Experiencing Dementia from Inside: The Expediency of Immersive Presence

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Abstract. The lengthening of life expectancy has shown a positive trend of neurodegenerative diseases and, among these, dementia seems to have a large incidence in the world population. Unfortunately, in their individual, social and institutional contexts people with dementia are very often stripped of their "being a person" and, finding themselves in a condition of particular frailty, they become the object of exclusion. More recently the idea of being aware about pathological cognitive decline linked to neurodegenerative diseases is growing worldwide through the Dementia Friendly Community movement. It is asking to general population to perform inclusive behaviors towards people living with different forms of dementia (including Alzheimer's disease) by maintaining their personal and professional role within the urban community. Despite the large amount of Dementia Friendly initiatives, if a member of the community doesn't have the opportunity to personally observe this living condition among her/his close relationships she/he probably tend to consider the dementia population as largely needful and highly usefulness, without exactly understand how they can contribute in this inclusive process. In order to support the urban community members in their broadly availability to adequately play their social role towards people living with dementia, the present research introduces ViveDe: examples of immersive experiences possible trough virtual reality. With the aim of pushing the general population in understanding how living with dementia could be like, different daily situation where proposed and social perspective change was analyzed.

ViveDe experience revealed how "being present" in the daily challenges an urban space proposes (e.g. exploiting her/his duty at home, going around in a unknown city, having some leisure time with friends) sheds new light on the role each community's member can play towards people with dementia.

Keywords: Cognitive frailty · Alzheimer · Dementia Friendly · ViveDe · 360° video · Virtual reality

1 Living with Dementia

1.1 The Cognitive Frailty Increasing

An urge amount of research in cognitive neuropsychology developed during the last 10 years was focused on dementia and cognitive decline. This research mainstream is addressable to the urgency data about aging population and to the exponential increase

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in neurodegenerative diseases [1]. The most recent report available about the spread of dementia in Italy, in fact, showed there are at least 1 million people with dementia in 2017 (of which about 600,000 with Alzheimer's dementia) and about 3 million people taking care of them. These numbers are estimated to tripling for 2050. Considering also that up to now about 50% of dementia diagnoses worldwide do not seem to detect mild cognitive decline in the elderly population, one can easily imagine the repercussions of these data on the economic and social landscape of the coming decades. At present it's a largely shared opinion that in the next 20 years' people suffering from dementia will increase and formal caregiving (such as health institutions and governmental welfare) will be insufficient for facing the wide amount of assistance request [2].

Dementia is specifically defined as a cognitive impairment (a decline in performance prior to the known or presumed beginning of the disease), global (involving all cognitive functions) and chronic (which is prolonged continuously over time). The cognitive performance required to face the external environment challenges becomes unsuccessful in dementia. Nowadays, to outline the nosographic boundaries of an intermediate situation between brain aging and dementia is still a difficult task, especially because the relationships between these two conditions are not yet clear. For some scholars, brain aging and dementia represent the extremes of a continuum in which dementia is the terminal phase of an inexorable process and an expression of functional exhaustion of the brain [3]. For others, dementia is a pure pathology, distinct from aging that represents a risk factor but not the cause of the disease [4]. However, a perspective that is not only biological, but embraces also the social dimension, shows how the term dementia should be used in a largely descriptive way to draw a clinically identified condition that refers to the person in its entirety and not exclusively to his or her brain [5]. Accordingly, "being a person in dementia" is a condition given to an individual by the others that constitute her/his relational and social context. Similarly, the definition of dementia in this case is referring to a multiple-cause clinical syndrome. In addition to cognitive decline, there are symptoms that affect the sphere of personality, of affectivity, of conception and perception, as well as of vegetative functions and of behavior. Thus, it is possible to define dementia as a progressive and irreversible disease of organic origin, prevalently found in elderly people, which presents a compromise of memory functions, with communicative difficulties in its forms of expression and understanding consequent to disturbance of language, with the inability to perform daily activities in spite of the integrity of motor skills, and with the consequent inability to perform goal oriented gestures and actions, such as taking care of personal hygiene or organizing domestic activities [6]. Therefore, the manifestations of dementia here described tend to have a strong impact on the functional status of the subject (both in the individual and social sphere) significantly interfering with her/his quality of life.

Luckily in the misfortune dementia course is not always so sudden but, in most cases, allows people to continue to live in partial autonomy especially in the early stages of the disease. Accordingly, it become necessary to value the person in order to warrantee her/him a good quality of life. It means to value also her/his temperament and her/his personality (built in the experience of life), on which depends, in large part, the way in which the individual faces both old age and eventually dementia. Hilman [7] in this regard claims that it is necessary:

- to last those parts of the character last that allow the person to always positively overcome the challenges of life in a creative and functional way according to her/his own well-being;
- to leave those parts of the character that hinder an optimal path in old age and dementia;
- to keep those parts of the character that allow the person to be considered by all those who surround it as unique, peculiar and special.

However, this autonomy is subordinated to the change in inclusiveness, that the contexts in which the person finds her/himself living daily, may have developed. We'll discuss about it later in the manuscript, after better understood what living with dementia could mean.

1.2 How Living with Dementia Is like?

The way a person with cognitive frailty experience everyday space plays a significant role in the ways she/he can face the contextual challenges and gain autonomy in daily activity. Moreover, the way the context is represented will become even more crucial in the ways the individual perceive the possibilities for building social relations.

Some aspects of how living with dementia can be like emerges from the experience reported by the patients themselves [8]. The personal experience of living with dementia is influenced by social elements (e.g. the modality in which member s of the community talk and behave toward them), and to have the opportunity of being considered with the full possibility of being a valued member of the society they live in, seems to have a great impact upon the emotional and psychological well-being of people with dementia [9]. Moreover, considering how people with dementia experience their surrounding space (both owns home and long term-care settings), showed that lived space continually decreases due to the progression of dementia but individuals continues to experience the spatial dimensions of life through lived space even in the illness [10].

Unfortunately, even the literature in the field can provide us with a detailed picture about the challenges/skill balance people with dementia do about living every day, it doesn't be able to give us an idea about how experiencing dementia daily can be. Generally, "from the outside" we observe people living with dementia without understanding why they are presenting some behaviors (such as agitation, wandering, irritation, memory fault and inability to conclude some easy tasks) during a daily situation (such as having a family lunch or going to bed). This inability to detect which cognitive difficulties can lead the person to not have socially adequate behaviors, often leads us to confuse these behaviors with evidence of a "personality change" and not as a symptom of an in progress cognitive impairment in the person who is living with dementia. Moreover, living with a cognitive frailty inevitably contains in itself suffering, fear, anguish and, often, a double difficulty of recognition. There is a difficulty in recognizing oneself, on the part of those who carry cognitive impairments and in integrating the new image of oneself with the past (especially when awareness in the pathology is preserved). Furthermore, there is a difficulty in recognizing the person with cognitive frailty on the part of the community members. Difficulty that often results in distancing oneself from those who start to be considered primarily as a burden. This double difficulty results in a mutual isolation, in which the community tends to exasperate the behavior of protection against the person with cognitive frailty, often limiting their daily autonomy. While the latter, in an attempt to silence the anxiety related to the progress of cognitive decline, will start towards an isolation that will lead it to live with the daily limitations to which the cognitive compromise binds she/he irreversibly.

Determining how every day social life could be for people with dementia might contribute to overcome this situation. This can be possible starting from the point of view of people with dementia who live in an urban community and at the same time by providing the community with insight about the role and actions to be taken in supporting all the members in identifying the cognitive and relational possibilities that can be brought at play including the person with dementia within the same community [11]. If this situation is kept and interwoven in a strongly interconnected social network that welcomes people living with dementia, supports them, enhances them, and gives them back competence, a good quality of social life can still be possible. For this to happen, however, there is a need to enhance "best practices" in education based on the idea that people with dementia require relational and emotional paths that unfold around the person to continue living an everyday life that is as autonomous as possible. Above all, in the cohabitation with the pathology, a more inclusive community have to be planned.

2 How to Implement a Dementia Friendly Community "Revolution"

By supporting the idea of inclusiveness for people living with dementia described above, Dementia Friendly communities (DFC) were developed worldwide [11]. DFC are urban realities in which each member, in her/his personal and professional role, learns to understand what to do and what the other person expects to be done in living with people who no longer have full control of their cognitive faculties and will continue being part of the same urban community. Accordingly, a DFC is not made up exclusively of health professionals and family members of people with dementia, but it is a community where each member finds its role in combining their possible life-paths with people with cognitive decline whether they are their customers, neighbors or simple acquaintances. Specifically, a Dementia Friendly Community has as its basis the relationship constituted by the various focal points of the community. Therefore, not only those who take daily-care of people with dementia are involved in this network and constitute its important node. Contrarywise, all the representative sectors of an urban community (such as the neighborhood, the transport services, the educational institutions, the legal and financial services, the sales companies, the religious communities, etc.) are involved in a DFC.

All-over the world many Dementia Friendly communities are growing with both private and governmental contribution, such for example the Alzheimer's Disease International in UK [12], the Dementia Friendly America, in USA [13] and the Alzheimer's Australia Dementia Friendly, in Australia [14]. Even if at present they can show several different perspectives on how to improve a DFC growth, their contribution appears to focus more on the institutional level (such as the local welfare services) than on the entire urban community. Moreover, their efforts seem overcome being focused on an educational intervention that can raise citizens' awareness about dementia and on the exercise of a responsible and inclusive citizenship. The neighborhoods, the public and the businesses services that the person with dementia face with every day, in fact, have to be supported in understanding what role they can have in order to create a friendly ground on which to allow the rooting of a full inclusiveness of the person himself. It is therefore necessary to learn how a "friendly" community can be formed around the person [5].

2.1 How to Become Dementia Friendly?

If the stated mission is to turn any urban community as an inclusive one toward people suffering from this kind of illness, any community member has to turn aware about "what living with dementia means". Thus, by this way the individual will be not excluded but will be fully understood and, above all, will be supported in continuing her/his individuality in spite of, and together with, her/his cognitive frailty.

Consistent with DFC this perspective, the bio-ecological theory of Urie Bronfenbrenner [15] illustrates the importance of experience in conveying an inclusive change towards people. It highlights the active role that have to be recognized to individuals who "inhabit" the environment, and, at the same time, it underlines the effects that their action has with respect to the determination of the surrounding environment. The behavior of the individuals belonging to a community is determined not only by the individuals-environment "per sè", but it is co-determined by the individual-environment coupling experienced at that peculiar moment. Accordingly, to find ways to start an inclusive change suitable for all the elements of the community network, it appears to be necessary studying the positioning people with dementia have in the community during their daily living. Thus, it is desirable to understand the perception people living with dementia have of the activity, of the roles and of the relationships that can be identified in the situations they live in. It will be, in fact, the active role that is recognized to the person with dementia, and the effects that their action has with respect to the determination of the surrounding environment, that can build an inclusive network of people. Maintaining people with dementia within it.

The rising question is still there: How to implement a DFC "cultural revolution" within community members? It is from this operationality question the present research starts. If the context itself is defining the idea of inclusion, it is exactly in the light of supporting a situation awareness that the DFC change will deem. Accordingly, the understanding of the context in which the person with dementia is living every day and of the situations within which she/he is building a close and mutual relationship with the member of the community can provide the possibility to identify the correct DFC educational approach. In our hypothesis, it is by negotiating meanings within the community, and by avoiding a prescriptive approach that imposes an "institutional" Dementia Friendly change, without understanding the points of view of all the elements involved in the community itself, that this essential revolution could be done.

2.2 Towards an Experiential Dementia Friendly Education Approach

At present the DFC programs worldwide doesn't seem to have individuated the experiential approach as one of the main expediencies for its educational mission. Instead to think about the opportunity provided from first-person perspective as one of the elective educative playgrounds in encouraging the performance of inclusive behaviors towards people living with dementia, several second- third-person actions were planned in urban situations requiring a large amount of efforts to organize it [11]. The main aim of this contribution is to show how, by providing people with appropriate contents to fully subjectively experience how living with dementia could be, we support them to understand which community role they can have in a Dementia Friendly perspective.

This first- person approach can be considered to be not an easy challenge for a double motivation. First, the wide experiential gap between the general population and people living with dementia introduces several emotional, cognitive and behavioral differences that convey the experience of living with dementia difficult to understand from the outside (especially if a member of the community doesn't have the opportunity to personally have closeness with this living condition in their family or among their daily relationships). Second, the dementia population is generally considered as largely needful and highly usefulness from the general public and this stereotyped representation appears to be stronger when addressed to severe cognitively impaired people (such as in Alzheimer disease). Thus, even if broadly available to adequately play their social role, urban community members don't exactly understand how they can contribute in a Dementia Friendly Community.

The recent wide diffusion of low-cost interactive technologies, such as 360° videos explorable through virtual reality eyeglasses, can provide new opportunities for creating experiences able to vehiculate a changing perspective on dementia. Moreover, such experiential technology, if accompanied with an educational program, will be able to support the adequate positioning of community members towards people living with this neurodegenerative disease.

2.3 The Role of Virtual Presence for Inclusiveness Change

The more recent development of virtual reality applications, due to its interactive nature, was made for pushing out storytelling [16]. At present, storytelling is considered as an effective pivot for emotions arousal that kick off correspondent actions. When user experience is warranted by optimal levels of virtual presence [17], some perspective changing is made possible by feeling of being "part of the story" while watching a meaningful content by interacting with it.

From the literature in the field we know that the sense of presence will be strong inasmuch as the virtual system enables an inclusive, extensive, surrounding and vivid illusion. The immersive quality of virtual experience would be enhanced by the perceptive features and by the proprioceptive feedback provided by the virtual technology and/or, as in the last years the research on presence has emphasized, by being exposed to interactive meaningful situations [18]. The sense of agency ownership, in fact, seems to be today the key presence element. It is provided not only by the visual reference of the agent body in the virtual environment, but also from the dynamic a virtual reality is able to support through a continuous coupling between perception and action. Thus, not only highly immersive technological solutions are needed to experience presence, but also subjective involvement plays an important role. Accordingly, some new generation researches are investigating how the virtual presence, the user flow-experience, and the storytelling identification, were significantly linked to empathetic disposal for actors and situations. Especially if empathetic situations are depicted in the proposed experience [19]. The results are highlighting how, like in the serious game for example, the same contextual and individual dimensions are related with an interest in learning different possibilities to face a situation considered as meaningful from the user. The "lived" virtual experience, in fact, appears to enhance interest in learning more about the game-specific topic, and on the specific skills the serious game would like to teach. Unfortunately, for how concerns the acquisition of socially valuable actions (e.g. inclusiveness) data suggests only that empathetic contents lead to motivation in increasing another's welfare, but only predicting this commitment without measuring it.

In order to overcome this gap and starting from the idea that presence is not a propriety of the immersive and interactive technology "per sè", but is a domain of human cognition that interplays with such kind of technological devices, the contribution proposed here aimed in understand how, when exposed by virtual reality to the perspective people with dementia have in exploring daily environments, users not only engage with the provided stories, but also construct and develop a perspective changing in their social role by actively adopting, consuming, and experiencing these immersively experienced stories. According to this, the ViveDe project was developed and introduced here.

In the next paragraphs different daily situations were described as presented to the general public by the use of immersive virtual reality in order to support a Dementia Friendly changing on them.

3 ViveDe: The Virtual Dementia Daily Experiences

The following paragraph will describe the ViveDe project developed from the Dementia Friendly Italia research group at the University of Bergamo (http://www.vivede.it). ViveDe introduces everyday situations that people can experience through the use of 360° videos explorable one the x/y axis by Virtual Reality eyeglasses. These daily experiences are provided from the point of view of a person living with dementia in order to give at the general public a first-person perspective on how living with dementia could be. ViveDe experiences take into account the different situations of dementia people ordinary everyday life.

3.1 ViveDe Scenario Developments

More than to tailor the scenarios on the well-known characteristics of cognitive impairment in dementia, derived from the neuropsychological expertise and from the wide symptoms description provided by the scientific literature in the field, in developing

ViveDe three different researches were conducted. Considering the main roles individual could have within a DFC community we had:

1. Early-dementia people (10 individuals) from different urban contexts (e.g. a big city, a smaller one, a seaside village, etc.) were involved in providing their perspective about how is difficult to face with everyday challenges without asking caregivers, relative, friends to support them daily. By introducing the Cultural Probe qualitative method [20] the daily dimension of aging-in-place with dementia was investigated. The 'capture artifacts' returned by people with dementia after a 2-months period were mainly small narratives, photographs, diagrams, calendar notes. They provide image-rich responses from the participant and constitutes useful elements in determining what could be the appropriate scenario to develop in ViveDe project.
2. Semi-structured interviews were conducted with caregivers, relatives, close friends about the daily habits people with dementia they live nearby have. These interviews were conducted in order to detect which could be the more frequent situations in which their support is required. In particular, focus was on the pattern of everyday activity the patient could still have faced with independently, if a collaborative context had been found.
3. A participatory ethnography was conducted by observing people with dementia and their caregivers in exploring the urban context they live within. From this perspective data were collected about activities proposed by neighbors, shopkeepers, desk clerks, bar and restaurant waiters to people with dementia. Main focus of this analysis, conducted following Bronfenbrenner's theoretical approach, was to determine the stereotypes and inappropriate behaviors usually presented from micro- to meso-situations that have to include individuals with dementia.

From the qualitative and quantitative data collected during this project phase the scripts proposed here were developed. The main ViveDe scenarios developed are:

Come Back Home

Day interior. The subjective of a panting person climbing the stairs of a building. One perceives the difficulty of returning home after a hypothetical outdoor walk. The person appears confused: there is no certainty about where the person is, nor about the exactness of the floor of the building in which the apartment he/she wants to reach is located. There is no one around, there are no distinctive elements to recognize the doors of the apartments. The person rings the house bell at one of the two doors on the floor and waits. No reply. She/he has keys in hand, but he does not use them. She/he waits. After a few moments the person, recognizing the doormat as a known element that can be placed in the sphere of the most remote memories, tries several times to use the bunch of keys he has in hand to ascertain the type of key with that of the lock on the door.

Entry into the apartment. Moment of emotional agitation due to not being sure to be on the right assessment. The apartment is perceived as definitely belonged to someone else. Running out of the apartment with the fear of being mistaken for thieves. The front door remains open. The person hesitates on the landing, he turns his gaze to the entrance and enters again recognizing him as his own.

Search for known elements in the living room and bedroom. Each "recognized" element decreases the state of agitation of the person. Confabulations on some of the elements encountered (e.g. basic necessities on the dining table, clothes in the closet) that obviously denote a confusion of space and time.

Search for a comfortable place in the apartment (e.g. a chair, a sofa). Waiting "watchful" of the arrival of a hypothetical landlord. Clear evidence of the impossibility of someone else arriving. Waiting with crescendo of anxiety and agitated thoughts. Dissolution.

Neighbors and Friends

Day interior. The subjective of a person sitting in an armchair inside an apartment. The person waits. The ambient conditions of the room are becoming unpleasant (e.g. too much noise coming in through the open window, the sun that overheats the living room and the seated person). Someone is ringing the doorbell. No reaction of the person in subjective. Noise of keys turned into the lock. The entrance door opens.

A person appears happily greets and enters carrying a shopping bag. It is understood that there is confidence between the two people but not full familiarity. The newly entered person, however, presents herself/himself making sure that she/he is recognized as the next-door neighbor. Show the keys and "justifies" for having used so it was agreed between them earlier. Once confirmed to agreement, closes the window and makes sure that the sun is not unpleasant for the person sitting in the chair.

The neighbor goes to the kitchen and finds in the fridge and in the pantry inappropriate objects (a hairdryer between the dishes and a book in the ice department). There is no negative reaction or judgment to the unusual findings. She shows objects to the person in the chair, appoints them, explains their main function and puts them in the right place while continues to show them to his interlocutor. Continuing to talk with the person sitting in the armchair, the neighbor begins to arrange the house and prepare lunch. Scene dissolution.

Having Lunch

Opening the scene with the subjective of being seated with the table set in a singular manner (e.g. soup in the citrus squeezer, fork instead of a dish and chopping board instead of a placemat).

The neighbor enters the dining room after finishing to work in the adjoining room. She is surprised about this arrangement of the table and, without judgement, shows to the person the inadequacy of this situation. The person in subjective gives a confused motivation about this and the neighbor understands how the person has no awareness of the difficulty in eating a soup with a fork. Scene dissolution.

Reopening of the scene with a table perfectly set for two. The tablecloth is well cleaned and ironed, the soup is steaming on the plate and the tablespoon is clearly visible on the napkin on the right. The neighbor puts a background music asking the person in subjective if this is her/his favorite song, which seems to be a song from many years ago. She sits in front of the person and asks to explain why she/he likes this song so much. As she begins to listen to the song together with the person in subjective, the scene ends.

Daily Shopping

At the Bakery

Day interior. Subjective of a person who enters alone in a bakery. There are some people waiting. The face of the waiting person reveals the belief that the person should not go around alone. There is a nod of agreement with the person at the desk.

The person's turn has arrived, while in the meantime the shop counts to fill people with evident haste. General consensus of people waiting to declare each one with different motivations (e.g. work, tiredness, reservations already made in advance, small amount of purchase to be made, etc.) to not have much time to waste. The evidence of the next loss of time is clearly attributable to the person who is about to be served.

The subjective of the person is focused on sheet of paper held in hand nervously. The perception of an "hostile" atmosphere does the person tend to hide the paper in his pocket, trying not to reveal the difficulties in making the purchase without the use of a memorandum. Some bystanders share an ill-considered moment of laughter. The atmosphere, however, is of nervous haste and little inclination to patience. As if this kind of episode was renewed every day.

The person is invited to make his order. Keeping the ticket hidden in the pocket, the person tries hesitantly to remember the written sequence, confusing types and quantities, omitting some things that are replaced with others in an attempt not to make others aware of the difficulty of memory. The order even if not quite, however, seems plausible to the person and bystanders. Even if, the bread seller kindly explains to him that they do not sell olive oil in this store but can find it in the fruit and vegetable shop across the street. The person says he has already planned to go to the greengrocer soon after.

The person prepares to pay by clumsily looking for the wallet in his pockets and dropping some things (scattered banknotes, small coins, some cards, including one with his own name and surname with emergency phone number written on it, that the person hides quickly from the view of the bystanders) while the bag is already ready its shopping bag.

While the person is about to pay something confuses the person who gives salesmen a 50 cents coin, solicits the rest and tries to quickly "take away" the bag with the goods purchased in an attempt to get out from that situation as soon as possible because it is developing anxiety on him. It is pointed out by the sales clerk that the amount is not sufficient to purchase, so the person replaces the 50 cents coin with 50 euro. While the salesman goes into the back of the shop to get the change, the person takes his bag and leaves, without realizing that he has not taken the change.

At the Greengrocer

Day interior. The person is greeted with a kind indifference. The other customer now in the shop does not seem to know the person at all. Both have a basket in hand to be filled between the boxes of fruit and vegetables present in the store. Items are placed in an order that only the merchant seems to understand. Everything is very confusing. Furthermore, the shopkeeper does not seem willing to help customers as he is distracted by the continuous ringing of cell phones for home orders.

The person therefore consults his shopping list and prepares to fill the basket where he replaces ginger in enormous quantities, mistaking it for potatoes and mixing zucchini and cucumbers thinking that they are the same vegetable. She/he delivers the basket to the shopkeeper to be weighed. While this operation is carried out with a small conversation the baker enters breathlessly in the shop waving the forgotten change just before.

The person at the beginning refuses this money and then thanks him surprised almost this money was a gift that someone is doing to him. The baker also reminds him that he was just looking for olive oil in the bakery that is available for sale right here. The person purchases it without much conviction.

Meanwhile, the other customer has placed his basket on the counter to wait for it to be weighed. The person observes it and potatoes contained in the basket are "taken furtively" and placed in their bag without the greengrocer nor the customer noticing, while the rest of the basket is clumsily thrown to the ground. The other customer is irritated, she would like to leave the store quickly. The person appears to be mortified and tries to convince the shopkeeper to accept a sum of money which seems to him to be suitable for the compensation of the damage but is not. The shopkeeper does not accept the money and urges him to go home.

After having noticed the loss of the person on this point, the shopkeeper proposes to the person to have the shopping at home and ask about any address she/he can have written in the pocket. In that way the phone number for emergencies was found. Thus, he calls the family member and agreeing with the latter the exact address where to meet.

Wandering in an Unknown Place

Exterior late night/early morning. Subjective of a person who is waking up approximately at 5 AM. The person exit home without being accompanied by a caregiver and she/he takes a bicycle. She/he is wandering while the city starts the daily activity (e.g. garbage truck working, people going by car). Time passes and becomes full day. The person reaches an isolated place and sits near the sea water edge as she/he is waiting for something.

After some time, a couple of adults is reaching the same place. They look at the person with some interest and, after a small discussion, the woman is approaching the seated person asking her/him if any help is eventually needed.

The person answers everything is ok and to be only waiting for a boat that will take her/him back to Milano. Considering the person as confused and disoriented the couple decided to friendly engage with the person a small conversation in order to understand if they could be helpful in accompanying the person at home. After a few exchanges the man ask to the person if she/he had some ticket in the pocket to catch the boat and if he can check it. Luckily the person shows a ticket with a name and a telephone number written on, thus the couple can reach the person's relatives providing them with the exact place in which they find the person waiting for a boat. After the phone call the couple goes away, leaving the person alone. The person continues to dangerously approach the seawater. Time is passing, the evening is arriving, no one is coming to take the person home.

At the Restaurant

Exterior night. Subjective of a person entering a restaurant accompanied by someone who could be a spouse. The restaurant is full of people, there is a lot of confusion:

chatter, background music, waiters who go fast between the tables, children playing at the entrance. The person hesitates, the spouse solicits entry.

They enter the room in search of known faces. They seem to arouse the curiosity of many. The person does not recognize any known face even if some greeted them as embarrassed or hastily. Having to untangle in such confusion causes in the person the desire to leave the restaurant immediately, also because the table is not positioned in the manner in which the person expected it to be. All this is immediately communicated to the spouse in an obsessive manner.

Meanwhile, the guests (all of the same age, therefore supposedly friends) are positioning themselves at the table (some undecided moving several times, even leaving occupied more places with bags and jackets that are constantly repositioned) and some of them get up to give the welcome to the person and his spouse who are coming. In “shuffling” the seats at the table the only disagreeing diner is sitting in front of the person. The dislike is overtly expressed by the person. Someone laughs, someone fears the worst.

Finally, everyone sits, and the waiter arrives. He speaks very quickly, often interrupting himself to respond to the jokes of the guests. The person grabs the menu, but the list of dishes graphically appears illegible and the noise continually distracts her/him from reading. She/he order quickly to not show its difficulty, repeating two different main courses and a dessert. This kind of uncommon request irritates the spouse and once again urges the sarcasm of the unsympathetic.

Everything proceeds quite well (even if for the person the music seems to have variations of volume and the conversation at times appears as non-sense) until the ordered dishes arrive. The person starts to eat spaghetti trying to roll them with a knife. Being unable in doing that, she/he reduces spaghetti into small pieces in order to take them with the dessert spoon. The spouse realizes the embarrassment arousing in diners and can’t hold back a frustration reaction that make her radically rethink the possibility of having an adequate social life that includes also the person with dementia (e.g. “You were right: it had been better to stay home!”).

3.2 Changing Social Perspective on Dementia: Preliminary Results

As explained before, the experiences proposed by ViveDe are easily experimented through a new generation smartphone by using a virtual reality cardboard. For this reason, following a series of public interventions aimed at discussing about Dementia Friendly behaviors with the population of the Lombardy area (in northern Italy) the scenarios described below were proposed to the general public during the last year. According with the end user target we had to work with in supporting the creation of a Dementia Friendly community, not all the scenarios were proposed every time. Instead, different scenarios were selected according to the social role and the activity perspective each group of community members can have on dementia and people living with it. Thus, for general public and high-school students, who were supposed to be people with dementia neighbors or family members, the “at home” scenario and/or the “going out” ones were proposed, while for people involved in commercial activities the “restaurant” and/or the “have shopping” were considered as more appropriate.

Within the several different supervision request on how to become Dementia Friendly requested to our research group from different urban communities a specific research on the effectiveness of ViveDe was planned in a II degree secondary school. As the main goal was to use the first-person experience provided by ViveDe 360° scenarios in supporting the understanding of perspective people living with dementia have in daily activity, perspective changes in end users after the ViveDe experience have to be measurable. Thus, before and after the immersive sessions, a questionnaire about the social perspective participants have on people living with dementia was proposed. The questionnaire is composed by 6 items through which every participant can answer on a five-point Likert's scale. Items are about the need for people with dementia to always be supported in everyday life, to be exclusively helped by family members, to have the urge in reaching health-care facilities and so on. Moreover, participants were asked about the awareness of having a key role as community member (both in their individual and professional roles) in supporting people with dementia autonomous living. At last, on the basis of the questionnaire answers provided, participants were involved in a 1-h debriefing session for discussing their opinion, comments, feelings, suggestion about how to be like a dementia person have created a better Dementia Friendly behavior in their personal and professional daily activity.

Data were collected on 74 participants (Female 38/Male 36) aged from 14 to 17 years old (Mean 15,31; Sd 0,97) attending a secondary school in northern Italy. The scenario proposed were the "Daily shopping" and "Wandering in a unknown place" ones. A paired-samples t-test was conducted to compare questionnaire answers. As summarized in Table 1 and depicted in Fig. 1, there were significant differences in answers provided pre and post ViveDe experiences.

Table 1. Means (standard deviation) and significance values for paired sample t Test on agreement/disagreement answers provided by participants before and after ViveDe experiences.

Item	Student's T	Significance	Mean (sd) Pre ViveDe	Mean (sd) Post ViveDe
Q1	T (73) = 7.1	P = .001	3.88 (0.92)	2.85 (0.97)
Q2	T (73) = 10.20	P = .001	2.09 (0.88)	3.39 (0.90)
Q3	T (73) = 3.70	P = .001	2.86 (0.73)	2.36 (0.97)
Q4	T (73) = 6.20	P = .001	3.78 (1.06)	2.73 (0.94)
Q5	T (73) = 12.40	P = .001	4.01 (0.96)	2.09 (0.86)
Q6	T (73) = 12.20	P = .001	2.16 (0.83)	3.96 (1.05)

These results show that ViveDe experience really does have an influence in changing social perspective about dementia people rights/needs and also on the role that each member of the community can have in creating a more inclusive behavior. Specifically, results suggest that when individuals were exposed to a first-person perspective on how could be living with dementia and having to face everyday challenges the idea of not being engaged in a possible relationship with them if not personally involved in a personal or professional way dramatically changes.

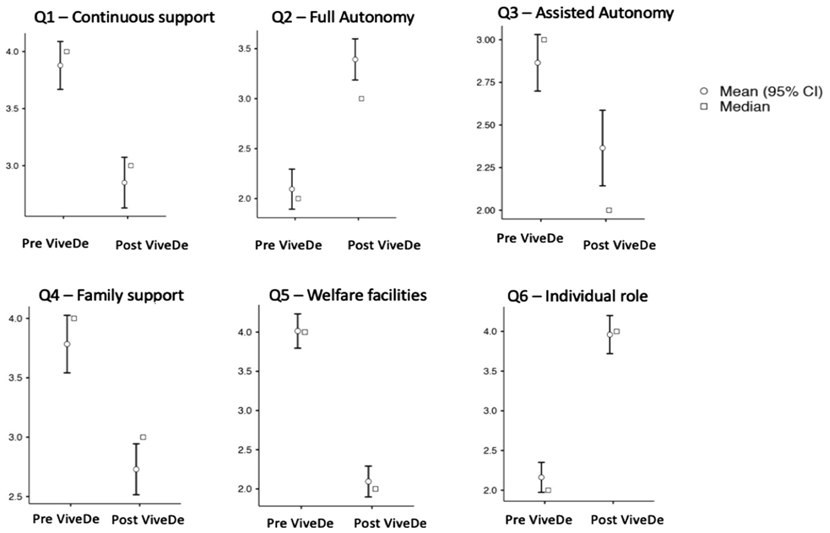

Fig. 1. Differences between pre and post ViveDe experiences for each questionnarire items

4 Conclusions

After the ViveDe experience many individuals have had the opportunity to discuss what it means to live daily with dementia. The reactions were multiple. It immediately emerged that it is difficult to define a person in dementia. What remains of the person when the rationality is intermittent? When the reasoning is fallacious, and exposes us to risks in the management of our assets or relationships? When the form of abstract and evolved reasoning is externally defined as a delirium or a hallucination? All these questions began to be answered after the experience in ViveDe.

Moreover, the question the pathology poses to the individuals has therefore become a question for the whole community: How to remains loving children, good neighbors or competent managers of a commercial exercise, even in front of a person with dementia who wants to continue living his daily life autonomously? Mainly because continuing to be people in dementia has risked the “ability to assemble and maintain relationships”. Therefore, trying to create relationships for individuals meant to understand and identify, not only with the disease, but also with the interests, desires and needs of the person with dementia.

The debriefings conducted with the people who have benefited from the experiences proposed by ViveDe have finally shown many surprising elements. First of all, the feeling of being unexpectedly involved in some uncomfortable experience, that the individuals may not think is concerning to them. The surprise of understanding how to be able to include the other, who had always been perceived as totally incapable or different before the ViveDe experience. The surprise of being able to play a fundamental role in including the unexpected in our daily practices. Finally, the surprise of having discovered potentially a little more Dementia Friendly or the surprise of willing to be in the next future.

The most radically surprising change, however, was the one made on mistrust. The fear of the other person who is different from us, but who has something that could concern us closely is, at the beginning of the experience, very present in individuals who had the ViveDe experience. In particular there were a mistrust in having to manage a situation that individuals know they could never have full government on. In addition, there were a mistrust in matching themselves with the ability to truly be able to do own's part in making the community really inclusive for people with dementia. Both these mistrusts were surprisingly won after experiencing ViveDe. Some behaviors, that were not considered useful, become essential. They appear to distrust the falls and people find themselves as Dementia Friendly.

Finally, community members generally experienced indifference regarding dementia that allowed them to say: "it's not me having to deal with this!". It leads individuals to delegating and to feel safe from any implication with the disease, if the latter does not really concern us closely. The possibility of experiencing the role of a person with dementia provided by ViveDe scenarios appeared also to modify this attitude. Accordingly, in the next future ViveDe will want to push on the possibility to reduce indifference and therefore it intends to continue to invite all members of the community to win the initial surprising mistrust even when this is persistently present. Only in this way will it be possible to create small Dementia Friendly communities even in contexts that can be defined as uninterested in inclusive culture.

In conclusion, the idea of using 360° videos regarding the daily life of people with dementia provided by ViveDe, has never had the ambition to provide universally repeatable solutions in order to build Dementia Friendly communities starting from effective action plans in any specific context. On the contrary, it plans to present experiential paths that led to choose a first-person privileged perspective for the observation of what it means to live with dementia in specific contexts. For every member of an urban community this will mean to have an opportunity to reflect on how to weigh up own's action choices, in order to choose the most practicable ones for the introduction of inclusive behaviors.

It will certainly not be possible to monitor the path that members of a future Dementia Friendly community have begun to undertake after the ViveDe experience, but this experience can be considered as warranting a smoother step towards the goal. It was started by allowing community members to have a moment of reflexivity on their experience, in order to have the possibility to understand the necessary change and to make it last in time. These were the first seeds of Dementia Friendly culture to be planted, and only the time passing will tell us if they have really paid off. For how concerns the present time, the wish is to have been able to give an example of how to convey more inclusive perspective change in a field in which a social perspective changing is, not only possible, but also strongly necessary.

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