Groups (ACT-OUT)



LOW PARTICIPATION

4 Domains of Place Types	Place Name	Control Group Past/ Present Participation (n=34)	Places Abandoned	Dementia Group Past/ Present Participation (n=35)	Place Name	4 Domains of Place Types				
D	Sports facility	26/11 (-15)	Î	34/11 (-23)	Forest, mountain, lake, sea	D				
D	Forest, mountain, lake, sea	33/20 (-13)		27/7 (-20)	Sports facility	D				
D	Transportation center	34/21 (-13)		30/16 (-14)	Cottage, summer house					
D	Cottage, summer house	32/21 (-11)		34/24 (-10)	Bank, post office					
В	Therapy	27/21 (-6)		34/25 (-9)	Transportation center					
D	Garden in your backyard	27/21 (-6)		34/26 (-8)	Entertainment, cultural places	С				
С	Friend, family member's place	34/30 (-4)		35/28 (-7)	Mall, supermarket	А				
С	Entertainment, cultural places	34/31 (-3)		24/17 (-7)	Therapy	В				
А	Small grocery store	27/25 (-2)		28/21 (-7)	Garden in your backyard	D				
А	Bank, post office	33/31 (-2)		33/28 (-5)	Park, green area	D				
В	Doctor's office	23/21 (-2)		27/23 (-4)	Small grocery store	А				
С	Senior center, social club	31/29 (-2)		35/31 (-4)	Pharmacy	А				
С	Building for worship	27/25 (-2)		30/27 (-3)	Small store	А				
D	Park, green area	32/30 (-2)		33/30 (-3)	Hairdresser	А				
А	Pharmacy	34/33 (-1)		35/32 (-3)	Friend, family member's place	С				
С	Restaurant, cafe, bar	32/31 (-1)		26/23 (-3)	Senior center, social club	С				
С	Cemetery, memorial place	31/30 (-1)		11/9 (-2)	Doctor's office	В				
А	Small store	27/27 (0)		35/33 (-2)	Dentist's office	В				
В	Hospital, health center	34/34 (0)		31/29 (-2)	Cemetery, memorial place	С				
В	Dentist's office	33/33 (0)		34/33 (-1)	Hospital, health center	В				
В	Day care	1/1 (0)		34/33 (-1)	Restaurant, cafe, bar					
D	Neighborhood	34/34 (0)		34/33 (-1)	Neighborhood	D				
А	Mall, supermarket	32/34 (2)		28/28 (0)	Building for worship	С				
А	Hairdresser	28/32 (4)	+	15/18 (3)	Day care					
Places Retained										

Figure 2. Hierarchies of Counts of Differences between Past and Present Participation in Places Visited within Public Space, Indicating

Places Abandoned (Lowest Count) or Retained (Highest Count) among the Control and Dementia Groups (ACT-OUT)