Dementia Simulation

Methods and systems for simulation of cognitive decline

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When one is diagnosed with dementia, the person with the diagnosis can become figuratively and literally lost. It is critical for caregivers, providers and the general public to not only treat the illness of dementia but treat the person with the illness, despite the challenges that come with the diagnosis. Dementia is an illness that affects the brain causing cell death resulting in cognitive dysfunction leaving the person unable to explain their feelings and behavior. The cognitive decline associated with dementia leaves the patient with limited social skills, difficulty communicating, unpredictable behavior and eventually an inability to care for themselves.

Patients battling physical maladies such as cancer or diabetes have the capacity to share their individual journeys, with others, many of whom have traveled the same road. In addition, the medical community is able to review concrete tests such as x-rays and blood tests and provide an accurate diagnosis. The interaction between doctor and patient allows for further understanding about the symptoms and disease management allowing for a well rounded assessment. This mutual understanding between the sufferer, the medical community and the public personalizes the disease and garners support.

However, people with dementia have no way to describe what is happening in their brain and frequently it’s the person closest to them who sees the first signs. People have difficulty relating to dementia because the loss of cognitive functioning results in the patients inability to articulate his state in a socially acceptable way. The person with dementia only has the voice of the people caring for them. While valuable, it is an outsider’s view of the disease. This research proposes that if we can attempt to connect with the patient by experiencing facets of the actual disease, we will go a long way to humanizing them and garnering the support this disease needs in order to develop comprehensive treatment strategies.

Alzheimer’s disease, the most common form of dementia, is affecting our economy in an unexpected way as well. Recent reports indicate the United States experiences $26 billion in lost worker productivity each year due to employees caring for a family member of loved one dealing with Alzheimer’s disease. According to Forbes, family caregivers are the backbone of the support system for the frail elderly. Yet, most families admit to knowing little about the management of the disease. The result, those receiving care may needlessly be in pain or discomfort creating greater risks of falls, infections, or even drug overdoses. The percentage of care that is given by families and untrained

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¹ Caregiving Costs: Declining Health in the Alzheimer’s Caregiver as dementia increases in the Care Recipient, National Alliance for caregiving, Nov, 2011
² We Need Better Ways to Train and Support Family Caregivers Forbes.com (2012)
http://www.forbes.com/sites/howardgleckman/2012/10/12/we-need-better-ways-to-train-and-support-family-caregivers/
Forbes
professionals is roughly 80% as cited in numerous studies\(^3\). In addition, help from the medical arena and surrounding support with training in dementia is limited with only 1,600 geriatricians providing 30% percent of the care according to the Alzheimer’s Association\(^4\). This chasm in care leaves untrained professionals to carry the brunt of this epidemic making it imperative that educational methods provide fast, accurate, observable and measurable change in the provider of care.

To date, programs that train caregivers range from websites, books, support groups, video series and lectures. Most methods of training offer a one-off approach to personalization of dementia by creating the expectation that the participant will project the corresponding emotions to the disease being studied. For example, when a video of a person with Alzheimer’s disease is shown, the caregiver sees the disease in action with no description of the feelings and concerns of the sufferer. It is implied that the participant will integrate the emotional and physical dynamics of dementia simply from hearing about it and viewing a sufferer.

To meet demands for better training options and grassroots care the Virtual Dementia Tour®, (VDT®), was designed. It is a sensitivity training tool used by professionals and lay public to help understand the impact of dementia on behavior and emotional status. This approach opens the dialogue between facilitator and participant, giving a more personal approach to designing direct care and enhancing the likelihood of stronger connections to dementia. Since 2001, the aspects and components of the VDT have been peer reviewed and published.\(^5\), \(^6\)

The purpose of this study is to simulate facets of dementia, examine the participant’s realization of their own dementia-like behavior and increase the likelihood of a deeper connection to the person with dementia. This deeper connection may result in increased understanding of the challenging behaviors and a lessening of abuse, overmedication and premature hospitalization.

Background

Professionals treating dementia of the Alzheimer’s type use staging of the disease as a way to identify various treatment strategies. Each stage of the disease has specific criteria as it relates to cognitive decline.\(^7\) The VDT simulation is based on Stage Four-Five of cognitive decline or mid stage.

- **Stage Four-Five – Moderate/Middle** – People at this stage can no longer cover up their problems. There is pervasive and persistent memory loss, including forgetfulness about personal history and inability to recognize friends and family. Rambling speech, unusual reasoning, and confusion about current events and time, are common. Getting lost in familiar

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\(^4\) Thomas, Bill Changing Aging http://changingaging.org/blog/many-geriatrics-few-geriatricians/

\(^5\) Beville, P.K., M.S. Virtual Dementia Tour Helps Sensitize Health Care Providers, American Journal of Alzheimer’s Disease and other Dementias May/June 2002 Vol 17#3 p183


\(^7\) Reisberg, Barry Stages of Cognitive Decline, American Journal of Nursing http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
settings, sleep disturbances, and changes in mood and behavior, experiencing delusions, aggression, and uninhibited behavior begin the difficult challenge of behavior management. Mobility and coordination is affected by slowness, rigidity, and tremors. This is the stage when most placements are made and psychoactive medications are prescribed because of behavioral challenges exhibited by the patient.

Development of simulation tools that result in dementia-like behavior in a normal person is the challenge in the VDT. Several avenues were used to create the development of sensitivity training tools used in the simulation.

1. **Behavioral Observation:** Clinicians trained in dementia care observed people in the middle stage of dementia in the home environment and in the long term care setting. The observations form was standard for all clinicians and tabulated frequency and duration of behaviors along with time of day. Clinicians also tabulated types of reinforcement used.

2. **Interviews:**
   a. Informal interviews were held with people suffering from early middle stage dementia. These interviews were conducted during support groups. Their descriptions of sounds in their head, misunderstanding of spoken word, feelings about their environment and most of all, descriptions of their emotions were invaluable.
   b. Interviews with family and professional caregivers helped determine how behaviors were perceived and what methods of behavior intervention were commonly used.

3. **Mini Mental State Evaluation:** Scores derived for mid stage Alzheimer’s disease were used to determine objective criteria for determination of cognitive decline. The tasks most commonly related to the score for mid stage cognitive decline in the MMSE gave the examiner insight into the types of things that could be simulated. For example, following a three step command and writing a sentence were difficult for mid stage scores on the MMSE. In addition, the types of responses to the MMSE assessment allowed a baseline for determination of participant response to the simulation.

4. **Brain Imaging:** AD can be seen on brain scans as the disease progresses. Areas studied were:
   a. Occipital Lobe impairs vision and the ability to integrate visual stimuli in the environment. We simulated this through patented eye wear, and environmental visual stimulation during the experience.
   b. Frontal Lobes control behavior and emotions, particularly on the right side of the brain. They also control language, usually on the left. The VDT simulates damage to these areas of the brain by placing expectations on the participant that they are unable to meet, impairing verbal, visual and executive functioning as well as integration. This is simulated through several modalities.
   c. Temporal Lobe. Damage to this area results in problems with auditory sensation and perception, difficulty attending to auditory and visual stimuli, problems organizing and categorizing verbal materials and language comprehension problems. In an attempt to

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9 Holsinger T, Deveau J, Boustani M, Williams JW (June 2007). "Does this patient have dementia?". JAMA 297 (21): 2391–404
10 Johnson, K.A. Brain Imaging in Alzheimer's Disease Cold Spring Harbor Perspectives in Medicine 2012.

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3312396/#lpo=27.1429
simulate the behavioral responses to this damage, the VDT altered sounds at various
decibels while overlaying additional auditory commands to make it difficult to attend to
and organize the verbal and visual messages.

d. Parietal lobe processes visual, auditory and touch information. The VDT integrates all
three of these areas by altering the visual field, introducing multiple sounds and
commands and inhibiting tactile sensation.

In addition to the simulation of impairments to the areas of the brain, a few common physiological
characteristics were added to the VDT to create a more realistic view of a patient’s behavior as it relates
to multiple diagnoses and common physical decline. Most notable, we simulated peripheral
neuropathy. This disease is diagnosed as either primary or secondary in 8% of Medicare patients.
This portion of the simulation was added to give the participant a sense of how pain influences behavior.

Previous studies examining the impact of the Virtual Dementia Tour have focused on participant
responses to questions about the experience. In this study, participants were asked to identify
characteristics of their own behavior before and during the tour. They were given a list of common
dementia like behaviors and asked to determine which ones applied to them before and during the tour.
This method added an additional facet of the VDT by giving the participant the opportunity to explain
why they exhibited the dementia like behavior during the tour. This insight into the feelings and
rationale for participant behavior during the tour is the basis of this research.

Developing strategies to trick the normal brain of the participants into believing their brain is unable to
process information was a key to creating an experience that simulates the emotional and behavioral
responses in the participants. While we will never fully understand the realities of dementia for the
individual, the VDT attempts to mimic as much as possible the overt losses while at the same time
simulating the cognitive decline through the use of tasks within a structured environment. Behavior
observers during the tour noted that participants begin to behave in the same way as a person with
dementia. They exhibit agitation, wandering, withdrawal and bizarre behavior within eight minutes.

During a debriefing with the participants the researchers helped draw the connection between the
participant’s reactions to the simulation and the behaviors exhibited by those with dementia. A standard
form was used to insure stability in the post tour interviews.

Specific attention was paid to determining common nomenclature for clinical terms so that the
participants could identify with the requested information. For instance, we wanted to study whether the
participant felt they were losing executive functioning during the simulation. To assess this, the
participant was asked whether they had difficulty following directions before and then during the tour.
The table in Figure 1 shows how we identified the remaining characteristics.

Method

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11 Torpy, Janet, MD Peripheral Neuropathy JAMA 2010; 303(15):1556. Doi:10.1001/jama 303.15.1556
12 www.neuropathy.org/site/PageServer?pagename=About_Facts
The Virtual Dementia Tour Community Edition was conducted with 203 participants throughout the United States. The participants were a homogenous mix of business professionals, healthcare providers, and home caregivers. The Tours were conducted in several locations with the isolated variables of garbing equipment, room setup and VDT clinician training.

When participants arrived at the Tour site, they were asked to complete a four question pre VDT form. In addition they were asked to indicate any of the behaviors listed (see Figure 1) in the 10 minutes before the Tour. The behaviors listed on the pretest and post test was selected because they are commonly seen in those with dementia.

After being garbed in goggles, shoe inserts, gloves and headphones with confusion sounds, the participant was led into the VDT experience room. This room is set up to simulate a room that a person with dementia would commonly be living. Items in the room and the room set up are replicated for each of the sites conducting the Virtual Dementia Tour. The alterations to the environment were developed in the initial VDT and studied over time for accuracy of participant response as compared to those with AD. Specific sounds, movement, light and tasks are positioned in the room. Once the participant entered the room, five simple tasks were read to the participant. The tasks were the same as the ones in the initial VDT study. A trained observer in the room tabulated behaviors exhibited by the participant along with the number of tasks completed. At the end of eight minutes, the participant was led to the post tour room where they were de-garbed and given the same assessment questions as before the tour. They were asked again to indicate behaviors they experienced during the tour. A brief follow up session was held with the participant by a trained dementia professional to help them understand their experience as it relates to dementia.

**Results**

A comparative analysis was made between the pre and post tests for each participant in unmatched pairs. They were asked to circle as many of the following behaviors as they felt they were experiencing within the past ten minutes. The fact that the participants were encouraged to circle multiple behaviors created a numerical scatter but when used solely as a comparison between the two points in time, the results show a significant spread between time frames. The table below shows the actual number of characteristics identified by the participants.

Figure 1
**Difficulty Following Directions:**
The participant’s insight into what it is like to be unable to understand directions give the participants information about the plight of dementia. As a person struggles to understand what is expected of them during the VDT, the frustration begins then leads to agitation and sometimes withdrawal. The behavior observer in the VDT experience room noted the majority of the participants didn’t understand what was expected of them. The range of resulting behavior went from withdrawal, to anger and acting out. The struggle to comprehend the environment resulted in some of the same behavioral responses as those with AD. Responses to this dynamic showed the largest pre/post test spread.

**Wandering:**
The spread pre and post for wandering (pacing and searching) was the smallest. This result suggests that many of the participants were coming to an unfamiliar location and had to search for the place the VDT was being conducted. Interestingly, wandering behavior is one of the most common behavioral expressions of AD. The fact that the responses from participants were self-reports make it interesting to note that they didn’t see themselves as wandering during the VDT experience. However, wandering was reported by the behavior observer in the experience room. When participants were queried about their wandering, they stated that they were just looking for something that they couldn’t find so they just kept trying. A classic description of wandering.

**Shadowing:**
Shadowing (following others) has been reported as a problem both by family and professional caregivers. It is evidenced by the patient following caregivers from place to place, even the bathroom. Frequent shadowing makes it difficult for the caregiver to complete duties of the day. When queried, participants in this study stated they felt safer when doing the same tasks as someone else or following them from place to place. They felt it was a good coping strategy and were unable to see it was causing difficulty for the person being shadowed.

**Subvocalization:**

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![Graph showing pre and post VDT behaviors](image-url)
This was queried because people with AD mumble, repeat things under their breath, hum, and mutter. It is hard to know the seed of this behavior but the examiner felt that this behavior, if exhibited by normal people in eight minutes, even though they were aware of an observer in the room, would give insight into the behavior exhibited by those with AD. This number is likely an underrepresentation of how many participants talked to themselves. In the original VDT study, the behavior observers heard the sub vocalizations and when the participant was queried about it, they denied doing it. It can be assumed that sub vocalization is a good coping strategy when there is confusing stimuli in the brain.

**Negative Thoughts:**
Negative self-talk as reported by the participants gives us great insight into the seeds of emotional despair during the VDT. A harbinger of depression is negative self-talk. Since this behavior increased three fold in the short eight minutes experience, it is easy to assume there is a connection to at least dysthymia. Studies indicate that depression increases confusion and confusion, especially at the moderate stage, increases depression\(^{13}\)\(^{14}\) This result shows that the ability to tease out the coexistence of depression and dementia is a fundamental challenge for every clinician from the beginning of the diagnostic process.

The participants were asked to answer a set of three questions of Yes or No by circling their response to the following questions. The charts below indicate the comparison between the pretest and the post test for the 203 participants.

**Do you feel capable of carrying out simple tasks?**

![Pie charts showing the comparison between pretest and post test responses to the question: Do you feel capable of carrying out simple tasks?](image)

Before the VDT, most everyone reported they were capable of carrying out simple tasks. During the VDT, the participants realized simple tasks are difficult and in most cases impossible for those with dementia like symptoms. Even a task to find a sweater and put it on was daunting and resulted in agitation when the sweater couldn’t easily be found. Compounding this realization was the fact that the participants knew before the simulation started they had five tasks to complete. Obtaining this insight from a participant is invaluable given the fact people with dementia have the same problem. The participant’s admission that they were incapable of carrying out simple tasks to such a large degree as


\(^{14}\) Graham, Judith Does Depression Contribute to dementia? New York Times 5/1/13
seen in the above diagram shows the depth of loss in a normal person. In some cases the participants didn’t know they were completing the wrong tasks or completing tasks only in part.

Are you relaxed?

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The concept of relaxation is relative to the individual but, as such, each of the participants related a value to the yes/no response. When viewed as a total picture, the pre and the post test show most of the participants were uneasy during the simulation and just after. The bombardment of sights, sounds, and information creates a feeling of agitation and sometime anger. It could be postulated that those who were feeling relaxed during and after the simulation were able to overcome the bombardment of sights, sounds and information.

Do people with dementia get the care they need?

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The majority of participants know, either intuitively or through experience, that people with dementia don’t get the care they need. Regardless, this result taken alone suggests the perception of dementia care is negative. The fact that the majority of participants were from a healthcare environment responsible for care and treatment of AD suggests an inability on the part of the participants to make things better for AD care. Helplessness in the care of AD undergirds the contention there are no strong care strategies for AD at least as perceived by the participants in this study. The larger number of No’s in the post tells us that after the VDT, participants realize to an even greater extent we still have a great deal of work to do in our field in order to provide the care people with dementia need.

Conclusion
The ability for a normal person, without the disease, to feel what it must be like to have the disease while exhibiting the same behaviors, becomes an invaluable tool to assist clinicians as they develop interventions that will make “problem behaviors” a thing of the past. Insuring all behaviors exhibited by those with AD are normal in light of the disease will go a long way to developing treatment plans. Normalization of this disease will reduce unnecessary medication as well as premature hospitalizations by providing strategies for the caregiver that is based on insight garnered from sensitivity training.

Those that remained relaxed during the VDT provided insight into an interesting dynamic and one that deserves future research. Those most able to cope with the difficulties of AD will clearly fare better throughout the disease. Future research needs to be done to determine how to create the comfort and stability for those with AD from the beginning of the disease. Learning the environmental and emotional dynamics of the person that is better adjusted to the disease and then insuring replication in newly diagnosed cases could help defray some of the current difficulties of dementia.

Humanizing AD through sensitivity training, in addition to other training models, encourages empathy and identification with the disease by allowing participants to reflect on themselves and project those feelings during the experience onto those in their care. Asking people to step outside their comfort zone and experience the most feared disease in the United States takes great personal courage. These pioneers in dementia care are providing insight into dementia that heretofore hasn’t been examined. Clearly, more research into this method of sensitivity training awaits us but in the meantime, attention to this model of training is garnering great results and calls to action. With no cure in sight, it is imperative that we take action now.