



SCIREA Journal of Sociology

<http://www.scirea.org/journal/Sociology>

September 25, 2020

Volume 4, Issue 4, August 2020

Perception of people living with dementia and entrepreneurs on dementia-friendly leisure activities in society

Olaf Timmermans^{1,2,3,*}, Iris van de Velde¹, Mathilde Matthijsse⁴

¹ Professorship Healthy Region, HZ University of Applied Sciences, Vlissingen, The Netherlands.

² University Antwerp, Centre for Research and Innovation in Care, Antwerp, Belgium

³ Academic Workplace Elderly Care Zeeland, Vlissingen, The Netherlands.

⁴ ZorgSaam Health Care. Terneuzen, The Netherlands.

*Corresponding author: olaf.timmermans@hz.nl (Olaf Timmermans)

Abstract

To maximize quality of life for people living with Dementia a continuous participation in society is indispensable. Within the CASCADE (Community Areas of Sustainable Care And Dementia Excellence in Europe) project we developed a strengths-based approach to maximise independence and participation of people living with dementia (PLWD) in the community. Important aspects of the continuous participation are participating in meaningful leisure activities in the way people always did. In a qualitative design using the dialogue tables technique we explored the experiences and perspectives of PLWD (N=12) and entrepreneurs (n=10) on dementia-friendly leisure. Results of the study show PLWD have the need for leisure activities and dementia-friendly holidays and entrepreneurs are interested in making their service more dementia-friendly, however both groups need more support to make this a reality. The PLWD have difficulty finding appropriate activities and information about dementia-friendly holidays,

and the entrepreneurs need more direction about how to make their business more dementia-friendly. PLWD report that the attitude of the community towards PLWD is an important barrier to enjoying leisure and holiday activities. Therefore promoting knowledge of and awareness about dementia within the wider community is an important step towards more inclusive communities where PLWD can participate fully and live their life to the full. We conclude awareness, support and understanding for PLWD and their behavior is needed in the community to make it possible for PLWD to enjoy participating in leisure activities. Also, with small adaptations, a number of contemporary leisure activities can be tailored dementia-friendly.

Keywords: people living with dementia, participation society, qualitative design, dialogue tables technique

Introduction

CASCADE (Community Areas of Sustainable Care And Dementia Excellence in Europe) is an European project which promotes a strengths based approach to holistic person-centred care to maximise independence and quality of life for PLWD in the community based on the principles of positive health and the values of PLWD (Interreg 2 Seas, 2014). This is in line with the WHO framework for people-centred and integrated health services, which expresses a salutogenic paradigm of health and stresses that a person's continued participation in the community is an important prerequisite for maintaining quality of life (World Health Organisation, 2015). Older people themselves also stress that engaging in leisure, physical, cultural and social activities are vital to maintaining quality of life. The WHO framework encourages close collaboration between health and other sectors (e.g. leisure sector) to improve population health. Embarrassment often leads to PLWD withdrawing from community life, and they often find themselves lost in the healthcare sector. CASCADE aims to enable the PLWD to remain in their own community for as long as possible. Involvement in everyday activities helps people with dementia to feel independent and responsible and provides a sense of continuity. This calls for targeted care-delivery, dementia-friendly leisure activities and services. The research question for this study was: What are the experiences and perspectives on dementia-friendly leisure activities in society, according to PLWD and entrepreneurs in two sites in Belgium?

Background

Multiple surveys show that leisure activities have a positive impact on cognitive function of people with dementia, e.g. slowing down deterioration and limiting increase of care intervention (Connell et.al. 2017; Karssemeijer et.al. 2017; Lautenschlager 2012). Involvement in everyday activities helps people with dementia to feel independent and responsible and provides a sense of continuity (Fernández-Mayoralas et.al. 2015). Leisure also helps to maintain identity in early-stage dementia, and to remain engaged in life (Innes et.al. 2016). Leisure and enjoyment can provide an escape from negative emotions, distract from distress and counter social isolation (Fernández-Mayoralas et.al. 2015; DiLauro et.al. 2017; Genoe 2013; Genoe & Dupuis 2011; Innes et.al. 2011). According to older people themselves, engaging in leisure, physical, cultural and social activities is vital for maintaining quality of life (Genoe 2013, Genoe & Dupuis 2014). However, these activities can bring many challenges (Wang et al., 2012)). Going on holiday is a leisure activity that normally provides relaxation, but PLWD might instead worry about safety and whether the accommodation and activities at the destination are suitable for the person with dementia (Innes et al., 2016b). In addition, the person with dementia might experience stress in an unfamiliar environment, leading to agitated behaviour or distress. This behaviour often leads to misunderstanding, lack of awareness and stigma, causing a negative view of dementia in society (Innes et al., 2016a). In turn, this results in PLWD feeling unwelcome (Connell et.al. 2017), embarrassed, frustrated and grieved, causing them to stay safe at home more and more (Genoe 2013). This trend could be reversed if leisure entrepreneurs adapt their service provision, so that the activities become more dementia-friendly (Connell et.al. 2017, Innes et.al. 2016, World Health Organisation 2012). Currently, there are limited holiday options available that are adapted to the life situation of PLWD (Innes et.al. 2016). Moreover, PLWD say it is difficult to find information on dementia-friendly leisure services.

Methods

Participants

Using dialogue tables the experiences and perspectives of PLWD and entrepreneurs on dementia-friendly leisure were explored. The participants were invited by professionals from a residential

care centre on a personal basis. The participants were known to have an interest in this topic. A total of four dialogue tables were held; one with entrepreneurs and one with PLWD in each of the two locations, namely Kortrijk and Heist-op-den-Berg. Ten entrepreneurs and 12 PLWD (two people with dementia and ten family caregivers) were involved in these sessions. All four dialogue tables were facilitated by the two researchers and lasted between one and a half and two hours. The entrepreneurs were professionals from different organisations in Belgium who were interested in providing dementia-friendly leisure activities. The professionals worked in tourism; elderly services and elderly care; social well-being in health and prevention; a local service centre providing support for homecare; a centre for culture and museum; a city council and a dementia expertise centre. The two people with dementia lived in a residential care home. Of the ten informal caregivers two were husbands, two were daughters, one was the son and five were wives of people diagnosed with dementia.

The dialogue table method

In the dialogue table method four steps are to be used to collect information: 1) in the introduction, participants introduced themselves and explained why they think it's important to organise and participate in leisure activities; 2) after this, they shared experiences about organising and undertaking leisure activities; 3) in the next phase they could share their dreams about what they really desired around leisure activities for PLWD if anything was possible; 4) and finally participants talked about what they can do tomorrow in their own context to get this dream a little bit closer.

There are five rules for a good dialogue: 1) listen with respect; 2) do not judge; 3) ask for clarification; 4) welcome new perspectives; 5) speak with passion from your own personal view (Witte & van de Weg, 2016).

Analysis

The dialogue tables were recorded and typed out as transcripts. The transcripts were read independently by the two researchers and were fragmented and labelled using the grounded theory approach (Glaser and Strauss, 2006). After this process the researchers compared the labels and themes, discussed their findings, and cross checked these in the original data until they reached a consensus on the different themes.

Ethics

Ethical approval was provided by the commission of ethics of Antwerp University, Belgium. An informed consent form, with information about the aim and design of the study was provided to the participants. Participation in this study was voluntary, confidential and anonymous and participants were reassured that they would not be identifiable in the transcripts, the audiotapes and any reports or published work.

Results

Results entrepreneurs

A total of four main themes were identified during the dialogue tables with the entrepreneurs: 1) how society views people with dementia, 2) importance of activities, 3) providing an accessible and suitable offer and 4) chances/opportunities in developing and providing dementia-friendly activities.

Theme how society views people with dementia

The theme ‘how society views people with dementia’ was built up from five subthemes: 1) stigma, 2) impact on family, 3) dementia-friendly city, 4) knowledge transfer and 5) fear. In reducing stigma it was identified that leisure activities for PLWD are important for continued participation in society, but that dementia currently doesn’t have its own place in society. In other words, PLWD shouldn’t be stigmatised, it is important to focus on the person with dementia, not on the dementia and the limitations this entails: every elderly person should have access to leisure activities. Another important consideration is that dementia has an impact on the whole family, therefore a dementia-friendly offer can help not only the person with dementia, but also the informal caregivers and the rest of the family. To achieve this, a greater understanding from society is crucial.

Several entrepreneurs were working on the creation of a dementia-friendly city. There is a lot of good-will, however, they noted that the first priority is to focus on the physical accessibility of public spaces. For PLWD, often other aspects of accessibility, such as a welcoming atmosphere, an appropriate code of conduct and a tranquil environment are more important. The entrepreneurs present thought a dementia-friendly environment could be created by first providing knowledge

transfer to staff in all public areas, for example in sports centres, supermarkets, cafes, museums and public transport. In the tourism sector there are opportunities in providing training for guides, staff at B&Bs and hotels, and in the hospitality industry.

From the entrepreneurs there was also some reluctance to welcome PLWD on their premises, as they fear the negative impact on other customers. At the same time, entrepreneurs stressed not every business needs to take steps to become more dementia-friendly, as some businesses do not target this audience.

Theme importance of activities

This theme was subdivided into two subthemes, namely added value and completing life.

Activities for PLWD are important as they provide added value to life. These activities could be a continuation of the life they used to lead, for example, a yearly return to the south of France with the caravan. Dementia-friendly walks or a reminiscence suitcase could provide a trigger for PLWD to remember activities from their past that could make them feel good and could stimulate interaction with their informal caregiver. This can result in spontaneous and emotional moments shared between the participants. The experience of the carers and healthcare professionals was that while the memories of an actual activity tend to fade fairly quickly the feelings generated by a pleasurable activity last for quite some time.

Completing life is an important aspect of travel and leisure activities. These activities could be a dream come true for the PLWD and a way to complete life, or finish things on the bucket-list, and could in that way be of great spiritual importance.

Theme providing an accessible and suitable offer

This theme was subdivided in seven subthemes: 1) offer for PLWD, 2) supporting informal caregivers, 3) accessibility, 4) customisation, 5) obstacles 6) embarrassment and 7) suitable label.

The current offer for PLWD includes a variety of services, e.g. dementia-friendly walks, visiting farms and picking fruit in the garden and reminiscence suitcases to enable contact between visitors to a museum. There are also residential care centres that organise holidays. The entrepreneurs questioned whether taking PLWD out of their familiar environment would have a positive effect, however, for people who were used to travelling previously, this was still

considered an enjoyable experience. The offer for young PLWD is quite extensive, however, these are not open for elderly PLWD.

For informal caregivers leisure activities are very important, but they need support to enable them to participate in these leisure activities with or without the person they care for. A dementia-friendly offer should therefore include professional care, to relieve the burden of care. There are also dementia cafes, where knowledge transfer and sharing experiences between people in a similar situation takes place.

In principle, many suitable facilities are already available, but accessibility for PLWD can be improved by respectful conduct, including helpful and respectful staff; a tranquil environment (limited stimuli) and offering a clear structure. One of the entrepreneurs offered this solution: “The sports centre could promote suitable times for PLWD to visit, which is when there are not many other users present, or the museum could provide a different entrance without a long and busy queue.”

Customisation of activities is of great importance, as all PLWD have different needs and different abilities, therefore it is not possible to provide an offer that will suit the needs and interests of all PLWD. A residential care centre developed a set of cards that can be used to initiate a conversation with PLWD about their interests in travelling, in this way entrepreneurs have the ability to provide a demand-driven offer.

Obstacles to enjoying leisure activities for PLWD include reactions from society towards misunderstood behaviour. The family also experiences obstacles in travelling by airplane, and worries about the family member with dementia travelling too far, or being able to cope with the change in environment and practicalities like small lifts in the accommodation. Some even experience embarrassment travelling and appearing in public with their partner with dementia. The entrepreneurs observed that people often do not visit the dementia cafes in their own region, but a little further from home. They thought this could well be connected to embarrassment as well, because they do not want the neighbourhood to know about the diagnosis.

But the PLWD often feel embarrassment themselves as well and when activities have a dementia-friendly label this could deter them from participating. Labelling activities as dementia-friendly could be a way to make the activity more accessible for PLWD, and easier to find for their caregivers. But on the other hand, it could also create stigma, this also applies to naming the

activities that are suitable for PLWD; when dementia is in the name, this could again deter people from participating and hamper interaction between PLWD and other members of society.

Theme chances/opportunities in developing and providing dementia-friendly activities

This theme was subdivided into five subthemes, namely 1) recognising dementia friendly places to visit 2) communication, 3) digital platform, 4) promotion and 5) cooperation.

The entrepreneurs mentioned that although a dementia-friendly label has its downsides, as mentioned above, on the other hand a label could help people find the right activities, where they know they will be treated with respect and can expect understanding. An example given was in Bruges (Belgium), where a red handkerchief with a knot in it is placed in shop windows that are dementia-friendly. This unobtrusive symbol is easily recognised by PLWD and signifies an establishment that is safe and suitable for them to visit. Another opportunity that was mentioned was to provide a travel insurance specifically for PLWD, which provides the opportunity for an earlier return when needed.

In terms of communication participants stipulated the necessity to spread the message about the needs of PLWD in the hospitality sector. “When people working here recognise their needs, these places can become much more accessible and friendly places for PLWD to visit.” Local businesses are encouraged to take up training opportunities and to qualify for accreditation as dementia-friendly. The more this is rolled out the more holiday opportunities will be created. “This does not necessitate a complete change in the offer, because everything is already present, the only thing that is needed is better communication.” Both in terms of knowledge of PLWD for the staff at these establishments and in terms of the offer available to PLWD. A dementia-welfare-helpline could assist in this exchange of information and could also provide answers to questions for anyone dealing with dementia in any way.

As another way to bundle information about leisure and travel for PLWD participants considered the need for the provision of a digital platform, where people can choose the type of trip they want to make and add the care they need during their trip. The platform will then list the customised holiday options available. “PLWD should be able to rate their experiences on holiday or during a leisure activity on a digital platform, for other PLWD to see, TripAdvisor is a suitable platform for this.”

Many opportunities for holiday and leisure activities for PLWD already exist, but these opportunities are not known to the target group, especially those in the early stages of dementia, still living at home. It is therefore important that these activities are promoted more efficiently. “This information should be made available through an inspiration page on a website, such as dementia.be in Belgium; by placing brochures in sites that PLWD visit frequently, such as the activity centre at the care home, the GP or the neurology ward of the hospital; by creating brochures for each town or city detailing the opportunities that exist there for PLWD; and by organising quarterly information meetings for caregivers to promote the offer available.”

More cooperation between medical and non-medical service providers is crucial to create more opportunities and chances for both PLWD and entrepreneurs in leisure activities.

“Fruitful co-operations could be established between (the social services of the) day-care centres, professional and informal caregivers and other sectors, such as hospitality, schools, cultural sector, sports clubs and fitness centres and shops. In cooperation, these different parties could form an action group and steering group, who will make an overview of what is already available. These activities could then be tested with caregivers and PLWD, creating an overview of suitable activities for PLWD. This overview must be promoted and communicated to all stakeholders, and new initiatives could be created and added.”

Leisure centres and swimming pools could develop opportunities for PLWD, and a pool of dementia volunteers could be created to assist in tourist activities.

Results PLWD

A total of four main themes were identified during the dialogue tables with PLWD and their informal caregivers. These four themes were 1) the need for suitable leisure activities, 2) the preconditions for making activities suitable for PLWD, 3) being a member of society and 4) chances and opportunities in dementia-friendly leisure.

Theme the need for suitable leisure activities

This theme was subdivided into four subthemes, namely 1) importance for PLWD, 2) supporting informal caregivers, 3) dementia-friendly offer and 4) obstacles. From the conversations it became apparent that PLWD want to continue living in the way they were used to before

diagnosis. “They are satisfied with simple things like going out for dinner, doing a city-walk, going cycling, dancing, singing and having a drink on a terrace or in the pub.” Sometimes they need a little bit more persuasion, but once they are engaged in an activity, it is obvious that they are enjoying themselves. However, someone who was not used to do many activities or go abroad for holidays earlier in life, will still not be interested in these activities now. Those who were used to going on holiday, still become enthusiastic when talking about holidays, or when the caravan is packed and ready to go. Seeing the enjoyment in the person with dementia, also gives pleasure to the informal caregiver, this mutual enjoyment is key.

Supporting informal caregivers is important, both when they want to undertake an activity with the person they are caring for, but also when they need time away from the person they are caring for. When going for a day out or a holiday, reliable home-care at the accommodation or campsite is needed. “This would ideally be the same person every day to build trust and rapport.” It is also important that whilst away from home the informal caregiver is not on his or her own in providing all necessary care, because the person with dementia cannot be left alone. An example mentioned was a family who went on a holiday to a residential care centre in Spain, where all necessary care was provided. The family and informal caregivers found this a very positive experience, however, they didn’t really notice the person with dementia enjoying himself.

“Holidays are important not only for enjoyment of the person with dementia, but it is also very important for me as an informal caregiver to recuperate from the taxing care duties. For many of us it is difficult to leave our partner with dementia behind. I need to have a lot of trust in the caregiver who takes over my duties, I need to be able to feel that my partner is in good hands, but I often feel uncomfortable leaving my husband with someone I don’t know.”

For informal caregivers who take care of the person living with dementia on their own it is especially important to spend time with people in a similar situation, to prevent them from becoming socially isolated. It is important that they can leave their cares behind for a moment, or do an activity on their own. A buddy assistant could make this possible.

During the conversations several dementia-friendly offers were mentioned. “Aalbeke is a dementia-friendly municipality which is easily reached by car, and offers dementia-friendly walks and a texture museum.”

“Another good destination is Zeeland (in the south of the Netherlands), which is close by, and in the off-season it is quiet and it has a good care-system, there are some holiday parks that are relatively small-scale.” As mentioned above, another holiday option is the residential care centre in Malaga, Spain. “Here everything from the airport until arrival at the residential care centre was perfectly arranged, and the care provided was in the Dutch language.”

Obstacles to enjoying a trip or holiday is that a change in environment can be disorientating for people with dementia. “Travel by plane is difficult as it is difficult to work to schedules because of the unpredictable behaviour of PLWD, and busy airports can be a challenge for PLWD.” Another problem PLWD encounter when going on a trip or holiday, is that they need to take a lot of materials with them, e.g. incontinence materials, extra clean clothing and other mobility materials. The participants expressed frustration that: “Many activities are tailored especially for young people with dementia, but these are not accessible for older people with dementia.”

Theme the preconditions for making activities suitable for PLWD

This theme is subdivided into the following seven subthemes: 1) structure, 2) tranquillity, 3) ways of travel, 4) location, 5) facilities, 6) safe surrounding/environment and 7) independence.

PLWD need structure in their life, this therefore is an important feature of leisure activities offered as well. During a holiday it is important to keep the same daily rhythm as much as possible and to be surrounded by familiar faces, for some PLWD it is impossible to find this abroad. One of the participants said: “We regularly go to the same café, we always sit at the same table to play a game. My wife becomes agitated when the table is taken.”

Another important aspect for PLWD is a tranquil environment; too many stimuli and noise can lead to unrest in the PLWD. One way to avoid this is to go on holiday outside of the high-season, and avoiding busy cities, and finding a more rural location instead. Other examples are to avoid peak times at the sport centre, avoid queuing at the museum (use a side entrance) and avoid a buffet restaurant.

The ways of travel also have a major impact on the experience of the PLWD. “Trains and cruises are ideal, as there is always a toilet nearby and the cruise company has experience with PLWD, they provide bracelets with name, room number and our phone numbers, which provides us with peace of mind.” Travelling with a caravan or camper is a way of taking your own, familiar environment with you, and for that reason also very suitable for PLWD.

In terms of places to stay a hotel doesn't feel like home and therefore is not considered suitable, but having a holiday apartment or cottage (with toilet and shower on the ground floor) closely resembles a home situation. However, some hotels do offer specific services for PLWD, for example in some hotels placing a shoe outside the room door indicates that staff keep an eye on that room to detect possible wandering of the person with dementia (especially in the evening and night). PLWD choose their holiday destination based on a quiet location outside of season, with good transportation links, friendliness and all facilities close by.

Places to visit, such as museums, cafes and campsites can make small changes that will make them more accessible and suitable for PLWD. Facilities like a side entrance away from busy queues and a toilet on the ground floor make for a more convenient visit for PLWD. Especially gender neutral toilets are needed, so that the informal caregiver can assist the person with dementia in the toilet. "People with dementia don't always look like they need care, but facilities for people with disabilities should also be accessible to them without being frowned upon by the other customers or visitors."

It is also important to provide a safe environment for PLWD. "My wife is afraid to make mistakes, sometimes we come home and she will say: they were looking at me." Because of this a familiar environment and being with close relatives or friends is important for them to feel at ease and be able to be themselves. Staying at home is considered to be safe and comfortable, here they are not confronted with difficult questions that they cannot answer. Because of this it sometimes takes some effort to persuade the person with dementia to leave the home and go to an activity. When undertaking an activity or going away for a holiday it is important to make sure that the person with dementia is stimulated to do all the things within his or her abilities in order to prevent further degradation of their faculties. Keeping a certain level of independence is required for the quality of life of the person with dementia.

Theme being a member of society

This theme is subdivided into three subthemes: 1) understanding, 2) participation and 3) dementia-friendly label.

There is a lack of understanding in society if people have no experience with dementia themselves - there is not enough empathy in society. The owners of establishments often don't mind if PLWD use the facilities for disabled people when they are asked, but other visitors or

guests do find it a problem. Another barrier to acceptance in society is that people with dementia often exhibit misunderstood behaviour, leading to discomfort in others in society and embarrassment in the PLWD. Therefore some PLWD decide not to go on holiday anymore. Within the social circles of the informal caregivers there is little support for the decision to take care of and go on holiday with a member of the family with dementia. “Many of our friends consider it irresponsible that we look after our father and assume that more professional and appropriate care can be provided in a residential care centre.” The people present had experienced that since the diagnosis of dementia, family and friends visit much less frequently, increasing feelings of social isolation.

This lack of understanding makes it difficult for PLWD to continue to participate fully in society, but their life doesn't stop when they are diagnosed. They still want to continue as much as possible to lead the same life as before and be surrounded with the same friends and family.

According to PLWD themselves putting a dementia-friendly label on a holiday park or activities and facilities has pros and cons. On the one hand it can create a sense of trust that knowledge and information is available and people with dementia are welcomed. On the other hand a label can lead to stigmatisation.

Theme chances and opportunities in dementia-friendly leisure

This theme is subdivided into three subthemes, namely 1) dreams, 2) co-operation and 3) promotion.

For PLWD it would be a dream if there was a holiday village or hotel where they could use a day-care centre, and professional care, that is accessible for people with a disability, both visible and invisible. Places like Benidorm and Torremolinos are likely to already offer these services, as they have many elderly visitors, but a concrete offer is not known to the participants. “I dream that it would still be possible to go on holiday with my husband, but I need help in finding the right information and care.” Another dream that was shared was that there should be an atelier where people can be creative and active in their own way with professional support.

There are many opportunities for cooperation to offer more suitable holiday or leisure activities for PLWD. “There could be an exchange between elderly care centres in different countries, for example an elderly care centre in Spain with an activity centre could organise an exchange with the Flemish centre.” The facilities to make this happen already exist, but a closer co-operation

between the elderly care centre and the hospitality and holiday sector, could lead to more opportunities. For example, holiday representatives could be instructed to provide information on dementia-friendly places to visit in the holiday destination. It is important that this information is freely available and accessible for PLWD looking for activities and holidays. This could be provided through a promotional folder in the activity centre at the care home.

Discussion

Results from the sessions with the PLWD provide information on the ways in which dementia is perceived by the community and how this affects their inclination to undertake activities. They also provide information on the conditions under which leisure activities become suitable for PLWD and the opportunities they see in adapting the current services and activities to suit the needs of PLWD. Another key point for the informal caregivers was that they need support to undertake activities both with and without their family member with dementia. From the entrepreneurs important findings include that they are interested in providing dementia-friendly services, but they feel more training is needed to enable this. In addition, there are many small, individual initiatives, but more collaboration is needed to provide a more complete offer and this needs to be promoted through a collaborative and accessible format. However, both the PLWD themselves and the entrepreneurs recognise that all PLWD have unique needs and interests, therefore, the offer needs to be customisable to suit individual needs. Another common thread in the dialogue tables with the PLWD and the entrepreneurs was how society reacts to people with dementia. Stigma, misunderstanding and fear towards PLWD have far-reaching consequences for the quality of life of PLWD and can lead to withdrawal from society and social isolation.

The findings show a large number of initiatives offering activities around tourism and leisure suitable for PLWD. For example, in line with the literature, attractions with a connection to past memories such as museums were highlighted as suitable attractions to visit (Innes et.al. 2016). Leisure activities are often initiated by residential care centres, or by individual leisure entrepreneurs. Earlier studies suggest it is the role of institutions for the care of the elderly to facilitate the participation and increase the opportunities for elderly residents (Genoe 2013). Particularly in the arts and culture arena, leisure and recreational activities for PLWD are now quite well established (Connell et.al. 2017).

Surprisingly, Wawrziczny et.al. (2017) notes that the vast majority of existing structures and proposed activities are designed for persons with late-onset dementia, and the facilities themselves do not address the needs of persons with early-onset dementia. This is in sharp contrast to the data collected from the dialogue tables, where informal caregivers expressed their frustration about the fact that many activities were designed for young persons with dementia, and not accessible for elderly PLWD. Moreover, the current offer for leisure activities suitable for PLWD is not easy to find. This was recognised both by PLWD and by entrepreneurs and could, in some cases eventually result in the PLWD staying home and experiencing increasing social isolation.

Wawrziczny et.al. (2017) studied the needs of informal caregivers of people with dementia and found that social isolation is indeed experienced by these spousal caregivers. This isolation is caused by three phenomena, namely '1) exchanges with the PLWD become more restricted qualitatively and quantitatively; 2) out-of-town trips become increasingly rare; and 3) the network of friends, family, and professional associates gradually distance themselves.' Spouse caregivers want to escape the gradual silence imposed by the disease and describe a need for exchange and talking about the disease and other things, to avoid exhausting themselves, and fight social isolation (Wawrziczny 2017). The PLWD participating in the dialogue tables expressed similar needs and experiences. They reported that they needed some time away from the person they cared for, to recuperate from the burden of care. However, leaving the person with dementia behind is difficult for many caregivers. For informal caregivers it is important that they spend time with people in a similar situation to prevent them from becoming socially isolated.

The literature stresses the importance of leisure activities. Involvement in everyday activities helps persons with dementia feel independent and responsible and provides a sense of continuity (Fernández-Mayoralas et.al. 2015). Leisure helps PLWD to maintain identity in early-stage dementia, and remain engaged in life. Leisure and enjoyment can provide escape from negative emotions and distract from distress (DiLauro et.al. 2017; Genoe 2013; Genoe & Dupuis 2011). In fact, Innes et.al. (2016) and Fernández-Mayoralas et.al. (2015) consider leisure an important strategy of resistance against social disabilities resulting from dementia and its potential impact on social isolation. According to older people themselves, engaging in leisure, physical, cultural and social activities is important for maintaining quality of life (Genoe 2013, Genoe & Dupuis

2014). Undertaking leisure activities can also slow deterioration and limit care interventions (Connell et.al. 2017). Leisure activities therefore are very important for PLWD to enable them to continue their participation in society. This way they feel they have a meaningful role and are able to contribute in household chores. For example, leisure activities provide an opportunity to fulfil the roles they used to take in their life, like being a mother, a poet, and being adventurous (Connell et.al. 2017). During the dialogue tables it became clear that being able to engage in normal everyday activities, such as they were used to before diagnosis, was considered special to PLWD. Going out for dinner, doing a city walk, going cycling and having a drink in the pub became a much valued leisure activity.

Leisure can also play a role in completing life, and fulfilling long held dreams. Genoe (2013) stated that PLWD want to fulfil particular dreams like attending a concert of a favourite singer or go travelling while they still can. DiLauro et.al. (2017) reported that participating in activities allows people in early stages of dementia to increase control over symptoms and focus on abilities and positive aspects of their lives. But this is not possible if people surrounding the person with dementia assume that they are incapable of fulfilling these roles (Genoe & Dupuis 2011). The value of leisure activities as a fulfilment of life goals or to complete a bucket list was also considered an important reason for entrepreneurs to provide dementia friendly leisure activities.

Still, the pursuit of leisure activities is difficult to realise. PLWD experience barriers in accessing and participating in leisure activities. For example, the informal caregivers could not leave the person with dementia alone for a moment, for fear of losing them (Innes et.al. 2016). This places a large burden on the informal caregiver, that could be diminished when other family members join the activity, or when staff is more aware and able to act in an appropriate manner when a situation occurs. Another barrier was access to public toilets, and the need for gender-neutral toilets, that enable the informal caregiver to assist the person with dementia without causing incomprehension in others (Fernández-Mayoralas et.al. 2015). Understanding PLWD and the barriers they experience can enhance their continued participation in society (Innes et.al. 2016; Connell et.al. 2017) and make society more dementia-friendly by creating “respectful and responsive businesses and services” where staff understand and recognise symptoms of dementia as displayed by customers (Connell et.al. 2017). A number of preconditions was noted in the dialogue tables, as well as in the literature, namely providing structure, tranquillity and a safe

environment (Innes et.al. 2016; Dementia Australia 2016). In order to realise this there is a need for education amongst service providers and society at large (Connell et.al. 2017), so that staff can make PLWD feel more welcome, safe and comfortable and to raise awareness and understanding of dementia in communities (Wang et.al. 2012). This need was recognised in the dialogue tables both with PLWD and entrepreneurs.

PLWD in this study also commented that there is a lack of understanding, and therefore acceptance, in society. PLWD sometimes exhibit misunderstood behaviour, leading to discomfort in others in society and embarrassment in PLWD. A solution to this problem would be to decrease stigmatisation and increase understanding in society, thus making society more dementia-friendly. To create more understanding in society, there is a need for opportunities for education and providing experience of interaction with PLWD. The behaviours associated with dementia that could be challenging in a leisure context are apathy, dependency, agitation and wandering. These behaviours could pose increased risk of harm and a need for supervision (Innes et.al. 2016). Moreover, this behaviour often leads to misunderstanding, lack of awareness and stigma, leading to a negative view of dementia in society (Innes et.al. 2016). In turn, PLWD feel unwelcome (Connell et.al. 2017), embarrassed, frustrated and grieved, causing them to stay safe at home more and more. This withdrawal could possibly be reversed by encouraging leisure service providers to become dementia-friendly and training people to become 'dementia friends', making more services accessible for PLWD (Innes et.al. 2016; Connell et.al. 2017). This issue has also been accentuated by the World Health Organisation (World Health Organisation 2012; World Health Organisation 2017). During the dialogue tables, the idea of businesses with a dementia-friendly label was also discussed, on the one hand this was seen as a positive development, as PLWD would be able to find and access these businesses and feel welcome there. On the other hand, a dementia-friendly label also creates stigma as these businesses will deter other people from visiting, thus limiting opportunities for PLWD to participate in society and hampering the normalisation of continued participation of PLWD in society.

The method of the dialogue tables was a suitable method for the population central to this research, as it enables them to speak from their own experiences, and concentrates on opportunities and wishes, not just on the limitations. However, this report is based mainly on the views of the informal caregivers. The involvement of people with dementia themselves was limited in this research. Future research should make more effort to add their voices to these

findings. Another limitation in this study is that the participants were invited on personal basis, and were people who had expressed an interest in this topic.

Conclusion

This study explored the experiences and perspectives of PLWD and entrepreneurs on dementia-friendly leisure activities in society. Findings indicate there is no need to create a new offer of activities suitable for PLWD, because there are a lot of initiatives for PLWD to participate in leisure activities. Still, participation is hindered by a number of barriers, e.g. activities aren't always dementia-friendly or are difficult to find for PLWD. With small adaptations, the current offer can be made more dementia-friendly. Also, information sharing and cooperation between care and leisure services could make it easier to find and optimise suitable activities for PLWD. At the same time, a more supportive and understanding society needs to be created so that PLWD can continue to participate and provide a meaningful contribution.

References

- [1] Connell J., Page S. J., Sheriff I., and Hibbert J. 2017. 'Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy', *Tourism Management*, vol. 61, pp. 110–128.
- [2] Dementia Australia, 2016 'Travelling and holidays with dementia'. Dementia Australia
- [3] DiLauro M., Pereira A., Carr J., Chiu M., and Wesson V. 2017. 'Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants', *Dementia*, vol. 16, no. 1, pp. 9–28
- [4] Fernández-Mayoralas G. et al. 2015. 'Active ageing and quality of life: factors associated with participation in leisure activities among institutionalized older adults, with and without dementia', *Aging & mental health*, vol. 19, no. 11, pp. 1031–1041.
- [5] Genoe M. R. and Dupuis S. L. 2011. "'I'm just like I always was": a phenomenological exploration of leisure, identity and dementia', *Leisure/Loisir*, vol. 35, no. 4, pp. 423–452
- [6] Genoe M. R. 2013. "'There is life after diagnosis": Dementia, leisure, and meaning-focused coping', *Recreation and Society in Africa, Asia and Latin America*, vol. 4, no. 1.

- [7] Genoe M. R. and Dupuis S. L. 2014. 'The role of leisure within the dementia context', *Dementia*, vol. 13, no. 1, pp. 33–58
- [8] Glaser and Strauss 2006. 'The discovery of Grounded Theory, Strategies for Qualitative Research' Aldine Transaction, New Brunswick, London.
- [9] Innes A., Page S. J., and Cutler C. 2016. 'Barriers to leisure participation for people with dementia and their carers: An exploratory analysis of carer and people with dementia's experiences', *Dementia*, vol. 15, no. 6, pp. 1643–1665.
- [10] Connell, J., Page, S.J., Sheriff, I., Hibbert, J., 2017a. Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy. *Tourism Management* 61, 110–128.
- [11] Connell, J., Page, S.J., Sheriff, I., Hibbert, J., 2017b. Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy. *Tourism Management* 61, 110–128.
- [12] Dementia Australia, 2016. Travelling and holidays with dementia.
- [13] DiLauro, M., Pereira, A., Carr, J., Chiu, M., Wesson, V., 2017. Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants. *Dementia* 16, 9–28.
- [14] Fernández-Mayoralas, G., Rojo-Pérez, F., Martínez-Martín, P., Prieto-Flores, M.-E., Rodríguez-Blázquez, C., Martín-García, S., Rojo-Abuín, J.-M., Forjaz, M.-J., 2015a. Active ageing and quality of life: factors associated with participation in leisure activities among institutionalized older adults, with and without dementia. *Aging & mental health* 19, 1031–1041.
- [15] Fernández-Mayoralas, G., Rojo-Pérez, F., Martínez-Martín, P., Prieto-Flores, M.-E., Rodríguez-Blázquez, C., Martín-García, S., Rojo-Abuín, J.-M., Forjaz, M.-J., 2015b. Active ageing and quality of life: factors associated with participation in leisure activities among institutionalized older adults, with and without dementia. *Aging & mental health* 19, 1031–1041.
- [16] Genoe, M.R., 2013. "There is life after diagnosis": Dementia, leisure, and meaning-focused coping. *Recreation and Society in Africa, Asia and Latin America* 4.
- [17] Genoe, M.R., Dupuis, S.L., 2014. The role of leisure within the dementia context. *Dementia* 13, 33–58.

- [18] Genoe, M.R., Dupuis, S.L., 2011. "I'm just like I always was": a phenomenological exploration of leisure, identity and dementia. *Leisure/Loisir* 35, 423–452.
- [19] Glaser, Strauss, 2006. *The discovery of Grounded Theory, Strategies for Qualitative Research*. Aldine Transaction, New Brunswick, London.
- [20] Innes, A., Page, S.J., Cutler, C., 2016a. Barriers to leisure participation for people with dementia and their carers: An exploratory analysis of carer and people with dementia's experiences. *Dementia* 15, 1643–1665.
- [21] Innes, A., Page, S.J., Cutler, C., 2016b. Barriers to leisure participation for people with dementia and their carers: An exploratory analysis of carer and people with dementia's experiences. *Dementia* 15, 1643–1665.
- [22] Wang, H.-X., Xu, W., Pei, J.-J., 2012. Leisure activities, cognition and dementia. *Biochimica et Biophysica Acta (BBA)-Molecular Basis of Disease* 1822, 482–491.
- [23] Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M.-J., Antoine, P., 2017. Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics* 17, 282–291.
- [24] Witte, R., van de Weg, A., 2016. *Trainingsmap dialooggespreksleider*.
- [25] World Health Organization, 2017. *Dementia: number of people affected to triple in next 30 years*.
- [26] World Health Organization, 2012. *Dementia: a public health priority*.